Looking for dementia friendly communities: towards an interdisciplinary understanding using a case study, fragments and cut-ups.

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Abstract

This thesis tries to develop an understanding of the phenomenon of 'Dementia Friendly Communities' (DFCs), a policy initiative which has been pursued during the last decade in the nations and regions of the UK, and other parts of the world. In Wales, this has coincided with a radical shrinking of state budgets to deliver social care support, often called 'austerity', and rising interest in the policy and cultural implications of an ageing society, and how dementia has seemingly become more central in that demographic trend.

This inquiry arises initially from a critical gerontology perspective but develops along lines which borrow from cultural geography and post-war, avantgarde literature. Such an interdisciplinary approach presents opportunities for using novel methods of collecting and analysing material. Though conventional ethnographic techniques such as participant observation, interviewing and photography were used throughout, I also introduce practises such as writing using spontaneous prose, collaging or cut-ups, as an alternative means of analysis. During fieldwork, I attended various events and meetings with those involved in developing DFCs, including 'dementia activists', and witnessed the development of 'Meeting Centres' as a chosen approach to support those with dementias and their carers in the market town of Brecon, south Wales.

From this, a picture emerges of a phenomenon which seems contingent and difficult to grasp, but offers space for critical counter-conducts, glimpses of community-making and types of citizenship. Foucauldian concepts such as biopolitics, governmentality and pastoral power, alongside more non-representational and affective approaches, were used throughout. Writers such as William S. Burroughs, Georges Perec and others inspired 'ways of doing and making that [could] intervene in the general distribution of ways of doing and making' (Rancière, 2004, p13). Findings are presented as a series of fragments, including fictocritical and anecdotal writing, collages and cut-ups of materials generated. The main contribution of this study is to attempt to a more nuanced portrayal of DFCs as found, whilst developing methods which question epistemic boundaries, and may have practical potential for synthesising new materials across disciplinary borders.

Declarations

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed..........[redacted].......... (candidate)

Date ....31.11.21..

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s). Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed ....[redacted]. (candidate)

Date ....31.11.21...

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Date ....31.11.21..

Acknowledgements

I would like to thank the ESRC, who funded this project for three years.

A piece of good advice given to me many years ago by a colleague about doing a PhD was to find supervisors who you can get on with. I could not have asked for better. My experience has been one of generosity, encouragement, openness and much toleration of my foibles, so *diolch o galon/*many thanks to both Professor Charles Musselwhite and Dr Angharad Closs Stephens. Their support has given me confidence to explore questions which may well have been with me for longer than I realised, and new ones I hope to pursue in the future. Maria Davis and Katie Retallick from the Post Graduate Research Office have also given excellent support and advice all along this journey. Thanks to Professor Judith Phillips, Dr Martin Hyde and Dr Catrin Hedd.

This work is genuinely inspired by, and dedicated to, Rhiannon, Nigel and Joan, in the first instance, but also all who've attended the Meeting Centre in Brecon as volunteers, staff or participants in the joyous goings-on there, and the many others all over Wales dedicated to making lives better. Long may this continue.

Many great conversations and deliberations have taken place, not least with Dr Aled Singleton, and I sincerely hope these will continue too. Wet and windy Saturday mornings, watching children play football, have also been sites of deliberations with Dr Keith Chapin and his father, Professor Terry Chapin, Dr Ilyas Khan, and Dr Dylan Foster Evans. Inspiration and support in previous postgrad adventures has come from Dr Finn Bowring (Cardiff University) and Professor David Peck, who on a teaching break at Leeds University, many years ago, greatly encouraged my interest in post-war American literature.

Finally, I'd like to thank my family, without whom this wouldn't have been possible: *diolch o galon am eich cariad, dealltwriaeth a chefnogaeth, Sioned ac Inigo, heb hynny does dim. I fy nhad, Huw Williams, a Dorothy, ac i John a Beryl, Dyfed a Catrin hefyd – ac i fy mam a fy mrawd, yma gyda ni mewn ysbryd, bob cam o'r ffordd.*

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Abbreviations

These are the abbreviations used for some of the organisations are mentioned in this thesis. Also, the names of some of the interviewees have been abbreviated after any initial use in the text – more details of interviewees in Annexe 2.

BADDFC – Brecon and District Dementia Friendly Communities

CIA – Centre for Innovative Ageing

DEEP – Dementia Engagement and Empowerment Project

DFC – Dementia Friendly Communities

DMiP – Dementia Matters in Powys

OPC – Older People's Commissioner

PAVO – Powys Association of Voluntary Organisations

PWD – People with Dementia

3NWG – 3 Nations Working Group

1. Preamble

> *Whatever could have happened for things to come to this? (Deleuze & Guattari, 2013, p.227)*
>
> ***Touchstone*** *(n) - Anything which serves to test the genuineness or value of anything; a test, a trial; a criterion or reference point by which something is assessed, judged, or recognized. OED*
>
> *It's about the importance of kindness... and yes I do believe that it was in tune with the spirit of our age, and I think it was always going to happen, you know, I happened to be there at the right time, and happened to be the one privileged enough to be given a role in a place, and I feel and I think that I took that opportunity, and did my best.*
>
> *Rhiannon Davies, founder of BADDFC*

A year or so before starting work on this thesis, I found myself at a Dementia Friendly Communities networking event, in south Powys, as part of another research project. It was at a Pentecostal church centre in Brecon, a large, open, modern building. I had just sat through a dramatized selection of stories performed by people living with dementia and their carers, heartfelt accounts of their own lived experiences, and *something* had happened in the room. Witnessing this performance piece called Memoria, by a Cardiff-based drama company, committed to 'Life Story theatre, Arts in Health group work and experiential training' (Re-Live, 2019) were assembled statutory services, from local hospital managers to social workers, representatives of voluntary organisations, councillors, academics, citizens. We had all felt it I think, felt the room change: a before and an after to the radical self-exposure that had unfolded. Later, as I mingled and listened some more, I noticed that those who were loosely from the statutory services, at this point beginning to feel the bite of budget cuts because of austerity, seemed muted, for want of a better word. A local social worker quickly gives me a picture of local provision – one of trying to do their best with limited resources, one of struggle.

In contrast, those from the voluntary sector seemed to dominate the rest of the proceedings. Undoubtedly, all there had an interest in trying to change the way people with dementia were being treated locally. One of the organisers of the day, along with the Older People's Commissioner for Wales staff present, got up and made an impassioned speech, saying that “we are all in this together”, that the hearts and minds of people needed to change in matters of dementia. But for me, suddenly, the *something* in that room, and the words incanted in the speeches had left me thinking that there was far more going on.

This thesis is my attempt at understanding what DFCs might mean in different contexts, including the 'jumpy moves and layered textures of a scene' (Stewart 2007, p4), like the one described above. The basic approach will be one that asks:

- how could a DFC ever exist, beyond a fragmented understanding of its constituent parts? Where do such ideas come from, and what are their effects in the world?
- how do we create knowledge about such phenomena? How do we present such knowledge, and are those forms of presentation /representation adequate? Are there alternative or creative means of doing or thinking about this?

On that day, I was also left questioning why are ‘we’ suddenly being told to be friendly, and why has ‘community’ become so *un*-friendly that our behaviour and conduct needs to change. This thesis is an attempt to answer these questions by giving an account of how I’ve pursued that elusive *something* by crossing a few disciplinary boundaries. Using the lenses of critical gerontology, human geography, and post-war avant-garde literature, I’ve used conventional ethnographic methods, such as participant observation, interviews and photography to do this. These have then been supplemented and developed using ways of recording and analysis inspired by creative styles loosely (but not exclusively) associated with American Beat writers and earlier avant-garde movements of the twentieth century and indebted to the fictocritcal style associated with Kathleen Stewart and others.

My main case study centres on the market town of Brecon, in south Wales, but fieldwork also meant travelling widely and attending many different gatherings either directly related to developing DFCs or dedicated to improving the lives of people with dementia (PWD)[1] and those who care for them. Even now, a few years later after my initial entry into this area, DFCs remain under-theorised and prone to imprecision in terms of how they're defined, with a literature that largely focusses on evaluating their worth in terms of policy outcomes in the face of an ageing society (see Buckner et al. 2019 for such an evaluative approach), with very little critical evaluation of where it might fit for example, in terms of austerity, or considerations of power more generally. However, a broad workable definition we can use initially might be that of DFCs being an approach to raising awareness around dementia, bringing together local organisations and services, engaging and normalising the experience of living with the condition (Buckner et al., 2019).

It would seem that 'dementia' has become part of many discourses: social, economic, academic and cultural, and even a critical political terrain - in the second of the three UK general elections during my research, it was claimed that a specific term, 'dementia tax' had a significant effect on the result (Heath and Goodwin, 2017). What was once associated with familial and inter-personal matters, has become part of the global public arena, often a signifier of anxieties around ageing populations. However, dementia remains a mystery, difficult to define and categorise, 'an elusive mobile target in which brain and mind are not necessarily in sync' (Lock 2013, p3), often characterised as an epidemic, even though it is not in any way contagious. Whether governmental strategies, social movements, health care initiatives, interdisciplinary academic work, consumer products, and literary, filmic, dramatic

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[1] This is the settled term and abbreviation that I will use throughout, after careful deliberation with those taking part who have the condition. For various reasons, not entirely consistent because of the heterogenous nature of both the condition and those involved, I decided to steer clear of what felt to many like the two ends of a spectrum of terms, from 'People living with dementia' to any mention, unless specified by an informant, of 'Suffering from dementia'.

and other cultural works, ‘there is literally a global investment in (making sense of) dementia’ (Commisso, 2015, p. 377).

The first two main sections in this thesis will present the necessary groundwork for the rest. In Orientations and Openings, I have grouped together some of the essential background, literature and thinking which has shaped and helped the work evolve to become more interdisciplinary. This material covers the theoretical ideas considered, the policy background and some necessary description of the main actors and events which will be highlighted in later fragments. Throughout, reflexivity – a commitment to self-reflection - has been fundamental to the process, acknowledging the ‘somewhat’ autoethnographic nature of this research journey (Horton, 2021, p.24), though also trying to acknowledge the limitations of this approach too.

The second main section is concerned with methodology and methods and elaborates on ways of producing knowledge, with overviews of all methods used. This includes forays into more creative approaches and why I decided to present findings using a variety of fragmentary texts, anecdotes, photos, collages and cut-ups, based around three main Touchstones. While justifying their use in this section, I’ve left more detailed descriptions of mechanics of how I did cut-up analysis and collaging in the Annexes, because I felt that it was more useful to document the value of these methods separately from how I use them.

I decided quite early on with my supervisors that I would prefer to group the findings around the idea of touchstones, rather than chapters. The three main conceptual areas in which the research was developing seemed to be producing multifaceted ‘bundles’ of data and ideas (Law, 2004), and it seemed best to arrange them in heaps of fragments. I decided to steer clear of the contested and seemingly imprecise nature of the word assemblage (Buchanan, 2021) in this context, though it appears when looking at a particular DFC-related object which was given to me, and the collages could be classified as ‘a temporary and changing arrangement of multiple parts’ (Coleman, 2018, p.62, Deleuze & Guattari, 2013) in this way.

The weaving of reflexivity and the different voices of those interviewed more formally can be found throughout the thesis, not just in the more ‘empirical’ parts. Quotations from Raymond Williams and many others are used liberally throughout also. In a sense, they are the true touchstones by which this work has been guided. Some were already lodged in my mind before even thinking about this field, and I fully expect that they will guide my thinking beyond this thesis. Also, following Davis (2019), I take ‘fragment’ as a form of writing that examines and explores, but also digresses, and questions ideas of wholeness, completion, incompletion or order (p.205). As the thesis progressed, a key personal and intellectual finding was learning to let go of ever fully having a complete understanding of the field of study, and a growing appreciation of embracing the taking-place of events (Anderson & Harrison, 2010).

After the initial sections, the work then proceeds to the First Touchstone containing fragments, collages and cut-ups organised loosely around the idea of activism, networking, and governance in dementia matters. This includes accounts of sitting through not only government consultations around dementia strategies, but also academic presentations with PWD present, and witnessing interesting and significant forms of resistance emerge in those scenarios.

The Second Touchstone continues in a similar trajectory, but offers a more disparate set of observations, modelled on the work of George Perec, ‘the bard of the mundane’ (Back, 2020, xv), containing various scenarios, anecdotes and lists relevant to thinking about dementia, community and neighbourhood.

The Third Touchstone concentrates on the main case study of Brecon, offering several different accounts of how dementia friendly communities has ultimately manifested itself in the market town, and attempting to describe the wider senses of dementia and community there.

Endings offers overall reflections on the conclusions that might be drawn from the search for DFCs, including the limitations and opportunities offered by the methods used, both conventional and creative.

As noted, the Annexes offer some more detailed descriptions or even ‘how-to’ guides to both cut-ups and collage as used, and further accounts of the learning opportunities that this thesis has given me. Even though I refer to key events throughout, I felt that some more detail of the kindness and inspiration offered through conferences and other events needed to be listed and acknowledged. As with any such research, only a fraction of what is recorded has eventually made it to the writing up process.

Finally, although I refer to ‘dementia friendly communities’ with an abbreviated form (DFC) through much of the text, the elusiveness of the concept at times made me feel that I was in pursuit of *tylwyth teg,* the Welsh term for something akin to fairies, or will o’ the wisp. This re-naming helped to remind me of the fleeting and contingent nature of things as I searched, and so I have kept the term in parts of the text that follows.

2. Positionality

As intimated already, there is a strongly reflexive and *somewhat* autoethnographic (Horton, 2020a) element to this work, which we will explore more thoroughly in the second section on. Beyond the neat labels of being white, male and middle-aged (though I’ve just crossed the official threshold in Wales into being an older person, as I turned fifty during writing this up), it’s difficult to underestimate at times the dynamic complexities of the way positionality might change during such research (Rose, 1997). This has included both ‘insider’ and ‘outsider’ roles – at an academic conference, for example, or sitting in a breakout session with PWD - or acknowledging previous experiences which have had a bearing on your own thinking, that might sensitise you to certain situations. As we see in the first section, this was very much the case for me, in more than one instance.

A significant area for these considerations in Wales is language. Welsh is my first language, my home language, and forms a significant part of my professional life both inside and outside of academia. Fieldwork meant having access to dementia related cultural experiences and policy areas in Welsh too, including interviewing in Welsh, but also finding myself at times the only 'volunteer' at the Meeting Centre in Brecon who could converse with some of the PWD whose first language was Welsh. It made a relational difference in how I've been able to approach certain circumstances and people.

The bedrock of my research are fieldnotes, written bilingually, in which not only have I experimented with writing styles which specify an open, autoethnographic approach to describing a situation (see Spontaneous Prose), but also contain a range of reflexive observations that have tried to be aware of affect and the range and intimacies of embodied experience (Butz & Besio, 2009). Additionally, in my use of anecdotal and fictocritical writing, where at times I am also a protagonist, at others I follow Stewart (2007) in referring to myself as 'he' in an effort to attune myself to a scene differently, to mark out 'the difference between this writerly identity and the kind of subject that arises as a daydream of simple presence' (p.5).

3. An alternative reading

Although this thesis has been loosely organised with Touchstones as a way of guiding the reading, and a roughly linear structure that gives background, methods then empirical chapters and a conclusion, I would encourage a more randomised approach, if so inclined. This is in keeping with some of the underlying ideas presented here that explore the cutting up of texts, juxtaposition and which touch on various types of avant-garde practice, and what I've experienced as the sometimes-fragmented nature of transdisciplinary research in pursuit of the *tylwyth teg*. Every section around the opening sections and Touchstones has a number, and therefore it would possible, using a suggested online randomiser[2], to come up with a unique sequence to guide the reading. This approach is not without precedent e.g., Beckett (2002), and such randomness is integral to some of the analytical methods inspired by avant-garde writing in what follows, but also 'a means of creating turning points in the here and now' (Anderson & Harrison, 2010, p23), giving several possibilities to the reading and maybe leading to more interesting avenues of thought in the process.

4. Orientations and openings

> *In the fields in which we are concerned, knowledge comes only in lightning flashes. The text is the long roll of thunder that follows. (Benjamin, 2003, p.456)*

In this first section, I will set out some of my opening thoughts and a relevant literature around dementia friendly communities, the necessary background reference points essential to locate aspects of the field as I've understood it over the last few years. I will sketch out the background to DFCs in terms of policy, before exploring a wider theoretical, gerontological and geographical literature. There is a substantial section bio-politics and related concepts because I feel that these are ideas which underpin various arguments that cross between both gerontology and geography, but also the underlying doomy 'apocalyptic demography' (Robertson, 1990, Lundgren & Ljuslinder, 2011) that often surrounds conceptions of ageing

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[2] I would suggest this site, having used it on other projects: https://www.random.org/#numbers . It uses atmospheric noise to generate 'true randomness'. It also has another feature relevant to the avant-garde underpinnings of this thesis, Samuel Beckett's randomly generated short prose, Lessness (Beckett, 2002), which can be generated differently each time 'to help explore the space of 'possible Lessnesses' (Trinity College, 2000).

and dementia. At the same time, I felt that it was unavoidable not to mention in this section the very real thanato-politics (Mbembe, 2013) which have taken place in the recent COVID-19 crisis, and which arguably serves to demonstrate partially how little a decade of policy drive towards DFCs has made, in certain light.

I also explore ideas of community, citizenship and giving a brief introduction to some of the relevant organisations and approaches taken. Deleuzoguattarian and Foucauldian ideas and metaphors have been of some use in this work (despite Deleuze and Guattari's suspicion of using metaphors). Michel Foucault's work was relatively familiar to me from previous research and thinking, while I was only dimly aware of Deleuze and Guattari, in part because of the relative lack of prominence in gerontology of both of their work, and post-structural and post-humanist ideas. My incorporation of geographical modes of thinking (and forays into avant-garde literature), plus the growing disciplinary interest from some quarters in gerontology (myself included) in both non-representational/more-than-representational thinking and the affective turn, have meant assembling a new conceptual 'toolbox'. Encouragement to explore such thinking had been there in some critical gerontological thinking, for example Katz (1996, 2009, 2019), and is certainly beginning to form part of the discipline via geographies of ageing approaches (Andrews, 2020, Skinner, 2015). At times it has felt like a highly beneficent interdisciplinary crash-course of ideas.

There are some background considerations which have had an influence on how I've thought about the field. I had already been actively engaged in work about dementia supportive communities before I embarked on this research, and so I came to this research with some formed ideas. Concretely, many questions which intrigued me arose, but were left unanswered, as I completed a quick evaluation of the dementia supportive communities in Wales through my department (the Centre for Innovative Ageing – CIA - at Swansea University), for the Older People's Commissioner, a key player in all ageing matters in Wales, there to safeguard the rights and interest of older people (OPC, 2016). Applying for the PhD, I tried to be conscious of how I could approach those further questions ethically and maintained an openness about my position. Through this previous project, inevitably I had got to know some of the people involved in promoting the idea of Dementia Friendly Communities. As a relatively experienced qualitative researcher, I realised the significance and importance of this for more long-term fieldwork, which is often necessarily interpersonal, and can rely on establishing and maintaining relationships with significant others in the field (Coffey, 1999). My social science research training, a Masters in Social Science Methods from Cardiff University many years ago, and own research habits meant, almost regardless of project, keeping in the back of my mind Bent Flyvbjerg's four value-rational questions for a social science (Flyvbjerg, 2001): Where are we going? Who gains, who loses, by which mechanisms of power? Is it desirable? What should be done? This is a way of constantly analysing the values that you and others might have and bring to the practise of research and acknowledging that 'an interaction between the general and the concrete…requires consideration, judgement and choice' (p.57).

Once the thesis process started formally, a series of serendipitous events ensued which became part of the journey. This included having to suddenly find a new supervisor, because my original second supervisor left academia to become a policeman. A departmental email advertising a seminar on 'Assembling Non-Knowledge' by the Geography Department drew my attention, and this is how I met Dr Angharad Closs-Stephens who chaired the session, and who eventually became my second supervisor.

At this point, though I had some grasp and interest in social theory and had formulated some thoughts I will set out here, I had no real background in human or cultural geography. However, working with Dr Closs Stephens led to several other events, opportunities and chance encounters which made a big difference to this thesis, and really expanded some of the interdisciplinary horizons of what is possible in such work. In my third year, I took a short sabbatical to work on a departmental research project (a systematic mapping of Well-being literature), then COVID-19 and its associated impacts on family life also delayed some of the writing up, while also being a spur to some of the collage work.

As mentioned, ‘the field’ is always already being constructed by researchers in ways which may have political effects (Latimer, 2008). That this has been the case here in several instances is no exception: during my time at the CIA both as staff member and student, I have been involved in formulating departmental responses to draft strategies on dementia brought out by the Welsh Government or sorting out free passes for dementia activists to gerontological conferences at the university, for example, so it’s been important to find a way of engaging with critique of my own bonds of complicity and limitations in each situation (Massumi, 2015).

5. Opening entanglements

> *It is not the elements or the sets which define the multiplicity. What defines it is the AND, as something which has its place between the sets. AND, AND, AND – stammering. (Deleuze & Parnet, 2008, p.26)*

In this fragment, I will map out some of the key works which have influenced my thinking, as an opening account of how various literatures have helped develop my contribution to both critical gerontology and geographical thinking around DFCs. I will not give an account here of the influence of avant-garde figures such as William S. Burroughs, which can be found elsewhere (e.g. Fragments 9, 21, 31), concentrating instead on the more conventional interdisciplinary curiosity which drove my literature review across relevant social science disciplines. Bringing together many sets of critical literature has meant some challenges; despite often hearing the call for more interdisciplinary approaches from within academia in general, the reality of trying to pick a relevant path to answer research questions has been one of having to immerse oneself in methodological and analytical debates which are often new. Personally, this has always been one of the pleasures of reading in an academic environment – to be able to roam across disciplinary barriers – but the crucial task for this thesis was to try and assimilate and make sense of concepts which were completely new to me.

However, the texts I outline in this section seemed to be the most important ones that helped bridge this difficulty, either practically (by suggesting further avenues methodologically or conceptually) or providing a foothold in the relevant discipline with which to pivot towards new, hopefully relevant, concepts. To recap, while starting work on this thesis, I was also in the process of trying to salvage the ending of a drug and alcohol charity that I had been a trustee (and latterly, chair of board) (see Fragment 18). I'd written a thesis looking at professionalization of drug outreach services as part of a Social Science Methods MSc, some six years earlier, which had alerted me to wider theoretical frameworks about advanced liberalism and governmentality, an early introduction to Foucault's work, as well as social theory more generally. However, by the point of departure for one thing and ending another, I was already part of the field I was to look at around ageing and cognitive decline. Along with other roles outside of academia - often a 'jobbing' qualitative researcher working on various projects - from the latter part of 2012 for example, I had been involved in longitudinal gerontological research at the CIA, a project that took me to North West Wales and Neath Port Talbot to investigate health literacy in the context of depression or diabetes, with cognitive functioning as a background theme (CFAS, 2016).

As I began to think about the PhD, the path emerging in front of me was one of interdisciplinarity, as my initial forays into the literature that I thought relevant began crossing several disciplinary boundaries in social sciences, and eventually, the humanities. Despite the mainly social science orientation of my experience of gerontology and my MSc work, after the change of supervisor, which began a journey into human/cultural geography and would have many implications for what I was trying to do, I had also become conscious that to explore dementia. I already had some appreciation of the 'interdisciplinarity' around the natural sciences and dementia, being already aware that neuroscience, for example – or specifically cognitive neuroscience, which I had touched upon in my previous role with CFAS - is deeply interdisciplinary, as it brings together not only biology, chemistry and physics, but also computer science, neurology and psychology, among other disciplines (Callard & Fitzgerald, 2015). This thought space was also increasingly of interest to those who had developed Foucauldian approaches over the years, and were now making the case that the human social life could no longer be disentangled from human animal life (and non-human animals) (Rose & Abi-Rached, 2013).

Throughout this thesis, Foucault's work that has been key to developing possible understandings of the concept of dementia friendly communities, a kind of point of departure and arrival. In particular, his conceptual development of bio-politics, and an earlier precursor to his ideas on governmentality, pastoral power - which can be traced almost chronologically in the lecture series at the Collège de France from 1975 onwards (Foucault, 2008, 2009b, 2011) – have led to my being able to think, right from the beginning, about how power, might operate in this field (see, for example Fragments 10, 12 and 13, along with many other references throughout). I also looked at earlier works in which he explores dementia (2009a), but also some of the broader discussions - often building on the work of those who taught him such as Canguilhem – that had been influenced by him, such as how the rise of anatomical pathology in the late 19th century gave rise to a particular medical gaze, a way of standardizing both 'the body', but also medicine (Foucault, 2003, Rose & Abi-Rached, 2013, Lock, 2013).

His thinking was foundational to both Rose & Abi-Rached (2013), looking at the development of the 'neuro' gaze – a 'homage' (p.56) to Foucault's The Birth of the Clinic (2003) - but also Margaret Lock's The Alzheimer Conundrum (2013), another key early reading as I thought about the significance of dementia in cultural terms. Her anthropological study of how neuroscientific research was being conducted, and the many debates around how the disease(s) under the umbrella of 'dementia' are to be analysed and 'treated', was key to developing my understanding of dementia as an inherently unstable concept, but also one that was intimately entwined with politics, public health, the types of 'bio-sociality' associated with citizenship (Rose & Novas, 2008, Rabinow,1996 – see Fragment 8). A raft of other useful and insightful reading based on Foucault's work can be found throughout this thesis e.g., Dean (2010, 2016), Deleuze (2006), Fassin (2009), Golder (2015), Walters (2012), Waring & Latif (2017).

As these various threads to my literature review became ‘entangled’, to extend the metaphor Lock uses (see Fragment 6), it was possible for me to draw on critical and cultural gerontological readings from Stephen Katz’s work – such as Disciplining Old Age: the Formation of Gerontological Knowledge (1996) or Cultural Aging (2009) - also greatly influenced by Foucault (see Fragment 10). This was relevant in developing a fuller understanding of the problematization of both old age and dementia, a key factor in the debates which I will highlight both from activist perspective on dementia, but more generally in how critical gerontology can have a livelier engagement with both theory and practice.

In terms of the latter, another important text which examined the various sociopolitical debates around dementia, citizenship and rights was Bartlett & O’Connor’s Broadening the Dementia Debate (2010). This prescient book postulated the appearance of a ‘Fourth Moment’ in dementia matters (see Fragment 8), one in which the discourse around dementia shifts towards a type of social citizenship for those with the condition, building on previous ideas of personhood (Kitwood, 1997). It also acknowledged the importance of activism within this shift, and as I began to explore the various networks across Wales (and beyond), it seemed to give a useful context to the emerging voices of PWD in and around DFCs, both critical and supportive. It also suggested very practical ways to approach how you research with people in this field, and encouraged the use of creative methods, such as sound walks, for example.

Another key influence, which enabled me to start thinking with the affective forces around this field, was Kathleen Stewart’s Ordinary Affects (2007), though it was another piece by her (Stewart, 2013), introduced during a postgraduate geography seminar on writing, which opened up the possibilities of her particular approach to observing everyday life (see Fragment 23). Through a very productive dialogue with my second supervisor, this then led to engaging with a wider literature, for example Berlant (2011), Sedgwick (2003) or Massumi (2015), leading to crucial moments of insight in the research journey (see Fragments 17 and 18, for example). However, it was Stewart’s work which I kept going back to, including many of the influences which she also cites e.g. Barthes (2000), or Williams (1985). Her earlier work (Stewart, 1996) made me question some of the assumptions often made about coding, for example, as a relatively unquestioned ethnographic practice, as a kind of '*forgetting* of cultural specificity, singularity and the dense mixture of things and words that are fabricated in people's everyday encounters with each other' (MacLure, 2013, p. 170). Having been a qualitative researcher for many years, and finding myself sceptical of the increasingly mechanical/quantitative nature of many coding practices, this was a space in which I could begin to explore 'the anecdotal, the accidental, the contingent and the fragmentary' (Stewart, 1996, p.11) (see also Fragments 23 and 30).

In terms of theory, I realized that Katz's work (including Ageing in Everyday Life (2018)- collection of edited essays and contributions), which encourages interdisciplinarity throughout, was also bridge into critical or cultural geography, as he is one of the few gerontologists to highlight the importance of Deleuze and Guattari, for example, to conceive of gerontology as a very 'nomadic thought-space' (Katz, 1996,2009 – see Fragment 11, 81). As I became more familiar with theorists that seemed more common in critical geography and non-representational theory, especially through Anderson and Harrison (2010), and some of the methodological implications e.g., as outlined in Coleman & Ringrose (2013), I explored texts such as A Thousand Plateaus (Deleuze & Guattari, 2013), in which ideas such as 'lines of flight', 'the rhizome' or 'the refrain', and latterly 'The Smooth and the Striated' (Deleuze & Guattari, 2013, p. 1, 361, 551) helped me to think through how we can think with a concept such as DFCs.

In my original interdisciplinary 'line of flight' – a process whereby the possibility of escape from one discipline into another came into view, a kind of threshold between ideas - I became more convinced that 'dementia' seems to have certain rhizomic properties (Deleuze & Guattari, 2013): a decentred-ness, an interconnect-ness, an ability to float above and yet be in the world. It seems to present as a multiple reality (Mol, 2002), acting through artistic endeavours, newspaper headlines, bodies (of course), and even in the tensions between short-term and long-term memory; the former rhizomic, that includes 'forgetting as a process' while the latter is 'arborescent, centralised [an] imprint, engram, tracing or photograph' (Deleuze & Guattari, 2013, p16). A random picture of the writer William S. Burroughs (see Fragment 9) suggested even more possibilities, in a sense overturning how I could conceive of methods which I could use to create knowledge about DFCs, or at least opening up the possibilities of AND…AND, a type of Deleuzean stammering between the conventions of interviewing and participant observation, and the more radical promise of cut-ups and collage. Thinking about this multiplicity, it was also useful to remind myself what Nigel, one of my interviewees and a prominent dementia activist, as well as others, often repeated: if you've met a person with dementia, then you've met one person with dementia. Stepping back from time to time to reflect, it was these three precepts which helped from the outset: keeping in mind that intensity of difference between each person with this condition, being aware of how I was becoming entangled in the various threads of thought around DFCs and being open to the sometimes-random pathways that might open up as the research progressed. Likewise, the refrain (see Fragment 7), smooth and striated space (37, 77), royal and nomad science (81).

The literature in the following fragments then reflects a story of progressive interdisciplinary entanglement, in fields where entanglement itself is so emblematic of aging brains (Lock, 2013), and one of 'rebel becomings' (MacLure, 2013, p.171), where I venture into more non-representational modes of thought (see Fragment 11). This in turn, has helped me to navigate and think about a very diverse set of objects, people and places, a lively 'ageing movement-space' (Andrews & Grenier, 2019, p.63) in the research. A sense of rhythm, momentum, vitality, infectiousness, and encounter came to the fore in the fieldwork, often bringing together the seemingly distant and disconnected in unexpected ways. These have been glimmers of worlds off the beaten path of what a lot 'dementia research' in gerontology focusses on perhaps - even though there have been various disciplinary 'turns', there is still a very bio-medical approach when it comes to such matters. In short, the more time I spent in the field, the more I saw 'dementia' operating by 'variation, expansion, conquest, capture, offshoot' (Deleuze & Guattari, 2013, p.22).

6. From dementia to a Dementia Friendly World

Figure 1: Charity cake stall, builder's yard

> *Dementia is like a kick to an ant-hill; it sets off an excited scurrying to and fro because the order of the security society, which seemed to be guaranteed, has been disrupted (Rothe et al, 2017, p.23)*

Indisputably, dementia has become to be seen as a pressing global issue (Prince et al, 2015). It is estimated that there are upwards of around 46,000 people with dementia in Wales (Wittemberg et al, 2019), a figure that is projected to grow to around 80,000 by 2040, though this was seriously questioned by some of my informants, and highlights one of the general problems of definition which arise when we try to pinpoint 'dementia'. This is a field in which numbers are regularly mobilized for political effect, but in which such figures can obscure the terms of what constitutes 'dementia'; the term has evolved and changed meaning many times over the years. Foucault in his History of Madness commented that the phenomenon appeared 'most secretly incoherent, in that it eludes the clutches of …forms of classification' (2006, p262). This observation would seem to still seem relevant: the term 'dementia' is still incredibly imprecise, describing a set of neurocognitive symptoms such memory loss or aphasia (speech difficulties) with over 200 (and counting) sub-types, even if one sub-type – Alzheimer's – has in effect:

> *[become] a social actor in its own right – an entity in association with which specific language, images, estimates of incidence and prevalence, and concerns about a looming epidemic are mobilized (Lock, 2013, p.53)*

If there is a moral economy which produces, circulates, appropriates, and contests values and affects (Fassin, 2018) around dementia, then hope must form part of that circulation, something 'to be sustained if funding is to keep flowing' (Lock, 2013, p.4), even if dementia is still frequently entangled in a vison over the last few decades of an 'apocalyptic demography' (Robertson, 1990, Lundgren & Ljuslinder, 2011). The use of such numbers helps to cajole and convince us of the need for action, for research funding. Lock's ethnographic account (2013) of the way in which, despite the mobilization of billions of dollars in medical research, neither an effective treatment nor a proper accounting for the neuropathology of Alzheimer's has been found, despite it being the most common form of dementia, is comprehensive and compelling. She explores how the aging brain is conceptualised and how the main medical theories - that of localisation versus entanglement, or individual genetic factors having a major role versus more environmental and complex social factors including ageing itself, are still in contention:

> *Localization theorists visualise AD [Alzheimer's Disease] as a demonstrable neuropathological entity, whereas entanglement theorists are more inclined to understand AD as an emergent process – the product of contextualised individual biologies and life experiences culminating in the clinical expression of the phenomenon of AD/dementia (p.10)*

For her account, she interviews some key people, including Professor Carol Brayne, who led the longitudinal project on which I was a researcher between 2012 and 2015 (CFAS, 2016), and who sums up what is still the perennial problem in biomedicine when thinking about dementia: '*deciding where normal aging stops and dementia starts'…such decisions depend in large part on expectations about aging that are profoundly influenced by culture and politics* (Lock, 2013, p.233).

The thrust of much research, however, remains wedded to versions of localisation, of individual neuropathology. However, the failure of any major therapeutic breakthrough so far in treating Alzheimer's and other forms of dementia has intensified the search for significant biomarkers, or changes in the body that are presumed to indicate future propensity to develop the condition. According to Rose & Abi-Rached (2013), in another thorough account of brain science, the search for such 'biomarkers' is part of a general trend with which 'technologies of anticipation' are seen as answer to the 'burden of brain disorder' (p.14), 'burden' here meaning the panoply of conditions which are seen as being localised in the brain, from anxiety and depression, to addiction, to dementia. Both Lock and Rose & Abi-Rached recognise this shift to prevention – through screening for such biomarkers, for example – as a shift into not only new 'divinatory practices' (Lock, 2013, p. 9), but a move 'from the risk management of everything to a general regime of futurity' (Rose & Abi-Rached, 2013, p.14) in terms of biopolitical governance (see Ageing, Bio-politics, Dementia). Latimer & Hillman (2019) likewise highlight the complexities and continuing uncertainties of using such biomarkers to predict dementia by looking at the latest attempts to do so in laboratories and clinics.

…

The World Health Organization (WHO) and the Alzheimer's Disease International (ADI) see 'dementia-friendly communities' as an 'approach' to normalizing dementia in society, but in the UK, most of the initiatives can be traced back to the Coalition Government (2010 -15) and links with the Alzheimer's Society, which publicly recognises and encourages cities, towns, villages and individual to become 'dementia-friendly' (Linn & Lewis, 2015). By now, this also runs in parallel with the move towards 'age-friendly' initiatives (WHO, 2007, Buffel & Phillipson, 2016).

A large part of the original impetus for DFCs can also be traced directly to the Prime Minister's Dementia Challenge in 2012 (Department of Health, 2015), and the subsequent G8 summit on dementia that took place in 2013 (UK Government, 2013). I have been present at fora where the whole notion of 'Dementia Friends' (Alzheimer's Society, 2019) – a scheme which became emblematic of the drive towards creating DFCs - has been attributed to the Cameron government. Jeremy Hunt, Health Minister during the coalition years, visited Japan in 2013, a key moment for the adoption of the idea of DFC's at a policy level, but also a year where there was already much activity according to some of the informants for this research. Because of its rapidly ageing population[3], Japan had already introduced schemes which were the model for the UK Alzheimer's Society 'Dementia Friends' scheme, called the 'Ninchiso Supporter' (Hayashi, 2013) together with a ten-year plan 'to understand Dementia and Build Community Networks' (Alzheimer's Disease International, 2017). Germany begun to develop similar schemes, such as *Aktion Demenz*, also concentrated on building a network of dementia friendly communities, from around 2004 (Rothe et al, 2017).

A further analysis of the Dementia Challenge 2012 document, however, indicates that it uses many rhetorical resources to highlight the plight of individuals faced with living with dementia, whilst simultaneously reframing the debate into one of an imminent crisis in social care funding (Burke, 2015). In subsequent speeches, Cameron calls for marketization of medical research and investment in global pharma and biotechnology as answers. After he left office because of the Brexit referendum, ex-Prime Minister Cameron was appointed

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[3] *Kōreika shakai* – the ageing society. According to Lock (2013, p.15), demographic changes that took 85 years to unfold in Sweden, 130 years in France, and 70 years in the US, have taken just 25 years in Japan , with a very small birth-rate, and over a third of the population classified as old.

president of Alzheimer's Research UK (Alzheimer's Research UK, 2017), where he remains at the time of writing.

These networks of interest coalesced to an extent with the Alzheimer's Society strategy to create 'Dementia Friends' and Dementia Friendly Communities as their stated aim, aided by an injection of £2.4million from the Social Fund and the Department of Health (for England only) (UK Government, 2012) and £6 million from the Lloyds Banking Group (Lloyd's Banking Group, 2014), in which, at the time, the UK taxpayer had an interest of 43.3% after the financial crash of 2008. The initiative was unequivocally Government-backed financially, but clearly also as a policy objective, in a time when Cameron and others were keen to change the relationship with the state under the auspices of 'The Big Society' (Cameron, 2009). There is not much critical literature out there, in gerontology or any other discipline, which links the two explicitly, though there are faint links and missing reports from policy forum instigated by the Department of Health National Dementia Strategy implementation programme in 2011 which attempted to link the two on a policy level (Dementia and Big Society Think Tank, 2011).

Thinking back to what sparked my initial interest in this field, during that dementia networking and awareness day in Brecon, it was the phrase 'we're all in this together', which I puzzled about initially, then remembered that they were words used by Chancellor George Osborne to justify a period of austerity (ITN, 2012). It was the financial crash of the banks (including Lloyds TSB) in 2008, which provided justification for cutting government budgets, including to the devolved administrations, and then a 'publicly owned' bank which partly funded the Alzheimer's Society scheme. Whatever the economic significance of government debt in global terms as a result of the crash, it was the period when the Chancellor declared that his aim was to reduce the cost of Government to 35% (Wintour & Elliot, 2014), an ideological position which has meant many more cuts to local authority budgets across both England and Wales, many of which have been to social care in its many forms: domiciliary, care homes, day centres. Even if, as in other countries, there was a global investment in the idea of dementia, including DFCs, in the UK as in other Western economies, ironically there was a deliberate *dis*-investment in the very services needed to make sure that many living with the condition could feel supported. By this point, I'd already heard some disillusioned accounts of the very idea of trying to create DFCs through a scheme such as 'Dementia Friends', by people who had already trained to be Dementia Champions – those who train others to be 'Friends'; in making those who live with dementia feel supported and welcome in their own communities, the approach to this was very reliant on different forms of stakeholder involvement and of largely voluntary (i.e. unpaid) effort, in a time when core services for those with care needs were being cut drastically (Ryan, 2019).

7. "We're all in this together"

> *I have been described by that particular newspaper as a tsunami, a catastrophe, you know a dementia tsunami, a dementia catastrophe, you know we're seeing...you know, where you continually promote a deficit rhetoric, rather than looking at older people as an asset, looking at them as a deficit, and blaming them for the lack of economic growth, a drain on resources, you know a handicap to the young, you know not the fact that we charge you people now for an education, we won't give them anything, we won't give them a future, it's old people's fault. Well, it is - because we created this. But within that is the media, the media dialogue, and people...and every time the media interviews and we all go "ohh we're in the newspaper", and off we go, they show a photograph of somebody with old hands …because that's what sells the newspaper, it's fear, because they can say 'look, we love to change, but we can't, these old people, bed blockers'.* ***NH***

As already indicated, during many meetings with people involved with trying to make the lives of those with dementias better, including those with dementias themselves, the phrase 'we're all in this together' (which has reappeared again during the COVID pandemic) was a commonplace during fieldwork. Its contested significance during the past ten years (Danziger, 2019), not least as a phrase which stands at the crossroads of several different austerity narratives (Raynor, 2016), and with the quasi-religious connotations (Forkert, 2014) and never far from ideas of citizen sacrifice (Brown, 2016), gave me a sense that in context of DFCs the phrase was some sort of 'contact zone where…circulations, events, conditions, technologies, and flows of power literally take place' (Stewart, 2007, p3). Deleuze & Guttari

(2013), identify the refrain as a song which marks out a territory, but also gives comfort, like a child singing out in the dark (p.362-363); I wondered if this feature of the phrase was that it 'draw[s] a circle around that uncertain and fragile center, to organise a limited space…The forces of chaos are kept outside as much as possible, and the interior space protects the germinal forces of a task to fulfill or a deed to do' (p.362). By creating this territory, order is restored. But such refrains can move (p.380). In a time of austerity and cuts, a fraying public realm, which task or deed needed to be done?

The phrase also seemed to haunt the places I visited where the work of DFCs was enacted: church vestries, vestries turned community centres, chapels, large chapels turned into municipal buildings, then arts centres, before (at least in one instance) closing down for lack of funding - because of cuts due in part to austerity- but also campuses, hotel conference centres. Arguably, hearing the phrase in the time frame of 2015-17 it was at the height of the 'moral economy' of 'dementia' (Fassin et al, 2015, p9, Fassin, 2018), that is, an apogee of social thinking and relations of power in a particular historical moment, for that particular issue. Whether it was through newspaper headlines, the campaigns of charities, celebrity stories, dramas, books: this period seemed to bring dementia more and more into view. In the First Touchstone, I create a cut-up of the newspaper headlines which seemed to appear every few days on the subject. Brexit and the Royal Family were and other key stories from that period.

I heard the phrase so much in part because I was beginning to get to know the network of activist and others involved in dementia matters, who were also turning up and becoming part of other networks, including academia. In the Touchstones, we will also hear the indignation in this growing dementia activist movement in these spaces, made up predominantly of those with young onset dementias, or those carers who felt let down by lack of resources, the indifference of various systems. This relatively recent movement in Wales -there's a longer history of activism in Scotland, for example, (see Hare, 2020) - has, in part, been sustained by a core a demand for a more inclusive type of citizenship for PWD (Nedlund, Bartlett & Clarke, 2019), and has some parallels and connections with disability activism, which has a longer history, including the adoption of such slogans as 'nothing about us without us' (Shakespeare, Zeilig, & Mittler, 2017). This was no coincidence for people such as Nigel, one of my informants, who has shared platforms with disability activists, and admires their long-standing expertise in fighting negative stereotypes, promoting inclusive strategies and participation at all levels for those with disabilities (Swinnen & Schweda, 2015).

8. Citizenship and dementia matters

Several different models of citizenship have been debated in the context of dementia matters over the last few years. In this section, I will consider them along with others which I think relevant. As already intimated, defining 'dementia' and all it means is a tricky business, let alone what constitutes 'citizens with dementia', but as we shall hear in the Touchstones , battles over such categorisations and conceptualisations can have effects on funding or support for PWD. In a sense, the various categories of citizenship in this field are continuously evolving and contingent upon the contexts and spaces in which PWD find themselves (Nedlund & Nordh, 2015), and appear to be dynamic.

For the most part, however, the empirical work for this thesis has taken place in a time when those PWD have increased agency, can be active both in their claims for rights and their own self-care and are generally encouraged, at least in theory, to exercise their citizenship claims to further belonging to society. That said, it must be remembered that a significant number of those with dementias over 65 years old in the UK, around 40% (over a third of a million people) reside in residential care or nursing homes (Prince et al, 2014), where this picture is more complicated. These latter spaces were recently shut down and closed off due to the health emergency of COVID-19. 'Old age' is often caught between the exhortations to a type of new vitalism, extolling the virtues of an active old age, and the images of the heterotopic deviation (Foucault, 1986) of old age, which are often present in countervailing images and spaces of care homes. These are perennial debates in gerontology, but as the grim scale of deaths of those with dementia living in such heterotopic spaces becomes increasingly apparent (ONS, 2021), it raises more questions about the rights of those living there (see Ageing, bio-politics, dementia).

Of all the discussions around citizenship, then perhaps it is the concept of social citizenship in dementia, largely posited by Ruth Bartlett, Deborah O'Connor and others (Bartlett & O'Connor, 2010, Bartlett, 2016, Nedlund & Bartlett, 2017, Nedlund et al, 2019) that has most prescient in recent years. Social citizenship is a form of citizenship which 'involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level' (Bartlett & O'Connor, 2010) for those with dementias. Bartlett and O'Connor (2010) saw the history of dementia matters as a series of 'moments', or paradigmatic shifts. On the basis of their reading, they posited the emergence of a 'fourth moment' in the dementia debate, one which has evolved from previous approaches, and this model of history largely concurs with other histories of this condition found in social gerontology (eg George & Whitehouse, 2013).

To summarise, the 'first moment' was one where dementia was relatively invisible, where cognitive deterioration was seen as part of 'senility' and the general 'decline' of older people; this state of affairs, in which the aged body was seen as separate from others was common for centuries, though obviously there varied histories of aging across different cultures (see Thane, 2005, for example, for a history of 'western' approaches to old age). Katz (1996) in his work on the formation of gerontological knowledge, demonstrates that medicine from the eighteenth century onwards started to reinterpret disease through sets of symptoms that separated the aged body from other age groups. Tracing the origins and development of the word 'senile' provides an illustrative example of this:

> Senectitude *in 1481 originally meant old age;* senescence *was used in 1695 to mean growing old; and* senile *was used in 1661 to signify what was suited to old age. But by 1848* senile *meant weakness, and by the late nineteenth century it indicated a pathological state…The term has taken on greater medical and negative connotations ever since (Katz, 1996, p.41)*

By the 1980s, however, a ‘second moment’ emerged when the acceptance of ‘senility’ was being challenged: the condition went through a process of biomedical re-labelling, as a neurodegenerative disorder. This medicalisation still provides the basis on which a lot of research and scientific interest in dementia is based, as recounted by Lock (2013) and others, and furthermore to the ‘Alzheimerization’ of the way people look at ageing (Higgs & Gilleard, 2017), a force which, for more critical gerontologists such as Higgs & Gilleard, has also meant the creeping ‘alzheimerization’ of gerontology itself.

The ‘third moment’ signalled a shift from the more negative consequences of this process of medicalisation, of a condition explained in purely neuropathological terms, or that the person living with dementia is often somehow negated in the process as a ‘sufferer’. The 1990s saw an important shift to a more person-centred, psychosocial approach, led by Tom Kitwood (1997) and others, and one which sought to displace the purely biomedical by acknowledging the importance of personal history, interactions with others and how people are perceived in a social context (O’Connor et al, 2007). Bartlett and O’Connor and others have argued that although this approach has had, and still has, a very positive influence on policy and actual practice, its limitations include an ongoing inattention to the agency or capacity of those to influence the circumstances in which they live, and that ‘personhood’ is still *conferred* on those living with the condition – ‘conveying a unidirectional understanding that continues to position a person with dementia as dependent on others for affirmation’ (Bartlett & O’Connor, 2010, p.22).

They also argue that personhood is also often framed apolitically: the socio-political position of people living with the condition, those who are paid and unpaid carers and the wider engagement with political and economic processes are often overlooked. Bartlett and O’Connor, some ten years ago posited that, in the ‘fourth moment’, a more interactive understanding that recognised agency and the importance of contextualising experience, including sociocultural and socio-political context, would be desirable. In a sense, they were articulating some of the more active and activist stances which since 2010, have arguably become far more commonplace, with more of those diagnosed with dementia seemingly shifting towards more ‘active’ modes of citizenship (Birt et al., 2017). Some of the quotes used here in this section from Nigel Hullah, for example, give a taste of how some PWD, especially those part of a younger cohort (but by no means all), are far more prepared to act politically where needed, and we will explore more of these issues in the First Touchstone.

Bartlett and others have gone on to write about activism, predicting a culture of resistance (2012) and in a recent book (2019), written in part in collaboration with Jim McKillop, a veteran Scottish dementia activist, have developed their ideas further, calling for a recognition of ‘everyday citizenship’ for PWD. This call recognises that very often, for PWD, it is the ‘mundane’ which can be very challenging in terms of social relationships, routine practices such as shopping or crossing the road (Nedlund et al, 2019), that it is in the idea of citizenship-in-and-as-practice that improvements can be made to the lives of PWD (Nedlund & Bartlett, 2017). For examples of this, along with other activities, the DEEP network (see In Deep) has produced Dementia Diaries (Innovations in Dementia, 2017), where PWD have phoned in and recorded their day-to-day experiences which highlight the kinds of difficulties faced, but also give a sense of how PWD are able to cope with the everyday experience of being with the condition. For many, ‘*the reality of everyday life – the sum total of all our relations – is built on the ground in daily activities and transactions* (Burkit, 2004, p.212). A relevant interdisciplinary point between geography and gerontology, emerging work around ageing and the everyday takes ‘the everyday’ as a key site for non-representational approaches too: the routine places where things occur (Andrews, 2014, Barron, 2019). Andrews & Grenier (2019, p. 66) argue that ‘*everyday events and places cannot be overlooked by academic scholarship because life happens all the time and everywhere, not just in the specialised areas prioritised in much research’.*

…

Others have conceptualised citizenship in dementia matters as one of ‘narrative citizenship’, that is ‘how people with dementia position themselves in relation to others, and in so doing have to negotiate their own and other’s understandings of dementia’ (Baldwin, 2008, Clarke

& Bailey, 2016). This emphasises the importance of relationships and attachments to and between people and place as an aspect of how identity and citizenship is produced, and on contextualising people's stories with personal and political contexts (Bailey et al., 2013). For my own work, this has been an approach borne in mind as I engaged with particular geographically defined communities e.g. in Brecon, and tried to build up a more detailed contextual knowledge of that area in the third Touchstone; work that started as I collected the accounts of my colleagues in and around Dementia Matters in Powys (DMiP), then spent time with those living locally with dementia as part of the Meeting Centre, but also other who weren't part of the Meeting Centre (see Market Stroll, for example).

In an age of biomedicine, citizenship could also be thought of in terms of struggles over identity, collectivization, demands for recognition, access to knowledge and claims to expertise (Heath et al, 2007). Another lens with which to look at the present state of dementia matters, one that relates to bio-politics in particular, is through the idea of 'biological citizenship', as articulated by Rose & Novas (2008), Rabinow (1996) and others: an emphasis on the making of citizens through collectivising moments that organize around particular biomedical classifications – from Huntingdon Disease to AIDS activism, for example, or dementia activism in our case.

The contention here is that there is a process of 'making up' the biological citizen, in the way political authorities, medical personnel, the legal profession, insurance companies, employers and others (including academics) might see a person with dementia, for example, and how this diagnostic and interpretive gaze then sets out boundaries which can be both 'dividing' and 'unifying'. It sets out how people with dementia might get treated in a certain way e.g. punishment, therapy, benefits, but it also unifies those within the category. Rose & Novas (2008) develop an argument which builds on previous ideas of bio-sociality, positing a 'political economy of hope', underpinned by what Fassin (2009) calls bio-legitimacy, where the aspirations of those affected by a condition fosters the necessary political and social activism to galvanise against injustices, such as ineffective or uncaring welfare policies, for example. They also cite the key role played in advocacy of creative individuals.

In a wider context, looking at ideas of community cohesion, Fortier (2010, 2016) and others (Johnson, 2010, DiGregorio & Merolli, 2016) explore how government increasingly draws on a register of emotions to define ‘good’ citizenship, such as being compassionate or empathetic to others, ‘the ways that [such] community cohesion…relies on strategies of governance that seek to design particular kinds of human behaviours such as ‘mixing’ or ‘meaningful interaction’ in view of ‘delivering’ cohesion in the community’ (Fortier, 2010, p.18), a way of managing ‘unease’. Given that the provenance of the whole concept of DFCs in the UK came at the height of the government drive for ‘austerity’, and that there are clear links between the major actors who initiated this approach (governmental, banking, charity), it would be possible to speculate that on one level, this strategy would have been a welcome response to the inevitable divisions that might emerge in community cohesion. Given the scale of the austerity cuts proposed, which hit areas such as the provision of social care and other key frontline services necessary for those with dementias and their carers, the encouragement of such affective citizenship, aimed in part at lessening ‘the burden’ on the state as much as raising awareness of dementias, was also another expression of the Cameron ‘Big Society’ project.

As we shall see in the First Touchstone, in Wales and beyond, Nigel and other PWD who take more activist roles, manage to engage prominently in processes such as the government consultations, ministerial task and finish groups, or as part of dementia think tanks or academic conferences (Dementia Policy Thinktank, 2016). People with early stages of dementia are being encouraged to engage, often through the support of organisations such as DEEP or the Alzheimer’s Society, with government of all types, and with technologies such as ‘the consultation’, or through various other such events/technologies – local voluntary sector meetings, health boards, think tanks etc. In a sense, such political solidarity and purpose based on living with their condition, is helping to constitute them as citizens (Isin, 2005). The stigmatised ‘outsider’ status, which has up until recently meant those living with the condition were often perceived as being isolated, unconnected even ‘socially dead’ (Sweeting & Gilhooly, 2008), seems to be shifting. Could this be because of the drive towards DFCs?

9. Interlude - A Man in Bethel Square

Figure 2: A Man in Bethel Square (copyright Harriet Crowder, 1960)

> *What is a place? Perhaps haunting is a pre-requisite to place. That is, a place takes place through a spectral event of displacing. There is place if there is a dislocation, or sudden uncertainty regarding location in space and time, uncertainty regarding even the reliability of these measurants; in other words if there is a disturbing irruption of doubt or memory, a confounding of past, present and presence all witnessed by a troubled, stricken figure, a figure haunted by this very process. (Wylie, 2007,p180-81)*

> *Without moving his lips, he dictates the script. You find yourself ventriloquized by texts he has not yet composed or will never compose. (Sinclair, 2013, p.160)*

A chance post-seminar conversation with a colleague led me to a relatively obscure picture of the writer William S. Burroughs – sometime Beat, *avant-garde* writer (Hawkins et al. 2019), godfather of punk and drug culture (Rae 2020, Miles 2015), bio-semiotic guerrilla even (Patoine 2019). Taken on a sunny afternoon in Brecon in 1960 by photographer Harriet Crowder, it is in the market town where I have spent considerable time in pursuit of the *tylwyth teg*.

The picture is in black and white, with sharp shadows, a telegraph pole on the right, wires horizontally cutting the top third over signage and windows. In the centre, in the bottom third, in front of a deep archway, is the writer, a slight but tallish figure in a heavy suit, one arm held in front, the other by his side, trilby and thick classes framing his skull. There is a chapel in the distance behind him, it's signage above the entrance to the square containing the church in bold letters ('BETHEL C.M. CHURCH. WELSH & ENGLISH', a bilingual Calvinist Methodist chapel). If old photos sometimes have the quality of haunting, of a type of death in life (Barthes 2000), then this photo, its deep archway reminiscent of a portal of some sort, feels like an invitation to another world[4], Burroughs 'a ghost in daylight' (Burroughs, 1977, p.29). A contemporary description of the writer in The Spectator magazine noted 'he has a withdrawn, isolated stillness, a kind of spectral presence' (Allsop, 1960, p8). This is not the only instance in this thesis where such spectral feelings seem, for an instant at least, to

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[4] For a full account of the history of this photoshoot: (The Function Rooms, 2015). Every effort has been made pursuing the copyright for this picture and trying to get in touch with Harriet Crowder, via the Vargas Organisation, who put on an exhibition of her work in 2015, and 'an independent scholar of Beat', Jim Pennington, who co-curated, but without success.

confound the orders of past and present (Wylie, 2007), but I returned to this spot several times to photograph and ponder his presence there on that day, and how it has led me to try to think differently about how to proceed with this exploration of dementia and community. The urban topography of Brecon - the market town in this picture - is familiar to me by the time my colleague had mentioned the image, as I'd already got to know some of the characters and spaces involved in making Brecon 'the first town in Wales to be granted the status of Working Towards Becoming Dementia Friendly' by the Alzheimer's Society (Dementia Matters in Powys 2017). Over the years, I'd also spent the occasional balmy August night with friends in what used be the annual international bacchanal of music called Brecon Jazz.

Burroughs stands on a corner: to the left of the scene, you will still find the Guild Hall, traditional seat of power where I had recently sat through meetings in which councillors, mayors, activists, representatives of charities local and national had pondered how to make the town 'dementia friendly', to the right, a back street that eventually re-joins a route down the hill on which these main squares and buildings reside. The poet Anne Carson, in a lecture about coming to terms with her own father's dementia, notes how it is in corners we can find a locus for understanding: 'Corners are what make a grid different from a line, a plaid shirt different to a striped one…corners make personality out of persons, maps out of surveillance' (The Graduate Centre, 2018). If research can be classified as a kind of surveillance, then this photo has helped me to form an idiosyncratic mapping of dementia friendly communities as I've experienced the phenomenon.

By now, the chapel has moved on from dispensing salvation to dispensing drugs as a pharmacy, the signage is perhaps more bilingual than in 1960; it even supplies free clean injecting equipment, which might have raised a thin smile from Old Bull Lee, as his sometime fellow-Beat Jack Kerouac called Burroughs in On the Road (1957). These grand husks of religion, the one here tucked away in its own square, still play an important role of sorts in this part of the world, peppered as they are throughout Welsh towns and villages. Occasionally they are still religious, but often they now act as civic, commercial, or even private buildings, and spaces where, as I experience in this research, certain types of governance or charity, often through volunteerism, are acted out or become visible, including matters arising around dementia. This is one of the spatial threads throughout this thesis; at times the feeling of being in such places was one in which 'Pasts and futures, even if they are no longer, even if they are not yet, still haunt the present, and are, in a supplemental relation to it, *always coming back'* (Wylie, 2007, p172). Reminiscence, memory, nostalgia, confusion, along with indignation, anger, or earnest exhortations to empathise and help: all form part of an ambient mapping (Stewart, 2015) of the 'not yet', at times, and 'things becoming phenomenon' at others, while exploring DFCs.

Being alerted to this picture gave pause for thought. His presence haunts this thesis in parts, much as he does others' work, from the slightly obsessive American odyssey of Iain Sinclair, quoted above (2013) to Taussig's ficto-critical account of Colombia (2004). In effect, his presence here introduces a line of flight (Deleuze & Guattari, 2013) a means of escape between the disciplinary and methodological boundaries of the research, as new possibilities become possible. This was a period when I was beginning to familiarise myself with some of the metaphors used by Deleuze and Guattari, and how I could work with them 'in a way that might produce previously unthought questions, practices and knowledge' (Grinberg, 2013, Mazzei & McCoy, 2010, p. 504). It occurred to me that by following this picture – it's story, what it represented, the influence and practises that Burroughs introduced – there might be creative clues into other ways of thinking about DFCs.

Moodier pictures from the very same photoshoot taken in the portal ended up on the cover of his first spoken word LP, whose liner notes were written in French by Jean Jacques Lebel, a key figure or 'radar scout' (Demers, 2018, p.67) who connects the Beat outpost in Paris (where Burroughs lived for a while) with figures such as Deleuze and Guattari[5], a figure who also connected the Beat generation to the French avant-garde (Heil, Fleck, and Mahon 2014), and someone who, along with Sylvère Lotringer, 'introduced' French thinkers such as Deleuze, Guttari and Foucault to North America (Demers 2018)[6] ; this ultimately led to the Schizo-culture conference in 1975, which brought together American counter-culture with prominent post-68 French thinkers.

These connections, and subsequent explorations in terms of methods and thinking, might not have become apparent to me without the picture coming into my consciousness. As we shall see in the touchstones, this leads to the use of methods associated with one of Burroughs's incarnations as part of the Beat movement, which themselves owe much to the *avant-garde* of the 1920s.

To be clear, my awareness of this picture came at a time when I had an increasing sense of impasse as I read my fieldnotes, inspected photos, thought about all the meetings, interviews, collections of pamphlets, theatre programmes and other ephemera, in my attempts to see what was emergent or even occluded in the idea of DFCs. How exactly was I to convey an increasing sense of a multiplicity, of the 'in-here' and 'out-there' of the research (Law 2004) as I'd lived with it, by that point for a couple of years? How would a collection of words, images and sounds of dementia, of friendliness, of community, come into being, not only here in this town, but in everyday life? What elements would reveal themselves in the

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[5] Another picture which I came across, taken by Lebel, is of Deleuze on Big Sur beach, California, taken after they embarked on a road trip of the US after the Schizo-culture conference of '75.

[6] On a trip to Paris, some six months after seeing the photo of Burroughs in Brecon, by accident I came across an exhibition by Kader Attia and Jean Jacques-Lebel at the Palais de Tokyo: https://www.palaisdetokyo.com/en/event/one-and-other which led me further into thinking about these connections.

daily dance of research, once you begin to attune to the practices and claims made in the name of DFCs, and what remains beyond, in excess and is never quite captured? The picture of Burroughs set me off in a direction that began 'a consideration of the politics of what Phelan (1993) calls the 'unmarked', that, is, an attempt to find, value, and retain what is not marked as 'here', yet palpably still reverberates; that invisible dust still singing, still dancing' (Thrift, 2000, p. 214).

10. Critical and cultural gerontology

> *As Cephalus suggested, in the past as in the present, the most striking feature of old age is diversity. 'Old Age' is a diverse phase of life partly because of its very length. It is said to extend from the fifth decade to past 100. Old people include some of the fittest and some of the most decrepit, some of the richest and some of the most powerful and the poorest and the most marginalized in any society (Thane, 2005, p.15)*
>
> *The image of the aging population is that of a burdensome and cumbersome behemoth that roves greedily across fiscal territories, demanding and consuming resources, and sacrificing the future prosperity of shrinking younger generations to priorities of its own needs (Katz, 2009, p.13)*

In chronicling the intellectual life of critical gerontology, Katz (2009) highlights a lineage of writers who have sketched out a terrain which seeks to 'challenge the instrumentalism of mainstream gerontology and broaden ageing studies beyond biomedical models' (p.85). Certainly, there seem to have been protracted internal debates in a discipline which is often seen as 'data-rich but theory poor' since at least the Eighties, one where, as already mentioned, reductionist biomedical models still remain prominent, even if there have been notable attempts at signposting and developing more theoretically critical stances from that period onwards (Phillipson & Walker, 1987, Cole et al, 1993, Cohen, 1994, Minkler & Estes, 1999, Bernard & Scharf, 2007). Katz could be seen as one of the more consistent voices in critical gerontological voices within these debates, his work spanning Foucauldian approaches to the formation of gerontological knowledge (Katz, 1996), approaches from the humanities, feminism and cultural theory (Katz, 2009), and further interdisciplinary analyses which address issues of materiality and embodiment in older lives (Katz, 2019). By no means the only critical voice in gerontology, he has nonetheless consistently maintained that such ‘criticality derives from the gerontological tradition of fracturing, transfiguring, borrowing and recombining theoretical ideas for *outside* of aging studies’ (Katz, 2009, p.15) [my emphasis]. Citing Cohen (1994) he is also careful to clarify that it is important that the criticality in critical gerontology should not be confused with a type of ‘mission practice’ (Cohen, 1994, p.146), a benevolent ‘mandate to liberate ageing and older people from an ageist world’ (Katz, 2009, p.91).

From my perspective, this strong liberational strand to ageing studies continues, partly because political economy perspectives that have been popular in gerontology since the late Eighties. The work of Estes (1986), Phillipson (1983, 1998) and others have examined the structural pressures of class, gender and ethnicity on the experience of ageing and are often critical of ‘unjust ageing’, including the social and health justice implications of this for older people. This perspective remains important within gerontology and a source of continued enquiry into issues of equality, diversity, and intersectionality (Westwood, 2019). However, Phillipson (1998) and others in the Nineties signalled a move towards a critical gerontology which recognised a more ‘humanistic’ approach. This meant turning attention to literature, narrative, and biography, and to exploring issues of meaning and experience in ageing, recognising not only the importance of social structures, but that individual lives could be seen as socio-culturally constructed.

This ‘cultural turn’ has increasingly tried to pay attention to older people’s everyday lives, by questioning the underlying structures, socio-cultural frames, technologies and institutional practices involved in their lives. Often referencing the work of Bauman, Beck and Giddens, and therefore acknowledging the changes brought on by the development of a ‘risk society’, radical changes in working practices and the role of globalisation, there has been a recognition that such changes in society seem to undermine previous certainties, and find ‘an increasing fluidity, indeterminacy and reflexivity in the formation and exercise of social identities and individual lifestyles’ (Gilleard & Higgs, 2015, p.29). While it’s certainly true that much of gerontology still seems to be predicated on ideas around frailty, or social welfare and medical perspectives, over the last twenty years or so there has also been a steady stream of work which is more concerned with subjectivity and identity, the body and embodiment, representation and the visual, time and space (Gilleard & Higgs, 2013, Kontos, 2005, Kontos et al, 2016, Twigg & Martin, 2014). This move recognised that the life-course was becoming 'de-standardised' (Brükner & Mayer, 2005), in particular because of factors such as the rise of a consumer society, but also through the reverberations of the social movements of the 60s, and 'the changing social geography of life and the changing nature of work and retirement' (Gilleard & Higgs, 2015, p.32).

These changing expectations of life apply equally to PWD, of course, and maybe in particular the younger cohort, with an emerging literature on how there are many shifts in expectations (Bartlett, 2014, Lazar & Dixon, 2019) and challenges to the status quo in many settings, as we shall see in the First Touchstone. It is also important to note that the spatial relations of ageing and later life have also engendered much research interest over the last couple of decades, through environmental or geographical gerontology (Hyde, 2019). The diversity of research in this area includes, for example, such subjects as retirement migration (Warnes, 2006), residential arrangements (Peace et al, 2007), place attachment (Smith, 2009) and age-friendly cities (Buffel et al, 2018). Buffel & Phillipson (2016) return to the theme of 'unjust ageing' and the need for spatial justice (Soja, 2010) by offering a sustained critique of the idea of that such age-friendly policies can ever be successful unless they are properly embedded in all aspects of policy making and urban development. They maintain that the impact of austerity-type cuts to social programmes, coupled with the shift towards the privatisation of a lot of urban space, have made such policies even harder to implement. This critique of the impact of austerity cuts on 'friendly' policies could be equally applied to dementia-friendly policies.

11. Geographies of ageing, non-representational theory and affect

Different disciplines take up ideas at different times. Critical gerontologists such as Katz have repeatedly called for a conception of the discipline as a 'pragmatic and nomadic thought-space across which ideas flow and become exchanged' (Katz, 2009, p.86, with similar point made in 1996, p.140, 2019). However, there does not seem to be a widespread shift in gerontological thinking towards post-structuralist or post-humanist approaches, for example which seem to have been embraced by many in human geography.

Andrews (2020), reflects that despite some overlapping critical perspectives in both gerontology and human geography, recent scholarship in gerontology, including that associated with the cultural turn, seems to still draw largely from humanism and social constructionism, even if there seems to have been a ‘spatial turn’ in gerontology over the last decade or so (Andrews, 2013). Skinner et al (2015) provide a comprehensive overview of the history of the geographies of ageing over the preceding twenty years, taking as a starting point a paper published by Harper and Laws (1995). Evidently, there are many points of mutual interest between both disciplines, which they set out at length (Skinner et al, 2015, p.778) and which are similar in scope to those set out by Hyde (2019) and reflect the work of researchers such as Barron (2019), or Singleton (2020), among others. They also set out quite clearly how the turn to non-representational/more-more-than representational approaches (which I’ll shorten to NRT), still a relatively common and important approach in human geography, could enrich gerontological research at that crucial interdisciplinary overlap between the two disciplines.

Certainly, my own exposure to NRT and affective approaches probably started in earnest just prior to the encounter with the picture of A Man in Bethel Square. Engaging in a wider literature around affect, for example, and some key texts (Anderson & Harrison, 2010, Stewart, 2007, Seigworth & Gregg, 2010) then opened the door to thinking differently about how to approach the field, and how to develop methodologically; these influences, though certainly not exclusively from geography, are speckled throughout the next section and the Touchstones to come.

My current understanding of NRT largely concurs with Skinner et al (2015, p. 788), in that it seeks to: ‘bring attention to the many unspoken and too often unacknowledged performances and practices involved in the reproduction of space, place, and social life’, and in trying to think what this means as I go about my research. This is an active process that has led me to think differently about what I value in the research process and what is often lost by trying to fix some kind of representation of the 'the world out there', even if it is almost inevitable that in the Touchstones to come, I have done this. However, Skinner et al (2015, p.788-89) provide a list of ten features or approaches which summarise and chime with my other readings what using NRT might mean. Here I've adapted and summarise some from the list, recognising them as 'tactical approaches':

- being aware of the onflow of life: appreciating the change and fluidity, potentiality and processional nature of the world
- appreciating that life is vivacious and full of energy and can often be moved by irrational and unpredictable impulses
- awareness of both materiality and relational materialism – so developing awareness of interaction between the human and non-human
- focussing on practice and performance, including engagement of the body, bodies together, and bodies and objects together
- taking notice of senses and sensations – the embodied corporeal experience of being in the world - this leads to 'affect' as an explanatory concept
- engaging with everyday events in life, and the everyday places where they occur – realizing life is all the time and everywhere (and that the mundane is, thus, as important as the remarkable).
- the importance of engagement and 'acting into' the active world, helping it to speak and change. This involves changes in methods and knowledge translation (and a more general agenda towards an activist and public scholarship).
- reading and re-reading theory for insights into the active world, and developing a livelier engagement with theory itself

Through my readings of Anderson & Harrison (2010), Vannini (2015) and many others, these have all been conclusions and ways of thinking that I can hopefully demonstrate I have used in the sections and Touchstones that follow.

Of all the concepts in this summary, it is attention to the 'affective' - the capacity of a body to be affected by bodies and objects, and to affect bodies, and how this is experienced as a pre-conscious, or just below conscious sensation or feeling state (Skinner et al, 2015, Massumi, 2002, Thrift, 2004, Anderson, 2009, 20016, Seigworth & Gregg, 2010), which has been one of the most important aspects of my learning over the past few years. Being aware that something was going on in that scene at the start of this thesis or acknowledging and trying to attune to the various events and happenings of the research has become an important concern in my work. Finding such a new vocabulary has been one of the most rewarding parts of this work.

12. Ageing, bio-politics, dementia

> *With the depoliticized, socially objective, expert administration and coordination of interests as the zero level of politics, the only way to introduce passion into this field, to actively mobilise people, is through fear, a basic constituent of today's subjectivity. For this reason, bio-politics is the politics of fear, it focuses on defence from potential victimization or harassment. (Žižek, 2008, p. 34)*

Gilleard & Higgs (2015), together with Katz (1996, 2009) and others point to the continuing importance of Foucault as a relevant current in critical, social and cultural modes of gerontology. The broad trajectory of his work could be outlined as one which moved from the punitive and disciplinary aspects of power to bio-power, which focuses on maximising the health and welfare of the population (Rose, 1999), to more actuarial strategies of governance, including governance of the self. His earlier account of discipline, with an emphasis on 'docile bodies' as surfaces where power was inscribed, later developed into one which recognised the importance of the active subject as an entity through which and by means of which power is exercised. His concept of the art of government or ‘governmentality’, the ‘conduct of conduct’ had been of particular interest to me in previous work (looking at drug ‘outreach’ and ‘harm reduction’ strategies, for instance) and in essence governmentality is a ‘political project – a way of problematizing life and seeking to act upon it, which identifies a territory (i.e. a social space) and a means of intervention’ (Campbell, 2002), an ‘art of government’ (Foucault, 1991, p.90). In the next section we’ll look at some of the ideas around pastoral power, a concept which seemingly came just before this phase in his work according to the published lecture series (Foucault, 2009b), and some of its implications when think about DFCs.

Governmentality, itself built on the idea of bio-power or biopolitics and the emergence ‘population’ and demography (Walters, 2012, p.15), the main subjects of this section, has resonances with our concern with dementia and the move to create DFCs, a type of conducting of conduct through various circuits of government and civil society, through schemes such as Dementia Friends, for example. As we shall see, though, such power circulates in all directions, encounters resistances. Katz (1996) demonstrates how the analytical use of an idea such as governmentality in relation to the politics of demography became crucial to the formation of gerontology itself:

> *The historical evidence demonstrates that in the nineteenth and early twentieth centuries, old age was cast as a social problem requiring governmental response. Custodial institutions and retirement and pension programs configured the elderly as a special kind of people, while statistical and survey knowledges elaborated their status as a demographic entity. Thus, the disciplinary formation of the elderly as a population made possible the government of old age and the cluster of professional knowledges that facilitated it. (p.24)*

Bio-politics seems to be a concept drawn mainly from Foucault’s lectures at the Collège de France in the late Seventies (Foucault, 1981, 2008, 2011), but has engaged the attention of many thinkers. The term covers a far larger lineage than that which can be attributed solely to Foucault, including the many racist and eugenicist horrors of the 19th and 20th Centuries (Lemke, 2011a, Campbell & Sitze, 2013). Even in more modern definitions, bio-politics can range from very expansive notions about anything to do with the management of human life, labour or existence, to a narrower understanding that it stands for administrative and legal procedures that police the boundaries of bio-technological interventions (Lemke, 2011a).

Nielsen (2006, 2012) and Latimer (2016) home in on how it relates to the formation of an ageing-dementia relation in particular, but most pertinently on 'the massive capital investment in the vitality of molecular life and the marked social disinvestment in forms of care and welfare that address the well-being of the body' (Nielsen, 2014, p.46), one of the underlying stories of the period we are looking at. As we have seen, the political impetus for creating DFCs came precisely as services were being cut in the name of austerity, while the thrust of the Cameron speeches on this matter from 2012-14 was that more investment in biomedical research to find the 'magic bullet' that was needed. During my fieldwork, this also suddenly became the priority for the Alzheimer's Society, committing ever greater sums to research, whilst funding for Dementia Friends was presumably tapering off (Alzheimer's Society, 2017). Fassin (2009), analysing the division between this macro level (e.g. questions of power and resistance) and the micro, notes that biopolitics can be about 'demography, epidemiology, psychology, on the one side; family planning, public health, policing of the self, on the other' (Fassin, 2009, p52). Lemke (2011) adds that:

> *the meaning of bio-politics lies in its ability to make visible the always contingent, always precarious difference between politics and life, culture and nature, between the realm of the intangible and unquestioned, on the one hand, and the sphere of moral and legal action, on the other' (p31).*

Thinking with biopolitics has a role when we consider how DFCs have been framed as one possible answer to a particular 'crisis of demography'. A biopolitical mobilisation of such a 'crisis' speaks to the broader literature on governing and problematization (Rose, 1999, 2007, Brown, 2015, 2016), and it 'unpacks how individual and collective life in liberal societies is increasingly governed through a variety of techniques, strategies and rationalities of emergency…[it] signals [a] problem-space amongst others where liberal order has become structured *through* an uncertain and dangerous future' (Anderson et al, 2020, p. 622, Collier & Lakoff, 2014, Foucault, 2011). If we consider the scalar dimension to such biopolitics, then government works not just on the macro, but also the micro, the ordinary: when we think of

PWD and their carers, and spend time with them, we can consider the ‘crisis ordinariness’ of their situations: ‘Crisis is not exceptional to history or consciousness but a process embedded in the ordinary that unfolds in stories about navigating what’s overwhelming’ (Berlant, 2011, p.10). In the three upcoming Touchstones, I hope to demonstrate some examples of how this navigating unfolds.

Concepts related to updating and exploring the ‘bio-political’ further, such as bio-legitimacy and bio-sociality, were explored in earlier fragments, highlighting how new collective and individual identities emerge through the interconnectedness of biomedical knowledge. Identity, selfhood and political action come to the fore: patient groups, self-help movements and organised family/carer involvement are in effect a kind of collective subject that breaks down the distinctions between ‘laypeople’ and ‘experts’. This kind of ‘bio-politics from below’ is relatively under-researched (Lemke, 2011), but there have been clear instances in the Touchstones where these distinctions have been blurred or challenged. In addition, this provides space for resistance in the form of counter-conducts, as outlined in the next section.

It is also worth noting how bio-politics and bio-power are also linked by some theorists to a politics of death, or necro-politics e.g. Mbembe (2013) or Agamben’s concept of ‘bare life’ (1998). As a background to this, Fassin (2009) explores the more nuanced differences between the two Foucauldian concepts of sovereign power and bio-power: sovereign power is the right to ‘make die and let live’, while bio-power ‘makes live and lets die’. From this, Fassin develops his notion of bio-legitimacy, the foundation of biological citizenship. He identifies the ‘hidden horizon of death’ (p.52) which accompanies bio-politics: how governments make decisions about health and social policies, education and welfare, can and do have massive impacts on the lives of the population[7]. As we shall hear in some of the

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[7] In common with other governments, the Welsh Government has consistently shown an interest in managing biological processes, including death, through the recent introduction of having to opt out

discussions during this research, PWD are constantly having to justify access to welfare for example, and struggle to gain legitimacy under a regime introduced in the shadow of austerity, and which is by now implicated as a causative factor in many deaths (Ryan, 2019, Williams, 2017), including those with disabilities or dementias. At the same time, there is an expectation that they are active, self-governing citizens.

As the scale of deaths of those with dementia because of COVID-19 living in care homes becomes increasingly apparent (ONS, 2021), then it would seem that a decade of promoting DFCs has ended with the grim realities of underprepared governments, and a social care system which is still riddled with chronic underinvestment, mainly because of austerity and a speculative private equity sector (Blakely & Quilter-Pinner, 2019), that owns most of this provision for those with dementias. This might well represent a not-so-hidden 'horizon of death' where biopolitics has tipped into a type of necro or thanato-politics, 'politics as the work of death' (Mbembe,2013, p162), enmeshed in the necro-economical (Montag, 2013), a true geography of violence (Doel, 2017). 'Who do we not save?' (Schraer, 2021), was written on the infamous Whitehall whiteboard in the initial stages of the pandemic, which begs the question of whether what happened was a 'negative population policy' (Gallagher, 1997). Comparisons and critiques have been made of Agamben's notion of 'bare life' and PWD who live in care homes (e.g. Leibing, 2006, Capstick, 2017 and a critique by Burke,2019). In truth, as one of my informants reported, this is not the first time in recent history that the lives of those in care homes had been disrespected– the Banerjee Report(2009) had , in the run up to its publication, highlighted the widespread abuse of antipsychotic medication which had led to over 2000 unnecessary deaths per year, mainly of people with dementias. Rhiannon,

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of organ donation at the point of death (Welsh Government, 2018b), in effect creating a new relationship between life and death in Wales, where death has become another process, 'a productive circuit…used to improve and extend life' (Lemke, 2011a, p95).

one of the founders of Brecon and District Dementia Friendly Communities, and the person who I'd heard say publicly 'we're all in this together' at that networking event, was an ex-pharmacist, and this had been part of her motivation to set up a DFC in Brecon. Even so, since then COVID-19 has laid bare much of the rhetoric around dementia, care and the precarity of older populations, but also notions such as the 'vulnerablilty' of ageing people (Tremain, 2021, Butler, 2009).

13. Pastoral power and critical counter-conducts

> *…government, by going with the grain of human behaviour… can influence social behaviour by changing social norms…with the right prompting or 'nudge', government can effect a whole culture change. (Cameron, 2009)*

An earlier phase of Foucault's work was preceded, at least in the Collège de France lectures (Foucault, 2009b), by his observations on pastoral power, which came from the question of 'where does a power that takes the form of guiding, shaping, leading, conducting humans first emerge?':

> *I think that we can say that the origin of the idea of a government of men should be sought in the East, in a pre-Christian East first of all, and then in the Christian East, and in two forms: first in the idea and organization of a pastoral type of power, and second, in the practice of spiritual direction, the direction of souls (Foucault, 2009b, p.123)*

Recently, there has been some renewed interest in this technology of governance (Rose, 2007, Walters, 2012, Jones, 2018) including in the field of healthcare (Mayes, 2009, Waring & Latif, 2017, Martin & Waring, 2018), and there are some references to this in the field of dementia, for example the use of the Activities for Daily Living Scale, used to assess those with dementia, as a form of 'pastoral' regulation (Cohen, 2006), and how it is a key component of 'self-care' for those with dementias (Jones, 2018).

Foucault asserted that the figure of the shepherd/pastor is key to the way that church leaders guide individuals and shape moral conduct. Walters (2012) states of pastoral power:

> *By means of certain exercises – notably confessional practice – [he/she] takes hold of techniques of individualization <u>and ties them into its practices of governing a multiplicity</u>. As much as of 'inner truth' and 'the self' might appear like second nature to us now – intimate experiences that could not seem further removed from the distant anonymous world of political rule – Foucault suggests that they are not eternal but have a history that is closely tied up with governance. (p.22)*

The act of confession encourages the examination and regulation of thought and actions, but Foucault's main assertion was that such rituals have migrated from those early Christian communities into a wide range of areas, from education to the family, to medicine and healthcare. Interrogations, interviews, consultations and biographical narratives - all are an essential part of state and other apparatuses, as we shall see in the Touchstones, imbued with power relations: not just pastor-parishioner, doctor-patient or teacher-pupil, but also the project worker–service user, or facilitator-participant, researcher-informant, Dementia Champion-Dementia Friend. Waring & Latif (2017) look at how a more modern 'pastorate' is made up of health experts, therapists, expert patients, pharmacists, cultivating self-governing patients, making sure that citizens take greater responsibility for their health. This contemporary pastoral power is often 'beyond the state', it:

> *is not organised by the state, even if we use this term to encompass the whole complex of legislative provision, state-funded research organisations…It takes place in a plural and contested field traversed by codes pronounced by ethics committees and professional associations…by researchers…the advice offered by self-help organisations (Rose, 2007, loc.1768)*

Jones (2018) asserts that if for Christian communities, salvation is in the next world, 'salvation' in this world can be 'better understood as health, wellbeing, security, or protection against accidents' (p.990). Rose (2007, loc.1768), however, draws an important distinction between the Christian pastorship in which power would usually flow in one way, requiring submission and more modern iterations which 'entail intense bidirectional affective entanglements between all the parties to the encounter'. For our purposes, pastoral power is a useful concept given the sheer range of confessional practices witnessed, and in which I participated, as we shall see in in the Touchstones. At the same time, rather than falling into some sort of rigid ‘applicationism’, the idea has been to regard each instance as a critical encounter, with its own dynamism (Walters, 2012, p.5).

If we read further (Foucault, 2009b) we find out how such pastoral power was resisted, by means of critical counter-conducts, concretely five practises which tend to ‘redistribute, reverse, nullify, and partially or totally discredit pastoral power in the systems of salvation, obedience and truth’ (p.204). These are ascetism, the formation of communities, mysticism, the return to scripture, and eschatology. Critique, or a critical attitude, was defined in a lecture delivered around the same time as ‘the art of not being governed too much’ (Foucault, 1996, p. 384). Golder (2015) in his book about Foucault and the politics of rights, asserts that to be critical in this specific sense is to pose questions of the government of conduct:

> *Using the available political resources and repertoire furnished by government itself, a kind of refractory turning of government against itself from within the discursive and political field of possibilities opened up by government (p.22)*

As we shall see, during the period when the call for DFCs was at their height, other communities began to form, and organise into networks (see In DEEP), and by means of consultations and other technologies of government, various strategies of counter-conduct, often centred around a very activated form of citizenship, began to emerge. At the same time, confessional practices were present in many forms throughout the fieldwork, from the macro (a government consultation), to the ‘circle work’ of the Meeting Centre in Brecon, to my interviews.

14. Community

> *…a knowable community, within country life as anywhere else, is still a matter of consciousness, and of continuing, as well as day-to-day experience (Williams, 1973, p.240)*

> *Consensus is always a product of a power-over. (Massumi, 2015, p.69)*
>
> *The search is on to reinvent community for a modern age, true to core values of fairness, co-operation and responsibility (Blair, 1996, in Miller & Rose, 2008, p.90)*

Over the last forty years or so, community has re-emerged as a central theme of public policy (Taylor, 2011), in tandem at times with neo- or advanced liberal moves to choice, personal responsibility, self-government on the one hand, and as a foil for market forces, remote governments on the other (Miller & Rose, 2008, p.92). As with ‘dementia’, the meaning and significance of ‘community’ seems to be quite contingent, slippery even, and seems to have changed over time. It is a word which invites several types of spatialization: a social space, a geographical space (a predefined territorial entity), a space of services, a governing space (Rose, 1999) or, on the other hand, we can have a ‘community of interests’, one that may be rooted in a bio-social form of citizenship, for instance. Crow & Allan (1994, p.1) characterise community as ‘…a convenient shorthand term for the broad realm of social arrangements beyond the private sphere of home and family but more familiar to us than the wider society’. However, this definition could equally be applied to the idea of neighbourhood, itself an important, ongoing spatial concept when thinking about dementia and place (Keady et al, 2012), and one that is prominent in recent NRT inspired work in geography and gerontology (Barron, 2019, Singleton, 2020).

In gerontological terms, there is also a growing interest in developing Community Gerontology as a type of research framework in ageing studies (Greenfield et al, 2019), with a research emphasis on the neighbourhood as a space older adults’ health and psychological well-being, research on aging in place, age-friendly communities and issues such as urbanization, migration, gentrification, and climate change as they affect older adults by impacting on local communities. Age-friendly communities, as already discussed, is a parallel framework to DFCs (Buffel et al, 2018, Buckner et al, 2018, Turner & Cannon, 2018).

However, Schillmeier (2014, p.14), quoting Goffman (1963, p.40), critiques the vision of communities in in DFCs as places which are thought to be or become ‘wise’ communities:

‘communities of ‘normals’ who are well-informed about people with dementia [i.e. stigmatised] and help to assist a similar ‘wise’ health system to enable people with dementia to re/gain normalcy…independency, discretion and self-control…to increase their quality of life’. The tension within this ‘wise’ idea is that of:

> *the will to normalize a bio-political [i.e. biomedical] understanding of dementia and to re-normalize the life of people with dementia…the former process of normalization defines dementia as a disease…[whilst] the latter recognizes independency, discretion and self-control as the ordinary forms of normal human life which reflect the modernist requirements of the human being as the self-reigning subject*

Effectively, thinking about DFCs this way also sees it as a means of redistribution of dementia care, externalising it in the ‘community’ – health care becomes a problem of public awareness, where the public is expected to assist overburdened health care systems. Instead of excluding participation, going back to ideas in previous sections, ‘bio-power operates to invest the citizen with a set of goals and self-understandings, and gives the citizen-subject an investment in participating voluntarily in programs, projects and institutions set up to help them’ (Cruikshank, 1999, p. 41).

This vision of community also sits with a vision of:

> *New modes of neighbourhood participation, local empowerment and engagement of residents in decisions over their own lives…government through the activation of individual commitments energies and choices, through personal morality and community setting…counterposed to centralizing, patronising and disabling social government (Miller & Rose, 2008, p.92)*

Miller & Rose maintain in this paper that community is not simply a territory of government, but a *means* of government, with bonds, ties and forces ‘to be nurtured, shaped and instrumentalised in the hope of producing consequences that are desirable for all and for each’ (p.93).

In another famous debate about community, Nancy claims that “death is indissociable from community…it is through death that community reveals itself” (Nancy, 1991 p14); it is reasonable to expect that in the near future communities will be created around the deadly workings of COVID-19; DFCs also have death lurking somewhere in the periphery, and certainly, it became part of my experience in Brecon, as some members of the community which formed there passed away. Some of those principally involved in organising DFCs in Brecon also had backgrounds in community development practices, some formally so. Either way, the formation of community would seem to have consequences, might even inspire creative counter-conducts. In the Third Touchstone, after some dancing and reading of leaflets, we will have community shaking.

15. In DEEP

The Dementia Engagement and Empowerment Project (DEEP) began as a one-year project in 2011, just prior to the big push for DFCs. The aim was to find out how many ‘involvement groups’ of people with dementia there were in the UK and look at how the groups worked. At the end of the project, they had counted 17 involvement groups and activities. This project was initially managed by Mental Health Foundation, supported by a small not-for-profit organisation called Innovations in Dementia, and funded by Joseph Rowntree Foundation. The emphasis is on developing the voice of those with dementias, to organise themselves into communities of interest: ‘the network belongs to the groups themselves, not to any organisation or service’ (Shea/DEEP, 2016).

It is difficult to imagine how some aspects of DFCs could have developed in Wales (and beyond) without the input of DEEP, because by now there are around eighty such groups around the UK. The network connects some of the people who feature as interviewees in this thesis, such as Nigel and Emma (from Muse and Fuse, the Swansea group, and the Dwyfor and Meirinonydd DEEP united groups respectively). They were also the joint facilitators (with the Alzheimer’s Society) of the consultation for a new dementia strategy for Wales which I attended, but there perhaps with different motivations ultimately.

16. What is a Meeting Centre?

Much of my case study in and around Brecon involved being at the Meeting Centre which was set up quite early on during the period of research. Establishing the Meeting Centre in the form that it took was a fork in the road for the development of Brecon's provision of services for those affected by dementia – but also, ironically, a kind of rupture in the idea of a Dementia Friendly Brecon. Much of the Third Touchtone concentrates on events and significance of the Meeting Centre, because by the time most of my fieldwork was able to commence properly, this rupture had already happened. In consultation with my supervisors, I decided that my energies would be best spent following the line that had been set in motion by the original energy from BADDFC, which created DMiP, that subsequently put the plan for a Meeting Centre into operation. This seemed like the most intuitive path to follow, to follow the rupture.

Meeting Centres are based on a Dutch model of caring for people with mild to moderate dementias in community settings (Brooker et al, 2017). They are meant to be local, friendly and a way to 'connect people to each other and to their sense of community' (Brooker et al, 2017), and have their basis in a psychological model developed by Professor Rose-Marie Dröes in the Netherlands called the Adaptation-Coping model, which encourages those with mild to moderate dementias to work with their significant carers to adapt to their condition (Dröes et al, 2004) – there are currently some 187 in that country, but the idea is catching on globally, with around 20 such centres either established or in progress in the UK (The Association for Dementia Studies, 2018). Originally, The Association for Dementia Studies at Worcester University was awarded a 3-year European Union research grant to carry out an international research project, known as MEETINGDEM, aimed to implement and evaluate the Meeting Centres Support Programme (which had achieved great success in the Netherlands) in the UK, Italy and Poland, by developing a pilot Meeting Centre in each country and then evaluating the impact of it on the people and family members who used it (MeetingDem,2018).

The initial test centres in the UK were in Leominster and Droitwitch Spa, so just over the border from Brecon, and two of the main people involved with BADDFC, Joan and Rhiannon, became convinced that this was a major aspect of the future development of DFCs in Brecon, as we shall see in the Third Touchstone. If the border between Wales and England can be seen in geographical or border studies terms as a process, then such a 'liminal status has also offered conditions in which hybrid, solidaristic and transborder encounters can be forged and in which creative, cultural practices …can emerge' (RGS-IBG, 2019). Far from being a confining feature between two different governance areas, with different priorities to an extent, the process had produced a certain porousness in around DFCs, a trade in ideas between Marcher market towns which eventually meant that Powys became one of the areas of the UK with the most Meeting Centres, in a very short space of time.

17. The cruel optimism of dementia friendly communities

> *Are we helping the privileged to stay privileged by creating DFCs? Are we disrupting things for people who are struggling? Are we going to change this into a critique of austerity and how we give support, or are we going to find, do you know what, Tarquin here has been lovely in letting his organic, artisan bakery in Crickhowell become dementia friendly, but is there anything in in Trevethin? No.* SH

One of the defining moments for me in terms of beginning to think DFCs came after a phone call in a previous research project. Tasked with trying to evaluate people's experience of being involved in this movement, I had been contacted by a care worker who worked in a residential care home. She had not only received dementia friends training but had been inducted as a dementia champion: 'a volunteer who encourages others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what they can do to help' (Alzheimer's Society, 2017). She and other care workers around her had all become Champions and had been holding Dementia Friends sessions – awareness raising about dementia – in and around the local town in West Wales where she lived. However, she had become completely disillusioned with the whole scheme and would not be doing any more, because she felt it was pointless.

She gave an example from her day-to-day experience of working in a care home that was gradually being starved of resources because of local authority cuts (this was at the height of austerity). Her frustration was palpable. 'Where are those people now?' she said, and she gave an example of budget cuts which meant they couldn't do the things which made life better for residents. 'When I want to look after Mrs Jones, who has dementia, and who sits in the corner every day. We used to have the money to take her to Aberystwyth, and she'd sing her heart out in Welsh on our daytrips and visits to the chapel there. We can't afford to do that anymore, and I can't speak Welsh, so she sits there on her own getting agitated, unable to understand the world around her. So who, of those people we've talked to, would help Mrs Jones? No-one.'

These words have rung in my ear since. Many of the people who I mention in this thesis are also 'Champions' and have put in lots of hours in raising awareness; undoubtedly, this has led to some positives which, for example. Rhiannon, Donna or Joan in Brecon, or Emma up in North Wales, can testify has made a difference in people's attitudes towards people with dementia. But variations of the story above – one of disillusion, loss of hope, bordering on resentment at times – was also heard more than once, and maybe forms part of a wider picture, a '*sensed* crisis' (Berlant, 2012, p19).

As the research progressed, I began to wonder whether the whole enterprise of dementia friendly communities – an enterprise that through Dementia Friends especially in the form as outlined in the above story with its intensities around austerity, lack of provision and loss of hope, was an example of what Lauren Berlant calls cruel optimism (Berlant, 2012): the attachment to imagining a better future ('let's create dementia friendly communities!') both keeps people going (carers, concerned citizens, PWD), but also locks people into a present that may be harmful, restrictive or constraining, that Berlant claims is characteristic of contemporary capitalism. In a time when millions of UK citizens were supposedly becoming ‘dementia friends’ (Alzheimer’s Society, 2019), as we’ll hear, austerity meant that PWD struggled to get the support they needed, or mortality rates among older people, many with dementias, went up for the first time: ‘This is almost certainly because care for people with dementia has worsened as austerity bites. People’s families are less able to care for them in these austerity years; and adult social services have been repeatedly decimated’ (Dorling, 2019).

18. The uses of paranoia

> *Right away everyone knew something was happening, that we were in something (Stewart, 2008, p.79)*
>
> *Critique is necessary but always insufficient (Anderson & Harrison, 2010 p. 23)*

At the time I was starting out with this thesis, I found myself trying to salvage what remained of a local street drugs charity where I’d been a trustee for over ten years, latterly as the chair of an (ever dwindling) management committee. We’d been relatively successful for almost two decades, in and around the city where I’d made a home, not least in helping and supporting all types of drug user into care where needed. This meant getting people into housing, showing how to use needles safely, how to save lives when overdosing, or dispassionately recognising that the desire to seek bodily pleasure and relief for whatever motives was universal. We’d managed to gain Welsh government investment in a purpose-built centre in a busy inner-city neighbourhood.

However, our ethos of harm reduction – respecting the autonomy of drug and alcohol users and recognizing that for many, coercion into ‘treatment’ would mean worse chances later on, a work of patience – had fallen out of favour in times of austerity, with emphasis now on the redemptive qualities of ‘recovery’ (with far shorter, and therefore cheaper, timescales). We had a shiny new building, built through the vision, hard work and experience of our senior drug workers together with an enlightened architect, out of the husk of an old orphanage, latterly a raucous backpacker’s hostel, full of dangerous surprises. No sooner had we opened the doors, we lost all core funding from the local authority, the same authority that had championed our funding application. The relevant commissioner cited an algorithmic decision-making that had favoured a far larger charity based many hundreds of miles away, with a turnover of millions, but we suspected otherwise.

The struggle to save what was left, and to avoid painful liabilities as trustees, was culmination on my part of many years of volunteerism and interest in drug and alcohol support. This took around two to three years, and involved briefly becoming part of another larger charity, more geographically close, as a trustee, whilst many other smaller local charities involved in the same field also collapsed or folded into larger organisations, our ultimate fate also.

Why is this relevant? In trying to untangle my own positionality in this research, for roughly the same period as the above took place, I felt there were fuzzy parallels: the desire for action to help a stigmatized population, desire which came from many directions and a variety of motives. Local action, which may have been effective, I suspected would eventually be superseded by battles over resources and legitimacy, as ‘technologies of agency’ (Dean, 2010, p.199) – farmed out, previously state-funded services, which often turn ‘high-risk’ groups into ‘active citizens’, would come into contact with ‘technologies of performance’, the need to make this calculable and to optimise – efficiencies, budgets, regulation and surveillance. The former often comes from the bottom, the latter from the top. Such battles seemed invariably won by large organisations which could offer efficiencies of scale, or regulatory compliance at higher levels. I was unfairly projecting a parallel trajectory here, but there are two main points to explore.

Firstly, that my overall impression, made early on, was that the idea of DFCs was primarily a strategy of responsibilization in a time of ideologically motivated austerity, one in which certain types of active citizenship is encouraged, has much in common with the development of similar models of citizenship developed earlier with another hidden population, also perceived as being a threat, namely drug-users. This implies a way of operating in which the important services supporting these populations which might have been found freely in other times, are gradually farmed out to the voluntary sector. They in turn become ever-more compromised in terms of what usually they started out doing: advocacy. Being both advocate and service provider, responsible for delivery of governmental objectives, is a hard line to follow. As Nigel, one of my dementia activist informants pointed out:

> *the role of charitable bodies and non-profits has shifted in the last decade, as dementia and ageing has gained all the attention and at its most crude, advocacy groups and charitable groups have become an extension of the government, happy to legitimise policies to access the funding…*

However, more importantly for this research, once the above featured in my own thinking, how was I to deal with a critique which had appeared fully formed, as it were? This theoretical hinterland which takes in biopolitics, forms of pastoral power and governmentality – all very applicable concepts for populations with dementia or 'substance abuse issues' – was all very well but began to be felt like 'the gorgeous narrative work … by the Foucauldian paranoid, transforming the simultaneous chaoses of institutions into a consecutive, drop-dead-elegant diagram of spiralling escapes and recaptures' (Sedgwick, 1986, xi). Touché, but thankfully very liberating to read at the time.

Reflecting on this, it became clear that one possible way of approaching this productively was to think further with Eve Sedgwick's work: what does knowledge do, in the light of a position in which you think you might already know the answer? How does knowledge perform in this way, become a barrier, making it 'less rather than more possible to unpack the local, contingent relations between any given piece of knowledge and its narrative/epistemological entailments for the seeker, knower or teller' (Sedgwick, 2003, p124).

Developing this awareness has not meant a wholesale rejection of the Foucauldian schematics, but maybe just holding them differently; as Barnwell (2020) points out, such a 'paranoid reading' might already be a feasible way to deal with the shifting ambiguities of our mercurial social structures and the authorial agencies they involve' (p.112), but it meant that I had to reflect more carefully on my day-to-day encounters and movements. Eventually, the space to do this appeared as I immersed myself in the possibilities of NRT, as outlined in a previous section, and of trying out different methodological approaches, as we shall see in the next section, but above all learning to ‘engage with the openness and processuality of events’ (Michael, 2012, p.166). The irony was that getting there meant following a line made by possibly one of the most paranoid of all American writers.

19. Methodology and methods

Figure 3: Fieldnotes

...the ways of measuring this are not only outside my discipline. They are somewhere else altogether, that I can feel but not handle, touch but not grasp. (Williams, 1960/2006, p.6)

when you go into a hospital, I see it in care homes, they're often task focussed and relationship building and communication and connection is not seen as and the reason being, and maybe this is the...it's because it's not measurable, so what happens is that it's something that isn't measurable, it tend to get kind of side-lined, whereas the other practical stuff is measurable, so no, the way that we look at things has to have a measure on it but actually people can organise and be accountable, and I think that that's what's happened, we've all become task focussed because of accountability and not recognising the importance of being accountable in other aspects as well. And that's why I suspect so many people are frustrated within in the workplace umm and that actually people work within systems that they struggle with, so we need to be building that back into our communities not just into our lives overall we need to be building back the fact that actually as human beings that we have to look at life and be holistic in our approach to life. RD

NOTHING IS TRUE. EVERYTHING IS PERMITTED. (Burroughs,1982, p.13)

Ethnographic research is usually concerned with 'producing descriptions and explanations of particular phenomenon, or with developing theories or explanations, rather than with testing existing hypotheses or even applying a prior theoretical framework' (Hammersley & Atkinson, 2019, p22). The research design for this thesis as initially outlined foresaw considerable fieldwork in the form of participant observation, photography, with relevant interviews in mind. The sheer amount of materials generated in ethnographic research can be daunting, but the process is necessarily non-linear, and always generating more than is needed:

> *In the field the ethnographer may work by indirection, creating tangents from which the principal subject can be observed (through 'the wider social context'). But what is tangential at one stage may become central at the next. (Strathern, 2004, p.5)*

What was generated eventually was not just material, but the tangential becoming a line of flight into a different way of approaching such material: research that started out in gerontology, then started to think in terms of human geography, then moved further into using analytical tools modelled from avantgarde literature.

There was also room in this for a participative approaches oriented towards action, but for various reasons, it was decided that this would not be suitable in the end (see Participant Observation), even though I felt at times that I was part of a constant feedback loop to some of the main people involved, and still sit on the Dementia Matters in Powys Advisory Panel – a position which I'd maintained in one way or another from the outset, and another way in which we must acknowledge how as researchers we frequently end up shaping the fields in which we're researching, even if only on a micro level (Latimer, 2008).

This section gives some background and an outline of this production process, the ins and outs of 'collecting data' about and with the people, places and objects involved in this multiplicity of DFCs. It makes the case for some more creative, even radical, approaches to both data collection and analysis, based on a particular line of flight taken in thinking about

DFCs, and the influence of more-than-representational approaches. It is often valuable to ask '*how* we document creativity and *how* we document creatively, but also *how* and *why* these methodologies are valuable' (Veal & Hawkins, 2020 p359) and the implications then for knowledge creation. I will try to outline how research which has used some conventional ethnographic techniques, such as participant observation, interviewing and photography to build up a case study of a particular subject area and phenomenon over time, can evolve and make use of different cultural forms to inspire more creative ways of analysis.

In terms of methods generally, as I began this research, I felt that there were a couple of anomalies that needed to be addressed in terms of how qualitative researchers can approach dementia. Firstly, encouraged through our training and experience 'to make the familiar strange', what is common to many dementias is that for those with the condition the familiar *has become* involuntarily strange, through cognitive changes, but as many of my interviewees stressed, if you meet a person with dementia, you meet that one person with dementia – everyone will have different experiences. Secondly, having worked in several research roles prior to this, I felt that using the 'traditional' methods of recording and analysis, with their emphasis on pattern recognition and 'repetition' would perhaps invite the danger of capturing what was somehow already known. Because dementia seemed such a slippery and contingent term, then maybe the best approach to finding out about DFCs would be to try and pay more attention to 'the ephemeral, the fleeting, the not-quite-graspable' (Vannini, 2015, p.6).

20. Ethical considerations

Research frameworks involving people as fellow participants can produce moral and ethical dilemmas, perhaps more so if that involves a group that is routinely perceived as 'vulnerable', such as people with dementias. The consequentialist and deontological principles that guide much of qualitative research practice were considered in this respect (Murphy & Dingwall, 2001), and a useful, trusty checklist of considerations was used (Bryman, 2004, p.516). As a relatively experienced qualitative researcher with experience of working with hidden populations e.g. intravenous drug users, I had also been working at the Centre for Innovative Ageing at Swansea University since 2012, involved in the Cognitive and Functioning Ageing In Society research (CFAS, 2016) and other projects involving people who had neurocognitive conditions, from mild cognitive impairment to dementias. From the outset, I recognised that there was a need for reflexivity in my dealings with all participants, and a need to clarify my own position both inside and outside the field at every opportunity if it involved people. In terms of best practice, I used the guidelines set out for research with people affected by dementia as set out by the Scottish Dementia Working Group (Scottish Dementia Working Group, 2014) which are also endorsed by DEEP, as mentioned a key player in some of the activist networks and events portrayed here. This was to ensure that the relationships with participants were as equal and inclusive as possible, that there was mutual respect, a sense of democratic participation, and a commitment to active learning from the research. In addition, one of the key principles outlined in the guidelines that ‘Knowledge comes from all sorts of places’, and I have taken this particular tenet to be a generous invitation to think freely about my epistemic and ontological position within the field of study.

Permission to proceed was given by the College Research Ethics Committee. All participants were given a clear outline of the research, often multiple times, and in accordance with the principles outlined, re-capping any previous encounters or interviews for example, to ensure that people were comfortable with my approach. A written outline and consent form was used with many, but verbal consent was also used in situations where written consent was not practical or even desirable. For example, in attending the Meeting Centre in Brecon, or some of the initiative/advisory committee meetings, I would make a point of introducing myself and giving a brief explanation of what I was doing and ask if they were happy for me to proceed. This was routine and repeated frequently in many encounters i.e. every meeting attended, even if people had become familiar with me.

Informed consent is a continuous process, and anonymity was discussed with all involved. Almost all interviewees have been happy for me to attribute their words to them in most circumstances, with any doubts or sensitivities – usually on my part - being discussed as the writing up process took place.

21. Sidelong glances: from punk sociology to a beat gerontology?

> *...a wooden jigsaw puzzle - is not a sum of elements to be distinguished from each other and analysed discreetly, but a pattern, that is to say a form, a structure: the element's existence does not precede the existence of the whole, it comes neither before nor after it, for the parts do not determine the pattern, but the pattern determines the parts; knowledge of the pattern and of its laws, of the set and its structure, could not possibly be derived from discrete knowledge of the elements that compose it. (Perec, 2003, Preamble)*
>
> *Surrealism is ethnography's secret sharer – for better or worse – in the description, analysis and extension of the grounds of twentieth century expression and meaning. (Clifford, 1988, p.121)*

Many of the debates around the 'crisis of representation' e.g. Clifford & Marcus, 1986, over the past thirty years are common to critical gerontology, cultural geography, and more widely in the sociological literature around methods. Insofar as there often seems to be a duty to keep on 'telling about society', and to think about what that telling entails (Back & Puwar, 2012), the need to develop a more bricolage type approach in critical gerontology, for example (Holstein & Minckler, 2007), has also long been recognised.

However, to date, more non-representational approaches, which might focus on the 'background experiences' (Anderson & Harrison, 2010) or the more-than-human, multi-sensual affective world (Lorimer, 2005) aren't so common in ageing studies, though there is growing interest in more interdisciplinary work between geography and gerontology, in the more-than- representational (Barron, 2019, Andrews & Grenier,2018), and in thinking through the complexities of the present by trying to account for the affective, political, social and personal forces which shape and a mediate it (Anderson, 2018). This has been part of my own interdisciplinary journey during this research: developing an epistemology which is more concerned with affect, rhythm, process, movement, performance, and creativity.

This journey has also been about the call for researchers in the social sciences 'not to play it safe' (e.g. Beer, 2014, Gane & Back, 2012). This has meant thinking through the possibilities of drawing upon other cultural forms and alternative forms of knowledge to re-imagine practice, ideas and forms of communication, to vary the ways of 'telling'. Beer (2014) uses the example of a 'punk sociology' for instance, where boldness, inventiveness, and a do-it-yourself ethic form part of the approach, as well as taking risks and even being provocative (2014, p. 67), accepting also that there is room for some improvisation when it comes to methods, even though for some 'improvisation is a skill that goes unrewarded, if not actively despised in academia' (Fuller, 2009, p.143). Though Beer's plea is relatively recent and is symptomatic of a wider call for the renewal of the sociological imagination (Back & Puwar, 2012) in the face of the casually oppressive emphasis on 'impact agendas', the roots of creative ethnographic approaches and the interplay with other cultural forms has a long history, for example in the 'ethnographic surrealism' between the two world wars of the twentieth century (Clifford, 1988).

As mentioned previously, a fruitful line of enquiry can be traced from that picture of Burroughs in Brecon, via Jean Jacques Lebel ('the radar scout'), both forwards to the post-structuralist thinkers of the sixties and seventies, and backwards to the surrealist movement, which in the interwar years – through the influence of Marcel Mauss, Georges Bataille, Antonin Artaud – experimented with using collage, juxta-positioned materials, invented subversive taxonomies. It was a period when 'the ethnographer, like the surrealist, is licensed to shock' (Clifford, 1988, p.133), when the fragmentation of culture as expressed in the juxtaposed, dissociated and citational style of Benjamin (2003), was prefigured in Bataille's journal, 'Documents', 'a war machine against received ideas' (Ades & Baker, 2006, p.11).

Echoes of this call for a return of 'attitude' can also be found in the cultural geography's creative turn (Veal & Hawkins, 2020), in a renewed interest in punk-inspired methods such as

Zines (Bagelman & Bagelman 2016), punk geographies (Woods, 2019, Gelbard, 2017) and punk pedagogies (Smith et al, 2018) for example. In response to this call, based on my curiosity in finding that picture of Burroughs, I began to imagine how elements taken from Beat and avant-garde writing could be used to get past my own analytical impasse, if there were 'ways of doing and making that [could] intervene in the general distribution of ways of doing and making'(Rancière, 2004, p13) and trying not to 'fret…about the risks of experimenting' (Dewsbury, 2010).

Burroughs had also been a key figure of influence not only in the Beat movement, but on both punk and post-punk artists, so in a way, this is not new territory. In keeping with this line of thought I've also had figures such as the writer Kathy Acker in mind, commonly regarded as a feminist punk writer (Henderson, 2021). She was greatly influenced by the European avant-garde and Burroughs, used both cut-ups and map-making as part of her work (Acker, 1984). Undoubtedly, during his life Burroughs was often a controversial figure, known for his perceived misogyny at times as much as his radical stances in writing and art, though many who knew him contend that there was a great difference between the writerly Burroughs - often sharp and satirical – and Burroughs on a personal level (Miles, 2013, Douglas et al, 2019).

For all his friendships with figures such as Patti Smith or Susan Sontag and others, there have been several discussions about this over the years and about the role and status of women in general in the Beat movement, and with Burroughs in particular (see Douglas et al. 2019, for a recent relevant critical roundtable on Burroughs and gender, but also Carden, 2018, Johnson & Grace, 2002, Peabody, 1997, Knight et al, 1996). However, it has often been female cultural critics who have either been some of the first to explore Burroughs's critical reception or championed some of his radicalism, especially earlier on (e.g. Lyndenberg, 1987, Skerl & Lydenberg, 1991, Grace & Skerl, 2012). Even though there had been an enthusiastic reception to some of his ideas by French thinkers, he (and the Beat generation in general) only had lukewarm enthusiasm in American intellectual circles, despite the success of various conferences linking Burroughs work in particular to radical ideas such as schizo-analysis

(Demers, 2018, Lotringer, 2001, Deleuze & Guattari, 1977) or such direct referencing in such Deleuzoguattarian concepts as the Body without Organs (Deleuze & Guattari, 2013), and latterly, control societies (Deleuze, 1995). Recent scholarship, some of which is highlighted here seems to be more enthusiastic and claim his work to be more relevant than ever. The recent opening of more archives has enabled a new generation to explore his output, including his photography, collage and art pieces alongside the writing and other correspondence (Hawkins & Wermer-Colan, 2019, Harris, 2019, Allmer & Sears, 2014).

'Beat' writers were a loosely associated, mainly American cultural and literary movement from the 50s and 60s, which included poets such as Allen Ginsberg, Gary Snyder, and novelists such as Jack Kerouac (who coined the term 'beat') and Burroughs – though figures such as Burroughs and Snyder in particular outlived that movement and are seen as being influential in others. Apart from the detailed work by Demers (2018), the links between the American and French literary and academic worlds of 50s, 60s and 70s has seen renewed interest (e.g. Lane, 2017), though this Transatlantic criss-crossing of ideas, support and influence has perhaps been overlooked until recently. The Beat movement, Kerouac and Burroughs in particular, are referred to enthusiastically by both Deleuze and Guattari in various texts (e.g. Deleuze & Guattari, 2013, Deleuze, 1995), the latter cited as a key influence some of Deleuze's essays on Control Societies: "Burroughs was the first to address this" (Deleuze 1995,174), and his work (Burroughs,1964) along with Artaud's, is freely quoted in How do you make yourself a Body without Organs (Deleuze & Guattari, 2013). But Kerouac's work was also influential, his novel On the Road seen a rhizomatic narrative treatment of travelling across America (Abel, 2002)[8], or in his use of 'minor' language.

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[8] A small biographical note overlooked for both writers is that they were both diagnosed of having 'dementia' in episodes in *earlier* life: what was then called 'dementia praecox' that would now be classed as a type of schizophrenia (Miles, 2015, p77, Nicosia, 1992, p106).

As I had become more aware of non-representational approaches, ones which paid more heed to more background perceptions or ‘engage in more creative or performative practices’ (Vannini, 2014, p.319), I had already begun to experiment with a ‘spontaneous prose’ approach, inspired by Kerouac’s uninhibited prose style (Honeybun-Arnolda, 2018). This calls for freeing your writing of too many full stops or commas, to keep from ‘crafting’ the sentence too much, and to ‘write outwards, swimming in the sea of language’ (Kerouac, 1992) (See Fieldnotes and Spontaneous Prose).

With Burroughs in particular, it may be underappreciated just how influential his fiction, including ideas around how ‘control was no longer exerted directly, through confinement and disciplines, but through more subtle mechanisms involving word and image, binarism and digital language’ (Lotringer, 2001, 16) can be heard echoing through French post-structuralism and more contemporary writing about affect and capitalism (Massumi, 2017, Berlant, 2017, Massumi, 2015). Recently released archival materials have also contributed to renewed interest the author. In his own lifetime he was resistant to any overt intellectualisation of his work. However, through various conferences and happenings which took place in New York in the 70s, where he had returned after years of exile in Paris, London and Tangier, and in growing number of scholarly works, there has been increasing recognition of Burroughs not only as a key figure in popularizing such ideas in art and performance movements such as punk (Rae, 2020, Miles, 2015), and as a member of the later, 60s avant-garde (Hawkins & Wermer-Colan, 2019), but also a link into earlier literary and avant-garde literature movements (Harris, 2019, Lane, 2017).

So, the idea that ‘inventiveness does not… equate to the new’ (Lury & Wakeford, 2014, p.6) encouraged me follow up that impromptu photoshoot on a sunny day in Brecon in 1960, (see

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Fragment 9). One of the moodier photos of Burroughs in the shadows of the entrance to Bethel Square subsequently made it around the world through the review of his most famous novel, The Naked Lunch, by English writer Anthony Burgess in the Guardian, as well as the spoken word album of his work, and by then, American 'Beat' writers were already famous.

Having been inspired by this, and heeding that call from critical gerontology, I developed a bricolage approach in this work based on the above, which I will sketch out in the following sections. I have taken this path in part as a way of 'crossing disciplinary and methodological boundaries so that…the different pathways in critical gerontology can together enlarge understanding and systematically challenge' (Meredith & Minckler, 2007, p.19) what I see as a lack of critical engagement with the idea of DFCs. Bricolage comes from the acceptance that to build this kind of knowledge, I need to critically employ several forms of enquiry and different types of narrative. Ontologically, such bricolage starts from an understanding that:

> *knowledge is always in process, developing, culturally specific, and power-inscribed… [one is] attuned to dynamic relationships connecting individuals, their contexts, and their activities instead of focusing on these separate entities in isolation from one another…[the idea is to] concentrate on social activity systems and larger cultural processes and the ways individuals engage or are engaged by them (Kincheloe, 2001, p. 689)*

It is to such forms of attunement and narrative practice – auto-ethography, ficto-critical writing and participant observation – that we turn in the next few fragments.

22. Auto-ethnography

Horton's (2021) recent definition of *somewhat* autoethnographic is that of a creative practice 'being plainly rooted in particular located personal experiences, but not necessarily wedded to a conventional autoethnographic narrative' (p.24) is perhaps the most accurate description of some of the practices in this thesis, as I've already tried to weave in some relevant personal experiences (see for example fragment 18, on the Uses of Paranoia), but have also tried to keep the key questions about DFCs in sight . As Horton points out, the term 'auto-ethnography' covers many different styles of writing and themes, including the creative use of material found in field-notes and photographs, for example. As a general definition, it is a style in which ‘ethnographic data are situated within…personal experiences and sense-making. They [the researcher] form part of the representational process in which they are engaging and are part of the story they are telling’ (Atkinson, Coffey & Delamont, 2003, p.62). It is also a genre of doubt and uncertainty (Bochner, 2017), which is one the underlying themes of the various fragments here, my attempts to explore how and why we create knowledge about something like DFCs. By reflecting autoethnographically, the contingency of the particular, the local, but also our own memories – which are often more embodied (see Dancing with Windsor) – can come to the fore, whilst acknowledging that each act of ‘remembering’ is, in part, an act of ongoing sense-making.

Auto-ethnography has a long history. Over the years, many researchers in the social sciences have written themselves into their texts or grounded their fieldwork in biography which informs their sociological analysis (Hammersley & Atkinson, 2019, Anderson, 2006). The blurred boundaries between more impersonal descriptions and reflexive biographical writing are common throughout the American interactionist tradition for example, as sociologists in particular have often studied their ‘own’ communities, or reflected their own personal interests and commitments, be that as jazz musicians (Becker,1951), cab-drivers (Davis, 1959), poker-players (Hayano, 1982) or as TB patients (Roth, 1963).

With the rise of this approach, and the use of an authorial voice (my own) along with other voices in a thesis such as this, there are some key relevant issues to consider. Striking a balance between the autobiographical and an ethnographic enquiry, one of the problems is getting that right between reflecting on my personal experiences during the period of study which I perceive to be relevant, and the analytic task of trying to answer the puzzle of thinking about DFCs as a phenomenon. In contrast to some of the autoethnographic accounts alluded to previously, my initial experience of dementia was one almost entirely mediated by my work as a researcher – I had no direct experience apart from this, and was not, in that sense a ‘[CMR] complete member in the social world under study’ (Anderson, 2006, p.379).

However, as the years have passed, this has changed. On a personal level, through my own family, I'm very aware of the beginnings of cognitive changes in older relatives and their networks, and locally where I live, I've become friendly with those who have the condition or care for those who do (which I've reflected in some of the anecdotes). But as I've already alluded, it is perhaps my broader experience as someone who had been active for many years in a small health-based charity, with its day-to-day complications and entwinement in discourses of responsibilization, empowerment, biomedicine and the rest, that have definitely informed the work, and has hopefully been of some analytic use. The ongoing self-knowledge from that field, with a broader socio-cultural context of austerity, local politics and community has needed some careful reflexive work on my part, which I've attempted to be open about in these pages.

As Atkinson (2006) contends, the irony at the heart of autoethnography is that though much of it claims to be creative and experimental, it can also show a lack of sociological imagination- while the (postmodern) promise 'is one of displacing the monological voice of the observer…contemporary autoethnography replaces it with the equally monological voice of the autobiographical author' (Hammersley and Atkinson, 2019, p. 211). In response to this, trying to make sure that the personal doesn't displace this task and become a form of self-indulgence, I have also tried to give great prominence throughout to the voices of those who have contributed through interviews and other encounters to this work of trying to understand DFCs.

23. Ficto-critical writing, fragments, atmospheres

> *Fragments of a vessel which are to be glued together must match one another in the smallest details, although they need not be like one another. In the same way a translation, instead of resembling the meaning of the original, must lovingly and in detail incorporate the original's mode of signification, thus making both the original and the translation recognizable as fragments of a greater language, just as fragments are part of a vessel.*

(Benjamin, 2019)

On the train to Swansea one morning, I read Kathleen Stewart's Regionality (2013) in preparation for a seminar workshop later that day. Its descriptive and evocative power, the keenness of the observation, the breathless possibility of such reflexive anthropological writing, made me very emotional - I'd literally never read anything like it. By the time I arrived at the station, I knew that this would help me work through the thinking about DFCs, as a possible way of 'sharpening…attention to the expressivity of something coming into existence' (Stewart, 2010, p.340). In this section, I'll explain the significance of this and how it has influenced the rest of this thesis in three important ways: by introducing me to aspects of affect theory, by helping me to decide on a fictocritical style to present some of the accounts of my exploration of DFCs (though by no means all), and within this recognising and linking to the broader methodological innovations that I've experimented with such as cut-ups, as allied to 'fictioning' practices. Fictioning is 'writing, imaging, performing or other material instantiation of worlds or social bodies that mark out trajectories different to those engendered by the dominant organisations of life currently in existence' (Burrows & O'Sullivan, 2019).

Exploring Stewart's work for the first time, especially Ordinary Affects (2007), began a dialogue with affect theory in my research, but also provided a way of trying to grasp the contingency and nebulousness I'd felt was inherent in the concept and realities of DFCs (as I saw them at that point), as some sort of national/notional 'project'. But that piece in particular (2013), as we were thinking about how to write about place for our doctoral studies, had a profound effect.

I was getting to know Brecon and its communities at that point: it taught that how we notice the air, the light, odours, accents, and, in that piece, how grief locates and dislocates, are all valid means of enquiry if we're going to take seriously the challenges of reflexive qualitative research. Also, from my own experience of other research projects over the years, I'd found that spoken language as in accent and dialect (and sometimes even multilingualism in ordinary circumstances) are almost always overlooked unless you are a sociolinguist or dialectologist – in the dim and distant past, this had been a small part of my own training –

but here was detail of that sort that sang, rhythmically, ‘with character and texture’ (Stewart, 2013, p277) from the page. It was asking us to tune in differently.

The train reading felt like a very Barthesian punctum (Barthes, 2000) in the research process, a phenomenon that Stewart also references in her introduction to Ordinary Affects: a moment of clarity and detail that sparked timely thoughts of ‘Venturing into a world that remains palpably unpredictable and seductive beyond the carefully cordoned zones of familiarity’ (Stewart, 2013, p.276). It was also one of my first readings about the ‘affective turn’, which would seem to cover quite a few different approaches, but it subsequently led to engaging productively with the work of Berlant (2012), Sedgewick (2003) and others, not least in trying to figure out how ‘a specific practice of critique can sit alongside and compliment speculation and description as ways of relating to affective life’ (Anderson, 2016, p. 19) (see The Uses of Paranoia). This was a pivotal experience.

Engaging with Stewart’s work has also encouraged me to experiment and to appreciate the use of a more fragmentary style of writing, to think in terms of a ‘speculative topography’ (Stewart, 2011, p.445) of DFCs while observing my own everyday experience of researching, thinking, meeting people affected by and affecting dementia, hearing the refrains which were emerging about the topic. Writing in fragments has a rich history and tradition of its own (Lichtenstein, 2009, Sandford, 2016, Davis, 2019), but for me it has also felt like a natural extension of my method of writing field notes, sometimes as ‘spontaneous prose’ (see Field Notes). I had realized at that point in the research that there can be no sense of ‘totality’ when trying to describe DFCs; using a more fragmentary style of writing seemed to be an appropriate way of approaching parts of the thesis because such fragments encourage you to think of what’s missing but may be still present in its empty form (Davis, 2019). You have to work harder as a reader to fill an gaps. They can act as ‘brief bursts’ of ‘beginnings’: ‘so many fragments, so many beginnings, so many pleasures’ (Barthes, 2010a). Also, in many of the Touchstone pieces, I’ve tried to leave them as they are, once written: the tendency, especially in academia, is to over-interpret at times, so for many pieces, I’ve just left them to breathe a bit more.

Stewart's writing in general, including her later work with Lauren Berlant, has helped me to articulate the atmosphere I felt in the room when I heard the phrase "we're all in this together" in the context of DFC, for example, a key moment foreshadowing this thesis. This something I felt and wrote about in my notes could be seen as part of 'an animate circuit that conducts force and maps connections, routes and disjunctures' (Stewart, 2007, p.3), an indeterminate force which held more than just its own illocutionary power. By thinking about affect, what I've learned here is that every instance of hearing that phrase during my research was a 'singular experience', an experience that 'is totally situation specific, but in an open kind of way' (Massumi, 2015, p13); this has enabled me to reflect on my initial critical impulse - connecting that phrase to neo-liberal austerity, for example - and realising that in the act of making such definitive judgments I was simultaneously not fully realising my own part in each situation, but also maybe not perceiving what else might be going on.

By noting such affective atmospheres (Closs Stephens, 2015) in our writing, it helps us to realise that something might not be emanating from a single authority, but rather semi-conducted (McCormack, 2014) through events, media and social media circuits, introductions, whispered criticisms over tepid cups of tea. The deliberate live theatricals with people affected by dementia, which changes a local authority 'networking' event, the dementia activist who challenges an esteemed professor in a lecture, the everyday scenes of relaxation of a roomful of carers waiting for a massage, the indignation felt at consultation events, suffused with the nebulous politics of devolved power: all have atmospheric qualities in the account of DFCs given here, 'ebbs and swells of intensities that pass between "bodies"… enabling bindings and unbindings, jarring disorientations and rhythmic attunements' (Seigworth & Gregg, 2010, p.2). A fictocritical approach to writing about some of these events tries to bring the material and ephemeral together, form and emergence, air and atmosphere (Stewart, 2013, p.284), a type of ambient mapping as Stewart has described it, but one where we also concern ourselves with the precision of things as they take place, on a 'fleshy plane of expressivity' (Stewart, 2015).

As Barnwell (2020) points out, it is *something* that ultimately and intimately haunts Stewart's work. This is not entirely unproblematic, in that there is an inherent contradiction to be found there also. Though there is a line of reasoning in Stewart's work which builds on rowing away from paranoid critique - building on Sedgewick's 'critique of critique' (2003) - into a more 'reparative' style, much of the subject matter in her fragments (from the moral panic of teenage massacres to trailer park surveillance to impending Christian apocalypses for example), document 'the ongoing ubiquity and gravitas of suspicious reading in everyday life' (Barnwell, 2020, p.112), often in the often exploitative long durée of late capitalism, as Stewart herself has pointed out in various discussions.

A counter-reading of Ordinary Affects in this way has also been helpful because it explores the accommodation between critique and the version of 'critique of critique' presented by Stewart and others. As highlighted above, this tension has been present as I've tried to understand more about DFCs also, but in essence I have learned how the neat, totalizing conceptualisation of biopower, governmentality or 'nudge' governance in a time of austerity can sit beside a more open fictocritical approach. In essence, the work here tries to discover something about the 'structure of feeling' (Williams, 1985): the emergent tensions between 'practical and official consciousness…[and the] ways of feeling and thinking' (Williams, 1985, p.131) which I've observed and been part of. Which brings this work back to Eve Sedgwick. In not having to think in binary, either/or terms, and in trying to develop a sense of being beside (as opposed to beneath or beyond) the ideas, places, spaces, people and situations contained in DFCs: 'Beside permits a spacious agnosticism about several of the linear logics that enforce dualistic thinking' (Sedgwick, 2003, p.8). Being able to recognise and articulate this position of beside-ness helped me approach to the work in general.

Evidently, in fictive and narrative terms, there has been a great appetite for trying to explore the meanings of dementia (see The Cultural Front), whether or not this is also a cipher for other anxieties at the start of the 21st century. Stephen Muecke, early proponent of fictocritical styles of writing, notes in Berlant & Stewart's The Hundreds (2019):

> *The ficto- side of fictocriticism follows the twists and turns of animated language as it finds new pathways. The -criticism part comes in the risky leap of taking the story to a different "world", where it may be tested by an unexpected public. (Berlant & Stewart, 2019, p.153)*

Some of the stories contained in this thesis will hopefully point to some interesting pathways around DFCs, though I recognise also that using methods which are relatively unfamiliar, at least in gerontology, might have its risks attached. Not all of them can be read as following a fictocritical impulse, but a consideration of this style of writing has been very influential on my work and the accounts of events and people as presented. I follow Stewart (2007, p. 4) in an attempt to build 'an idiosyncratic map of connections between singularities' as much as anything else. I also borrowed the idea of making reference to myself if I appear in some of the stories as 'he', in an attempt to give some productive space between the voice you read here as an 'I' – the researcher, PhD candidate, co-ordinator of this information about dementia friendly communities – and a 'he' who goes to the doctor, get his car to the garage, chats with his neighbours, takes a bus to work.

24. Participant observation

> *Panic is the sudden realisation that everything around you is alive*
> *(Burroughs, 2002)*

Participant observation represents one of the core skills one must develop when attempting ethnographic fieldwork. A straightforward definition would be: 'establishing a place in some natural setting on a relatively long-term basis, in order to investigate, experience and represent the social life and social processes that occur in that setting' (Emerson et al., 2007, p.352). Added to this is production of descriptions of these worlds, forms of inscription (Geertz, 1973) (see Spontaneous Prose and fieldnotes), which by their very nature can only ever be partial. Beyond what are straight forward descriptions of events (who, what, where and when), my own concern has been to use them 'as an opportunity to expand…habits of thought, and attentiveness to [your] senses' (Richardson, 1994, p.525).In whichever context or setting – attending a particular group, going to a conference or meeting as an observer or contributor, for example – if this is done with a particular set of questions in mind, often the experience is, to put it more colloquially, one of loitering or hanging about, often sipping cups of tea or coffee, talking to people, whether that's with any intended interrogative purpose or not.

As indicated, my own involvement with people in and around Brecon, and eventually, the Meeting Centre which was set up by Dementia Matters in Powys (which in turn was set up by the Brecon and District Dementia Friendly Community initiative), became my case study and where I spent time on a relatively long-term basis. During the initial phase of the research, and indicated in my ethics application, we (myself, my supervisors, and DMIP) acknowledged that this research could have been formally recognised as a type of Participatory Action Research (PAR), and I attended a meeting of the UK Participatory Research Network in anticipation of this. As acknowledged throughout, I was already part of the field, and had been invited to take part in many fora which had led to the formation of Dementia Matters in Powys, and latterly, the Meeting Centre initiative. Although not formally attending to the classic three phases of action research – looking, thinking, acting (Stringer, 2007, Koch & Kralik, 2006) – my own experience as a researcher underpinned by a social science approach in Flyvbjerg (2001) (see Case Study) gave me confidence that this approach could have been possible. My impression remains that often these research 'modes' are on some kind of continuum: bookended by stricter approaches to participant observation one the one end, and participatory action research on the other, with gradations in-between.

It was agreed that my research practice would be closer to the participant observer end of this continuum. This was negotiated carefully in an open dialogue with DMIP, in part because by the point that fieldwork was beginning to intensify, they had decided that they need outside evaluation of their processes, having secured three years of Heritage Lottery funding to develop the Meeting Centres across Powys (which they did rapidly -four such centres were opened eventually). I felt that this gave me far more freedom than a PAR approach, with attendant formal expectations, would have given; ironically enough, the critical distance it also gave me meant that I could also give a more ‘objective’ view of how things were developing in Brecon, when asked.

Reflecting on this further, I also had to recognise my own unease at times around the rhetoric of participation and empowerment, two terms which are often conflated for policy purposes (Kamruzzaman, 2020, Cruikshank, 2001), and seem to be very firmly in the discourse of ‘best practice’ or a ‘never-ending’ loop between researcher and practitioners and …diverse endeavours and institutions – firms, families, factories, schools, government, NGOs’ (Brown, 2015). While my position has never been one to regard the practical application of such practices as a ‘tyranny’ (Cooke & Kothari, 2001), nonetheless I realised subsequently that part of my analytical task in this thesis has been to stay alert to the polyvalent nature of this discourse around participation (Kesby, 2001), one that is ‘an unstable process… [that can be] both an instrument and effect of power, but also a hindrance, a stumbling block, a point of resistance, and a starting point for an opposing strategy’ (Foucault, 1981, p.101). In my exploration of both dementia activism and Brecon, I would argue that such participatory rhetoric has been used for tactical reasons which form part of a broader, critical counter-conduct (see Pastoral power). By loitering about, and not having to grapple with some of the demands that a PAR approach would have necessitated to be carried out properly, I have had sufficient space to consider these issues further.

25. Strolling about

Figure 4: Brecon High St

> *so many lives, jostling, colliding, disrupting, adjusting, recognizing, settling, moving again to new spaces (Williams, 1973, p.218)*

Part of my method has involved just strolling about, sometimes on my own, sometimes with others. Strolling is a word which I've chosen for two main reasons: the lightness it conveys in contrast to the increasingly interesting but not so relevant (in its fullest sense, for me) 'walking methods', and secondly, because it has such strong associations in my mind with Brecon. Concretely, a Brecon Jazz Stroller ticket, mainstay of what used to be Brecon Jazz, a weekend by the Honddu river and its canal, listening to music from all over the world and being in the company of friends.

A stroll 'lacks the density of long excursions, but other dimensions can be felt, more humble, less suited to grand mystical poses, metaphysical frauds and pretentious declarations' (Gros, 2015, p159). Maybe Gros overstates it somewhat (here I am after all making a potentially pretentious claim for strolls), but the object here over the various walks around Brecon and other places has been get a feel for the openness of the unfolding scene as you walk about, and even if there are ulterior motives for the researcher – so trying to think about what dementia friendly communities might mean in a certain place, for example – being open might necessarily mean trying to notice all phenomenon, related or not.

Such flânerie is not without precedent, of course, in earlier avant-gardes (Torsi & Ardito, 2018, Featherstone, 1998), but beyond any wish to be a fully committed 'botanist of the asphalt' (Benjamin, 1973), there are some key points here which would seem to be in keeping with the rest of my method, including collecting the inconspicuous ephemera around DFCs, taking photos of places and spaces, in particular the varied noticeboards of Brecon, juxtaposing these through collage and cut-up, and attempting to note 'the push' of life which interrupts, settles, and haunts persons, places or things' (Anderson & Harrison, 2010, p.16, Bennett, 2001).

As Mike Featherstone comments on the significance of Benjamin's Arcades Project (Benjamin, 2003): 'The flaneur, then, is not just the stroller in the city, something to be studied. Flânerie is a method for reading texts, for reading the traces of the city. It is also a method of writing, of producing and constructing texts.' (1998, p.910). My strolling about in the market town of Brecon, but also in the variegated drift in and out of conferences, networking meetings and consultations, has been part of trying to read the traces of this *tylwyth teg,* and this thesis with its attendant fragments and touchstones is its result for now. In time, physical walks along paths in a place which you feel you've got to know well can become simultaneously automatic and varied. In Brecon, I made a habit of having a quick walk around either before or after being at the Meeting Centre or having been in any other meeting, of taking a photo of the entrance to Bethel Square. As time wore on, my feet seemed to walk these paths almost automatically, as I tried to take in the seasons, the movements, the river, the decorations on lamposts; got to know the faces, the café owners, the dark corners, and various civic buildings, religious or not. Though there are only two named 'Brecon Strollers' in the empirical parts of this thesis, other walks took place, accompanied or otherwise, including those with fellow-PhD candidates, to think out and help formulate the thesis.

26. Interview encounters

> *This inscription, what does it cost us? What do we lose? What do we win? (Barthes, 2010b, p.3)*
>
> *Successful field research depends on the trained investigator's abilities to look at people, listen to them, think and feel with them, talk with them rather than at them. It does not depend on some impersonal apparatus, such as a camera or a tape recorder. (Polsky, 1967/2007, p.126)*

Ned Polsky's quote above, from Hustlers, Beats and Others (1967) was from a period when 'interviewing' might have had different connotations, and maybe from the outset, we can recognise that there is a sense that modern life may be far more suffused by interviews in many forms, and that this technology is 'part and parcel of society, not simply a mode of inquiry into and about society... the interview's ubiquity serves to produce communicatively and ratify the very culture it ostensibly only inquires about' (Gubrium & Holstein 2001, p.30).

Reflecting on my own prior experience of qualitative interviewing, focus groups and the like, such an adaptable technology would seem to be integral and ubiquitous to all kinds of scenarios by now, from auditing and confessional modes of assessment to 'personal development records', from dens full of eponymous, entrepreneurial dragons, to acts of podcasting. What was once perhaps the preserve of priests, police, doctors and journalists (not to forget researchers, of course), can be found as a normalised part of many institutional practices, workplaces or acts of 'engagement' with 'publics'.

As part of the research strategy for this thesis, I also understood that some more in-depth conversations (interviews) might be needed to give people space to express their views about 'dementia friendly communities'. I decided to pursue a small purposive sample either around my main case study in Brecon, or otherwise with individuals who I'd identified as having some significant practical or strategic take on DFCs. In many cases too, it was the informal conversations around the topics which have ended up here as fragments or parts of anecdotes and were as revealing or interesting as the nine or so 'sit-down' (or even walking about) interviews which were deliberately recorded or carried out more 'formally'. Such spontaneous accounts, often ‘informal conversations in the course of other activities’ (Hammersley & Atkinson, 2019, p.112) have formed an important part of this work, resulting in some of the anecdotes and fictocritical writing in this thesis.

Wherever possible, I’ve tried to take into account the contextual ‘embedded-ness’ of each conversation that I’ve felt was relevant. With appropriate anonymisation and other ethical consideration, a fictocritical account of something said about dementia in passing by a stranger while on a bus journey will convey something different to a conversation with a dementia activist I’ve got to know over time, or the or someone strategically coordinating support for dementia friendly communities, but my contention here is that all have a place as research encounters in my overall account of DFCs:

> *The focus falls on how life takes shape and gains expression in shared experiences, everyday routines, fleeting encounters, embodied movements, precognitive triggers, practical skills, affective intensities, enduring urges, unexceptional interactions and sensuous dispositions. Attention to these kinds of expression, it is contended, offers an escape from the established academic habit of striving to uncover meanings and values that apparently await our discovery, interpretation, judge- ment and ultimate representation. In short, so much ordinary action gives no advance notice of what it will become. (Lorimer, 2005, p. 84)*

But fundamentally, an interview in the context of this research can loosely be seen as ‘a conversation which has a structure and a purpose’ (Kvale 1996, p.6), and I found that it didn’t take much for people to start talking about dementia once a conversation had got round to explaining what I did. At its best, the approach taken has been much more interested in exploring, rather than interrogating (Charmaz, 2006), and I decided early on that my approach would be very open-ended and iterative when it came to such conversations, treating each encounter as unique.

Because the sample for the more ‘formal’ interviews was purposive, in most conversations I had already some rapport built up from getting to know people either locally in Brecon or through various networking events; inevitably the questioning might be more specific.

Following up with emails for further conversations for the eventual sample didn't always prove to be successful though; getting to talk to someone from the Alzheimer's Society or even DEEP proved to be elusive and ultimately fruitless, though I managed to talk informally to people from both organisations, and to people part of their associated networks.

In total, there were about eight 'sit-down' interviews which have either been featured here or have influenced the development of the work, among the myriad other encounters noted. Some are quoted extensively, with permission, whereas at times, comments have been anonymised (ascribed simply to 'Interviewee') when either expressly asked to do so by the interviewee or I felt that there would be some compromise with my perception of their roles. Three interviews – with Emma, Nigel and Joan – have been given a section each, more or less, because I felt that they benefit from more concentrated attention, either because they represented something unique or because (as in Emma's interview), the geographical distance (and local set -up) were somehow uniquely reflective of the workings of DFCs. This should not, however, be taken as lessening the importance of others who I quote as much as is possible throughout. These are the voices which have shaped the work, and much of the story that needs to be told can be found in the words spoken and the interactions. This thesis seeks to be about a polyphony of voices. I've resisted the temptation to over-analyse thematically and have given large chunks of the exchanges verbatim.

At the end of the day, interviews are an active, interactional process (Holstein & Gubrium 2004, p.151). At the same time, meaning might not necessarily be constantly renewed by participants during each interaction, but could reflect relatively enduring local contingencies and conditions of possibility (Foucault 1979 cited in Holstein & Gubrium, 2004), or institutionalized ways of understanding certain topics. For some, the act of interviewing can also be seen as a distinctive technology of the self, one directly related to governmentality as 'it gives an "objective" and "scientific" cast to the notion of the individual self' (Gubrium & Holstein 2001, p.8). If its formal rituals include operating some form of recorder, or sitting down with a notebook and then putting it away at the end, then 'these parameters mark a culturally canonical form of talk and interaction... [a] communicative subjectivity in a society whose knowledge is technological, capillary, and powerful' (Warren et al., 2003, p.109) . As mentioned though, very often it was the smaller fragments of unscripted or unsolicited conversation which hooked my thoughts and I would scribble down later on, or thinking about the room, space or objects around such interviews: these felt equally fruitful to me.

There was also a fundamental shift in how I thought of 'interviewing' as I became aware of more non-representational modes of research, Deleuzean approaches (Coleman & Ringrose, 2013) and also the various debates around developing a more 'lively sociology' (Back & Puwar, 2012, Lury & Wakeford, 2014). This was quite liberating, as someone who had many years' experience of qualitative interviewing within quite a traditional framework: semi-structured interviews would be conducted with relevant informants on said topic, interviews would be transcribed, then coded for 'meaning', before a final 'analysis'. Numbers of interviews were seen as significant.

As intimated, this thesis has given me alternative ways of thinking about how such knowledge is produced and enabled me to recognise some of the unease I've often found in qualitative research of this sort, where at times you can feel that interviews are treated as a way of excavating knowledge for a narrow purpose, however worthy, and that vast amounts of interesting detail in each encounter are lost or ignored. A recognition that the interview is a dynamic encounter that doesn't need to be 'fixed' or a 'place where social forms are staged rather than a resource to understand the nature of society beyond' (Back 2014, p.249) has always been at the back of my mind, but here I've also tried to respect a sense of 'becoming' in each reading or listening to recordings. Instead of looking for fixed meaning or codings, I've tried to 'encounter with the work a literal 'event' in which something always new transpires' (Massumi, 1996), including attending to the other 'surface[s] of sonic vitality' (Back 2014, p.251) in any recordings made, for example, so listening out to other background details as part of this. The further away from recording, the more intriguing it can sometimes get e.g. the background of a Kate Bush song as I strolled around the indoor market in Brecon (see Market Stroll).

In practice, all of the recorded interview encounters were pretty free flowing, but some of the events around the interviews were also interesting. Several 'after the interview' effects were noted, the underreported phenomenon of what happens after the recorder is turned off (Warren et al. 2003), but one over the years as a qualitative researcher I've always tried to sensitise myself to. In particular, it would be possible to relate these periods to Goffman's 'strips' of interaction and talk, and footing (Goffman 1974; Goffman 1981). Interview situations can often be defined by four 'strips': greetings and introductions, the interview, after the interview, and leave-taking. It was Goffman's observation that 'after the interview' encounters tend to be 'looser', as the frame of reference changes, and this was certainly true of some of the encounters in this paper. Comments which were made could be loosely divided into 'off the record', or 'interrogating the interviewer' often about my own experience elsewhere, though in fact many were a continuation of some of the subjects talked about, but with slightly different detail. Goffman's work in general came to mind in particular conversations which took place in the Meeting Centre environment also, with a small kitchen attached to the main area of activity, there were various 'front of stage and backstage' type encounters (see Meeting Centre). For a list of the interviewees, see Annexe 2.

27. Recording Method 1: Fieldnotes and Spontaneous Prose

> *The task is to imagine methods when they no longer seek the definite, the repeatable, the more or less stable (Law, 2004, p.6)*
>
> *'Memory Babe'[Jack Kerouac], an inspired celebrator of the ordinary: passing seasons, winter streets, floods, bars, factories (from the outside), woodsmoke, night, touch, family, friends, restlessness, kitchens, insanity, murder (Sinclair, 2013, p.25)*
>
> *They found it, they lost it, they wrestled for it, they found it again, they laughed, they moaned—and Dean sweated at the table and told them to go, go, go. (Kerouac, 1988, p.228)*

If, as it is sometimes claimed, there is a need to think of a more generous and broader sense of methodologies as they attend to the mobile, messy, creative, performative and affective elements of our social and cultural worlds, then maybe we also need to start with a clear idea that social science methods don't purely describe these worlds but have a hand in creating and inventing them (Coleman & Ringrose, 2013). In terms of the methods 'technology' used for this thesis, then probably one of the most important has been the use of fieldnotes, a standard ethnographic technique, which although can be selective and will change over the course of a given research project (Hammersley & Atkinson, 2019), does have conventions such as 'headnotes', 'jottings' (open or not) and certainly individual idiosyncrasies for any experienced researcher, myself included (Emerson, Fretz, & Shaw, 2014). I explain here how this thesis has given me the opportunity to think about and implement a more creative way of 'doing fieldnotes'.

Having been a qualitative researcher for around ten years prior to this research, then my own preferences for certain types of observation or kit as standard (weather, journeys to and from, certain makes of A5 notebooks or pens) are no less idiosyncratic to begin with. Spatially defined as they are, useful, evocative and usually witnessing some lived experience on behalf of the taker-of-notes or those people, places and objects involved, fieldnotes aren't ever 'finished'. In fact, it may be better to see fieldnotes as ongoing creative acts of collection, a lively part of the research strategy. In some cases, they also have a performative quality when read aloud. Undoubtedly, a good fieldnote can lead to an anecdote or vignette, if sufficiently stirred. But maybe they should be characterised as 'text-as-it-happens', spatial events for all concerned (Hones, 2015; Anderson, 2018) - writer, text and reader – including readers of this thesis. Each reading is different and maybe needs to be acknowledged as such.

In light of what has been quite an iterative qualitative approach, very much in line with the recognition of messiness made by Law (2004) and others, and the calls for innovation outlined in previous sections, I also started to think of what a more interdisciplinary, 'Beat' approach to fieldnotes might look (feel? smell? taste?) like, once more inspired by the ‘writing place’ seminars in the Geography Department. Apart from opening my eyes to the affective through the work of Stewart or making me think anew about writers such as Perec or Burroughs, these reawakened some of my knowledge and interests from my first degree, where I’d written a dissertation on the picaresque in the work of Jack Kerouac, some thirty years ago, having read widely about the Beats in that period.

Kerouac’s nickname from his bilingual childhood, ‘Memory Babe’ – because of his legendary memory, even in his declining years (Nicosia, 1992) - also seemed to echo what is often required of fieldnote writing: to recall events, feelings, sensations and other details usually after things have happened. In his day, Kerouac had stipulated a set of ‘Essentials for Modern prose’ (Kerouac, 1958), and it is to those, and his ‘Belief & Technique for Modern Prose’ (Kerouac, 1957) I turned for inspiration, specifically his method of a type of stream-of-consciousness writing called ‘spontaneous prose’. I recalled how the essence of some of his writing is about finding that ‘undisturbed flow’, which was inspired by the be-bop jazz players of his day and wondered if this would be something useful when we get to writing my own fieldnotes.

In essence, using a spontaneous prose style means at times writing without worrying so much about grammatical conventions, of being in some ways ‘in-trance’ when recalling what has happened, ‘surfing the situation…[recognizing that] We are our situations, we are our moving through them’ (Massumi, 2015, p14). The technique involves consciously dispensing with commas and full-stops, capitals, using abbreviations, using hyphens to denote where the breath might come in a phrase. It means discouraging too much alteration or the re-crafting of texts, and it means an openness (and maybe more honesty?) in our approach to fieldnote-taking, to try to be in that moment as entirely as possible, even if that moment is a few days later. It might lead to creative opportunities which may animate, more than mimic in a repetitive sense, the lifeworlds we come across in our research encounters (Vannini, 2015). It could be seen also as an appeal to use more of a rhetorical stream-of-consciousness, but then there are certain characteristics of Kerouac’s approach to prose that can be boiled down to:

- Anamnesis: the act of focusing and remembering, concentrating intensely
- Mimesis – or a ‘mimicking’, but mainly here of sounds, repetitions that occur as we sit and listen or a refrain we might pick up on – so try to write the down as they come up in consciousness
- Congeries – or heaps of words, adjectives that come in no particular order, to be exhausted once the writer is satisfied

(Juarez, n.d.)

Of course, there is a much wider literature on how people write about interacting with places and spaces (Reynolds, 2007), and other types of automatic or ‘writing in place’ can be tried in the spirit of experimentation (Riding, 2017). I haven’t been the only person who has recently picked up on or used this technique in a research context either. In a recent paper, Honeybun-Arnolda (2018), uses it to describe being in a Norwegian petroleum museum, and explicitly links the spontaneous prose to non-representational theory: he finds it a practice that

> *decentres traditional preconceptions of what to write and observe…by attempting to write what is directly unfolding, writing outwards… the ability to capture interactions and the actuality of events becomes manageable and more meaningful. (Honeybun-Arnolda, 2018, p.398).*

Others seem to be trying to capture rhythm and movement in a not too dissimilar way in ageing studies, even if there are no references to Kerouac, again making links to non-representational theory (Andrews & Grenier, 2018). Some of the pieces in this thesis which use this technique are ones in which I try to find a way of expressing the visual in movement and place, as well as sound (in particular Brecon), and my place as an active participant in this; the praxis of spontaneous prose proved useful in these instances, and I hope to be able to continue using it in further research.

28. Recording Method 2: Photography

Photography is a well-established recording technique in qualitative ethnographic and anthropological research (Hammersley & Atkinson, 2019), but can also be a powerful medium for 'breaking the frame' (Butler, 2009, p. 12), a way in which taken for granted reality can be questioned so that a viewer can 'move beyond the image itself and their own emotional response to its content' (Mannay, 2016, p. 79). As noted, a particular photograph taken roughly sixty years ago in Brecon provided an affective 'punctum' (Barthes, 2000) that has gently pushed this thesis in a particular direction. The details in the picture - Burroughs's ghostly appearance, the deep archway behind - seemed like an invitation to further investigation. It provided an emotional link back to both my younger self and to being in place in Brecon itself: an abiding interest in the Beat writers from an early age, but also hazy knowledge of various indoor and outdoor spaces in the town from attending the jazz festival there.

As a method of recording, digital photography gives the researcher instant and accessible possibilities for working even more multimodally (Pink, 2011), adding to a way of working in which arguably all senses should be engaged anyway. The 500+ photos which I've taken during this research are mainly a collection of visual jottings when either it was far quicker to note what was going on through taking a photo, or I felt that there was something in the overall scene which spoke to me about dementia, community or place. For example, I would regularly come across headlines which related to dementia whilst walking about or shopping, and it was convenient to take a photo of any such instances. This grew into quite a collection over the years, which I then use as a basis for one of the cut-ups and some collages; I felt that the ubiquity with which the word 'dementia' or 'Alzheimer's' might crop up on a notice-board or in supermarket aisles was worth noting.

At the same time, other photos taken in contexts which initially didn't have a direct link to DFCs subsequently became unexpected routes into thinking about the phenomena and highlighted that methodologically there was the need for a 'focus on multiplicity, relationality and assemblage…[how] concepts change, they connect, are in relation to each other' (Coleman & Ringrose, 2013b, p13). During this period, I took photos at robotics exhibitions, political demonstrations, art shows, of graffiti, of multiple public noticeboards, as well as landscapes or interesting found objects, and some of these have ended up being used here in the collage work, sometimes as idiosyncratic 'connections of a peculiar sort'(Rajchman, 2000, p.4) that potentially create yet more connections: my rationale for snapping the various public noticeboards in Brecon for example was that in some way, it showed the strength and breadth of activity in the area. Equally, as noted previously, stumbling across an exhibition of by Jean Jacques Lebel while on a trip to Paris, jotting some of the visual ideas there in an assemblage of objects which he called 'rhizomic', provided more insightful connections into how juxtaposition, collage and cut-ups might be used 'not to predict, but to remain attentive to the unknown knocking at the door' (Deleuze, 1992, p. 165).

I tried to be as sensitive as possible when photographing people as part of this research, out of respect for their privacy. If people were in a shot, I would always ask their permission having explained what I was doing. Apart from some significant objects, I took many photos of the spaces where DFCs were debated, provoked events: many were religious buildings which currently had other use or had been converted to secular uses. Out of some instinct or habit, I also took a photo of the entrance to Bethel Square with almost every visit to Brecon, noting the minimal differentiations in light, shade and movement. The physical act of taking a photo around the portal served to take me back to the original punctum, but in a sense, each time these photos are taken then revisited, sometimes multiple times, it's been another way of sensing anew, seeing 'generative preludes and supportive supplements to the inventive devising of something else' (McCormack, 2015, p. 100).

29. Case study

> *Above all, one should not wish to divest existence of its* rich ambiguity.
> *(Nietzsche, 1974, p.353)*

> *I can only answer the question 'What am I to do?' if I can answer the prior question 'Of what story or stories do I find myself part?'(Macintyre, 1984, p.216)*

Bent Flyvbjerg's Making Social Science Matter (2001), has probably been one of the most influential books on my approach to qualitative research in the years since I read it as part of an MSc in Social Science Research methods, completed well over a decade ago. It dissects some of the essential differences between the natural sciences and social sciences, and gives some methodological guidelines for researchers that can be boiled down to five questions, in theory applicable to most fields of qualitative enquiry: where are we going? Is it desirable? Who wins, who loses and by which mechanisms of power? What should be done? Behind each question there is a set of considerations around power, values and narratives, and a call to develop social science that accepts the dialogical polyphony of voices in any ongoing social enquiry (Flyvbjerg, 2001, p139), rather than produce ultimate, verifiable and generalizable 'truth'. These considerations have stayed with me and been a helpful grounding for most of my varied research experience. Even if particular projects didn't overtly require this approach, this checklist of questions has grounded my considerations whenever called upon to think or explore with others.

In this book, and in other papers eg Flyvbjerg, 2006, he also makes an eloquent plea for the value of the case study, and dissects the misunderstandings that are frequently made about the method and its validity, highlighting that good case studies often involve complex and contradictory narratives. Such narratives are hard to summarise into 'neat scientific formulae, general propositions' (Flyvbjerg, 2001 p.84), the resulting 'thick' descriptions are the foundations for exploring the 'rich ambiguity' of events and situation in which we find ourselves during research.

Mol (2008) makes the point that good cases studies can helps us to look for points of contrast, comparison and reference for other situations:

> *It does not tell us what to expect – or do- anywhere else, but it does suggest pertinent questions. Case studies increase our sensitivity…a meticulously*

> *studied case study…allows us to unravel what remains the same and what changes form one situation to the next (p.11)*

If, as Berlant (2007) argues, the case has an actuarial element to it that sets it apart from an ‘instance’ or ‘example’, and that it raises questions of precedent and futurity, then my decision to follow events in Brecon could be seen as following that line of reasoning. Prior to my starting this work, the work of BADDFC after all was held as some form of exemplar of how to develop dementia friendly communities in Wales. By following what happened next just after that point of ‘national example’. Above all, therefore, it may well be that ‘the case can incite an opening, an altered way of feeling things out, of falling out of line’ (Berlant, 2007, p. 666).

30. Anecdote and vignette

In a collection which explores novel approaches to research, Mike Michael speculates as to the usefulness of the anecdote as a form, and how they are essentially for telling, to be circulated in the world (Michael, 2014). The auto-ethnographic element which is part of my method is largely a natural ally to this approach: the stories performed here of how I have witnessed and taken part in DFCs are a methodological *tactic*, and to extent opportunistic pieces revealed in the daily toing and froing of not just *doing a research project* or *writing a thesis*, but everyday life; ‘the chance offerings of the moment borne of mobility…an art of the weak’ (De Certeau,1988, p.37). Each one tries to tell of the way I’ve navigated some of the ordinary encounters I’ve had with the idea, places and people involved in ‘dementia friendly communities’ for the last few years.

Building on the work of others (e.g. Fineman, 1989), Michael presents five key features which sets the anecdote apart from other forms, noting the ambiguity of the textual form (it holds both the ‘real’ and the ‘constructed’ in a type of tension), and that though it might report an episode it also ‘acts upon’ them, with a type of performativity. An anecdote might also report something out of the ordinary, which is also therefore a way of highlighting the usual events around that. Often, they also tend to point towards broader lessons, to ‘the general’ in some way. Finally, it can be a way of 'writing self into the narrative in order to problematize the authorial voice' (Michael, 2014, p28).

A microsocial incident which may start in private life, for example paying off an overdue bill for repairs to an old car or scraping off seagull droppings in spring, may become an observation on feelings of neighbourliness, proximity, the sharing of experience around caring for someone with dementia. In both these example scenarios, there is also a tension between neighbourly curiosity and concern intersecting with a certain amount of presumed expertise on behalf of the interlocutor, and feelings of unease on behalf of the author, while simultaneously appreciating the space of understanding and the intimacy being played out in different spaces – on the street, in a small office - that might open out during a conversation, and even help both parties in some way. Usually, some form of conversation or utterance takes place, an exchange.

Equally importantly perhaps, a perceived moment of understanding might arise, or lead to further reflection, months or even years later. The re-telling or sharing of the anecdote later on might shift perspectives, lead us to query our interpretations of an event. Was it really a chance conversation at the end of a seminar that led me to that photo of Bill Burroughs? What was the story behind him being there in the first place? Would that person in the train station really prefer to be tagged if she developed dementia? 'The anecdote has at once something of the literary and something that exceeds the literary, a narrative form and a pointed, referential access to what lies beyond or beneath that form' (Greenblatt, 1990).

Such smallish incidents usually involve a process of listening for a story, a way of practising the listener's art (Back, 2013), trying to pay attention. The significance of such episodes might not be immediately apparent, and many are an attempt to find movement between the 'personal' – where I am a spectator of my own life as much as any other character in an anecdote – and the public, as in the elusive *tylwyth teg*, the variegated, rhizomic forms that connect say, the violence of Big Society citizen sacrifice in austerity to moments of connection and community-making, over dancing, indoor cricket, eating chocolate brownies at conferences, or just catching a bus. They are often smaller texts or fragments which, for the sake of this thesis, are intimately related to the contexts of dementia and communities, and even ‘friendliness’ or ‘neighbourliness’; they may or may not highlight something out of the ordinary, but they have sufficient force as events to be ‘quoted raw, like notes in a bottle’ (Geertz & Darnton, 1973), to be in a sense ‘a touch of the real’ (Gallagher & Greenblatt, 2000, p.74), and at times a counterhistory, a puncture.

An example. One of the motivations I had for starting this research came from a previous piece of work in which I had interviewed a care worker who had trained to be a ‘Dementia Champion’ but was had become utterly disillusioned at delivering ‘Dementia Friends’ training. ‘What’s the point, because where are all these people when I’m trying to look after Mrs Jones, who’s had dementia for years and nobody visits her or can speak to her in Welsh?’, she said. This single short exchange when relayed or performed as an anecdote during this research has started many conversations which run counter to the largely critique-free assumption that the act of becoming a ‘Dementia Friend’ as stipulated by the Alzheimer Society training is unquestionably positive. The teleological narrative of this positivity – one that might include ‘we’re all in this together’ for example – has often felt ubiquitous but is seldom linked to the historical aspirations of Big Society Conservatism or the moves to responsibilization often occluded in volunteerism, and in this context, the effects of austerity or the inability of political forces to make better provision for social care. This single anecdote in a sense exposes that, and when performed during conversation, has led to further anecdotes which form a counterhistory of sorts, where care workers or those affected by dementia have ‘voice’ (for example during academic conferences about robot care – see Darla’s story). A tactical art of the weak, the fragments in bundles and heaps are stockpiled here in an attempt to shed a different light.

In his essay Lives of Infamous Men, Foucault recounts his fascination with the glimpses of lives found in very historical accounts of those committed to jail or ‘hospital’ at the start of the eighteenth century: ‘fragments of a discourse trailing the fragments of a reality they are part of’ (Foucault, 2000, p.160). Through the obscure accounts of seditious friars or usurious madmen, he finds the workings of power made visible – but reflexively also acknowledges 'his complicity with the dirty business of power' by doing so (Gallagher & Greenblatt, 2000, p70). The anecdotes and vignettes in this thesis make no real claims beyond highlighting the events around them (the research interview, the academic conference, catching a bus, paying a bill). Power circulates in all these sites also, and I am part of that circulation, though attempting to make some purpose to this research more visible through the re-telling of these stories.

31. Cut-up analysis

> *Take a newspaper.*
> *Take some scissors.*
> *Choose from this paper an article of the length you want to make your poem.*
> *Cut out the article.*
> *Next carefully cut out each of the words that makes up this article and put them all in a bag.*
> *Shake gently.*
> *Next take out each cutting one after the other.*
> *Copy conscientiously in the order in which they left the bag.*
> *The poem will resemble you.*
> *And there you are – an infinitely original author of charming sensibility, even though unappreciated by the vulgar herd (Tzara, 1920)*
>
> *Language trembles from head to toe. (Deleuze, 2009, p.109)*
>
> *By default, networked society exists in a state of remix. We curate, edit, archive and reappropriate the constant feed of online content fashioning our personal and professional informational landscape. There is, however, a clear disconnect between traditional, hierarchical systems of information distribution and the emergent rhizomatic flattened digital data flow. (Falconer, 2020, p.259)*

The has been a steady stream of academic interest in William Burroughs' work on ideas of 'control society', and in his use of cut-ups, that has intensified over the last few years (e.g. Raley 2020, Gontarski 2020, Patoine 2019, Feireiss, 2019, Hawkins et al. 2019). The chance encounter with a picture of him in Brecon led me to wonder about the value of experimenting with the materials gathered in my own research, as I was attempting to think and write about DFCs. As explained elsewhere in this thesis, having reached an impasse of sorts in my thinking around how this particular field might fit neatly into critiques around governmentality or neo-liberal governance of ageing populations, I found myself trying to heed Eve Sedgwick's call to develop a form of thinking that does something other than seek to get *behind* or *beneath* a topic (Sedgwick, 2003), though it is not without a hefty pinch of irony that it was a picture of William Burroughs, arguably one of the most emblematic literary figures writing from a post-war paranoid viewpoint (Melley, 2000) which led me to this, as I explored earlier.

Nonetheless, finding myself entangled in this multiplicity of materials created by DFCs, I was conscious also of what Barad (2007) and others have encouraged social scientists to acknowledge, that there is a 'need to be responsible for the 'cuts' that are made in the practice of boundary-making' (Coleman & Ringrose, 2013, p.6), when we make our knowledge claims. By only considering analysis in straightforward, systematic terms, for example by considering thematic patterns around the experience of watching such ideas develop, might there be opportunities lost? If a fundamental tenet of qualitative research practice is 'to make the familiar strange', then why not experiment with a form of analysis which introduces an element of randomisation, inducing types of strangeness perhaps, why not try to make the strange more familiar?

Using a form of analysis which attempts to look for 'a strange language within language' (Deleuze, 2006, p.109) might therefore be apt, not necessarily to replace what was somehow already known, but to try to appreciate the multiplicities contained in each experience. Because dementia seems such a slippery and contingent term, then maybe it was worth considering how to pay more attention to 'the ephemeral, the fleeting, the not-quite-graspable' (Vannini, 2015, p6), and cut-ups, in a mimetic sense, present a 'fragmented perception of an unordered universe' (Lydenberg, 1987, p.61). I acknowledge this might be unorthodox, though not unprecedented as an approach in health and social care (Biley, 2004).

It may, however, also give us space to think in a way that *dwells alongside* dementia friendly communities, 'a way of being with and becoming with the ageing-dementia relation and be affected by it in ways that challenge dominant forms of what counts as successful forms of personhood' (Latimer, 2018, p. 14). As can be seen in one of the cut-ups in this thesis that uses a collection of newspaper headlines on the theme of dementia, it is possible in this way to question dominant, prescriptive forms of thinking on dementia. By means of novel or randomised juxtaposition either text or photos, for example, we potentially create 'boundary objects' (Bowker & Star, 2000, p.297) - new forms of bringing together the different registers, materials, viewpoints, portrayals of communities of practice found in the collected material, with the potential for provoking new insights if, bringing out some of the invisible tensions that are present when thinking of dementia friendly communities, but also a means of developing interdisciplinary work, lighting fires.

Cut-ups, to an extent, are an attempt to loosen these boundaries around what is known, to 'undo control'; by juxtaposing and cutting up familiar material randomly, by letting go of or challenging the established control in linear texts, in syntax, it constitutes a new way of experiencing that material: 'the folding of one text onto another, which constitutes multiple and even adventitious roots (like a cutting) implies a supplementary dimension to that of the texts under consideration'(Deleuze and Guattari,2013, p.4). The technique has its literary roots in avant-garde montage painting techniques, and the Dadaist movement, though Burroughs - and his friend, the fellow writer Brion Gysin, who was expelled from the Surrealist movement by André Breton in the 30s - were by no means been the only writers or artists of note to use the technique (Robinson, 2011).

However, it has become a far more ubiquitous pursuit that it first seems, with a new generation of academics and practitioners willing to investigate not only that which was popularised by Burroughs and Gysin (Hawkins & Wermer-Colan, 2019), but more broadly how cut-ups should be recognised as an important contemporary model of cultural production (Feireiss, 2019, Harris, 2019). There has also been an interest in cut-ups as a form of experimental poetry (Kenneth Goldsmith), experimental feminist poetry (for example that of Dodie Bellamy in Merrydew, 2022) as radical remix (Falconer, 2019, or the work of Kate Armstrong or Emma Wolf-Haugh), or queer pedagogy (Waite, 2019) – which in some senses, brings the cut-up back to the author of Queer (Burroughs, 1985), but also the work of Eve Sedgwick. Remix culture, for example, and latterly meme culture all would seem to be descendants of this line of creativity, and apart from more literary or text-based approaches, it can also be found in architectural studies and masters courses (Feireiss, 2019), even recently in fictocritical studies of architecture (Gibbs, 2020). At its loosest and potentially most useful, 'the term cut-up serves as an open container for a long list of terms and actions that describe the combination and reassembly of existing motifs, fragments, images, and ideas from diverse and disconnected origins into newly synthesized entities' (Feireiss, 2019, p.10). By now, Burroughs' work and methods are increasingly recognised across many disciplines, in literary, media and gender studies, to writings about post-coloniality, history and geography, as well as the visual arts (Hawkins & Wermer-Colan, 2019).

From the early sixties onwards, Burroughs and Gysin experimented extensively with not only the possibilities of cutting up written texts, but also using photography and sound in a similar way. Although Burroughs is often though of primarily as a writer or novelist, a more accurate description would also include performance artist or media theorist (Gontarski, 2020, Rae 2019), and his sustained critique of what he termed 'control' from the early sixties onwards was a theme which for some provides the missing link between both Foucault's idea of biopower and Deleuze's influential idea of 'control societies' (Nail, 2016). In his lecture series dedicated to Foucault, Deleuze acknowledges this influence on both French thinkers (Purdue University, 2016), as he did in his writings with Guattari and in other texts.

However, Burroughs popularized the use of this technique from the sixties onwards, and this has had its cultural effect, from the lyrics of David Bowie or Patti Smith to the punk movement (Rae 2019), or the writings of Kathy Acker, Carl Weissner and Stewart Home (Robinson 2011). If writing is a kind of technology, Burroughs maintained that it was being left behind by painting or photography, and in part, the cut-up technique was his attempt to develop a way of 'foreground[ing] the matter of language – especially its affective character -

whilst at the same time introducing an element of chance, something outside of conscious control' (Burrows & O'Sullivan 2019, p.36). If language often transmits order, a type of politics to be obeyed (Deleuze & Guattari 2013, p. 88) then what's common in the work of Burroughs and others is that, to an extent, they undercut some of the norms and ordering which are expected, which by implication can make their work profoundly political, but also personal. By attempting to disrupt some of the linearity and tone, it becomes a deliberate 'stuttering' or 'fictioning practice' (Burrows and O'Sullivan 2019).

In essence, cut-ups mean cutting, folding or splicing a single text or two texts together to produce a new narrative, which is then carefully selected and edited. The point is that the resulting text isn't entirely random, but that some surprising connections or juxtapositions might come into view that make us experience something about the subject matter in hand. Letting go of conscious control, the fixed nature of authorship and authority can be questioned, and a kind of intertextuality is approached directly through the practice (Lydenberg, 1987). In contrast to the theoretical explorations of intertextuality found in the work of Kristeva, Barthes and others, contemporaries of Deleuze, Guattari, Derrida and others who occasionally shared platforms with the author (Demers, 2018), Burroughs produced novel-length experimental texts, sound recordings and photocollages from the late Fifties onwards, effectively exporting the potential of this method into popular culture. It is a move '*in which assertions of objectivity, scientific rigour, methodological stability and other highly rationalistic-sounding terms are replaced by an emphasis on uncertainty, indeterminacy, incommunicability, subjectivity, desire, pleasure and play (Allen 2000, p.3)*.

As noted, the use of cut-ups as a form of analysis in health and social care research is not entirely unprecedented. Biley (2004) in a ground-breaking essay, explained that the goal is to try and to experience any emerging text, rather than understand it, and gives the moving example of an account of a mother losing her grown child to leukaemia. The account is cut-up using a computer program, and in the resulting prose-poetry, a different rhythm and cadence emerges which gives another sense to what happened (and is equally moving). I had been alerted to his work through a colleague at the Geography Department, and another colleague at my home department, who had been a nurse practitioner, had taken part in one of Biley's workshops using the cut-up technique, when he was based in South Wales, so this encouraged me further into using this technique with some of my research material. For a more practical account of the methods used, see Annexe 3.

32. Collaging and photomontage

> *montage is the essential gesture of non-representational styles of thought and action (Doel & Clarke, 2007, p.899)*
>
> *To write ethnographies on the model of collage would be to avoid the portrayal of cultures as organic wholes or as unified, realistic worlds subject to a continuous explanatory discourse. (Clifford, 1988, p.146)*

Closely allied to the cut-up as a practice is collaging and montaging. They are often seen as being analogous practices, having originated roughly the same time at the start of the twentieth century, not least through the 'collage hermeneutics' of the Cubist movement, where 'knowledge no longer answers uncertainty with certainty, rather with more uncertainty' (Brockelman 2001, p.186). In keeping with my line of flight into developing Beat-inspired methods, I noted that William Burroughs was also a keen photographer and collagist, who in later life became known for his visual artworks (Allmer & Sears 2014, Miles, 2014), and used photocollages and juxtaposed found objects extensively from the early sixties onwards. As with the cut-up method, this was initially in collaboration with Brion Gysin. As a reflexive point for both collaging and cut-ups, it is valuable to ask '*how* we document creativity and *how* we document creatively, but also *how* and *why* these methodologies are valuable' (Veal & Hawkins 2020, 359) and the implications then for knowledge creation. As noted in other parts of this thesis, both methods would seem to loosen the boundaries and have the capacity to bring together or juxtapose different registers, whether textual or visual, but as rather niche methods within social science, might be thought of as 'ways of doing and making that intervene in the general distribution of ways of doing and making' (Rancière, 2004, p13).

However, unlike cut-ups, collaging already has a slightly longer history of being part of an array of visual creative methods in the social sciences (Mannay, 2016) and perhaps has a more conventional status in that sense, often used in therapeutic settings, for example. In the context of this thesis, collaging has been another way of pushing the boundaries of representation, through the non-linear juxtaposition of the fragments of material and data that arose over the period of research: from chocolate eggs covered with flannel sold as easter bunnies in aid of a dementia charity, to the refrains of 'we're all in this together' or 'get Brexit done', to pictures of the spaces, places and objects involved. Analytically, it allows the expression of an appropriate degree of ambiguity (Butler-Kisber, 2010), and the possibility of more multiple ways of interpreting what I contend here to be a very contingent field of inquiry to begin with. The practice of creating collage, and then contemplating the variously juxtaposed elements has felt like a way of 'enter[ing] the middle, the between; to relate' (Coleman & Ringrose, 2013, p.9), and even though there is a 'fixed' end product, the process of creating and then contemplating has felt very dynamic. For more details on the Collaging process, see Annexe 2.

Reflecting back on the 'writing up process' in general, developing this method was also a great help during periods of impasse, for example during the lockdowns because of the global pandemic situation; during the first few months of the COVID pandemic, overstretched by work and other responsibilities, it was a way of keeping up with my research, when I found it difficult to write. Having taken roughly around 500+ photos of varying objects, places, and spaces during the course of my research, and having collected a plethora of pamphlets, newspaper cuttings, it became a very 'hands-on' way of recalling memories of events and places, at times maybe to think about certain event or situations– but also questioning and finding new ways of thinking through those issues. Beyond the excitement of trying something new, the main objective here has been to document the research creatively and help the process of analysis. Most of my research contains relatively straightforward accounts of how DFCs emerge (or don't) through observation, talking to people, being alongside PWD. But as with taking the cut-up approach, collages have helped to disrupt the more linear thinking, and pay attention differently.

As Rose notes, ‘visual imagery is never innocent; it is always constructed through various practices, technologies, and knowledges’ (Rose 2010, p.26). Photomontage, or collage using mainly photos, can also disrupt linearity, and can be profoundly political (Ingram 2019), for example in the works of Martha Rosler or kennardphillips. Again, as with developing my writing when thinking about place, attending that seminar early in the PhD process alerted me to these possibilities, and their creative potential to help me think, and, as Shapiro (2013, xv) in particular put it ‘to compose the discourse of investigation with critical juxtapositions that unbind what are ordinarily presumed to belong together…to challenge institutionalized ways of reproducing and understanding phenomena’.

The collages developed during writing up this thesis have not set out with the intention of being political, rather some have reflected the politics of events along the way during the period of research. My early collages were literally random sets of photos taken during research, juxtaposed using software. As my knowledge and confidence increased, I learned how to mount collections of photos, cuttings, pamphlets on prepared A2 boards, and then add another layer of interpretation through taking a photo of the board on an I-pad. They are messy, sometimes repetitive, and are the ‘workings’ of trying to move beyond what I’d experienced in my research. Unlike cut-ups, in general they do not have such a strong element of randomness; the thought process behind the physical process had more ‘rumination’ behind it, some ideas and groupings literally coming into view over months as I thought of events and things said, people, objects and atmospheres encountered. However, I’ve tried to keep some integrity in this process: all pictures were taken strictly during the research period, as were the images ripped from magazines or newspapers, and the fragments of pamphlets or postcards picked up events around DFCs. Looking at them and revisiting them has sometimes enabled me to ask different questions of what was going on across different times and spaces, times of the year.

In the sections to come, I’ve included some commentary on the collages and cut-ups, though conscious that perhaps these are the limits of my own ‘interdisciplinary practice’. I reiterate: because much of my background and practice day-to-day is loosely in ‘social science’, the danger perhaps is to over-interpret and contextualise. As a creative practice, it lies at a point which should invite more interpretation from the viewer or reader, and I would encourage them to do that. Each ‘looking’ and ‘reading’ should be regarded as unique in this respect. For a more practical account of the methods used, see Annexe 4.

33. First touchstone - activism/networks/events

> *I would say that dementia is like a mirror, it's like a mirror on our society, how are and accepting are we of things that we perceive as being different form, in inverted commas, "the norm"? Umm it's a mirror of our communities again, how accepting are we of people in our own communities, who might need more understanding, more kindness, how accepting are we of that? Umm it also mirrors back to us our services, what's on offer both voluntary, statutory, through schools whatever umm is that how well do they genuinely fit the needs of those whose needs are most so it mirrors that back to us, when we looked at it in practice, it was pretty crap really, and then, that's the most important thing it mirrors back to us as individuals who or what we've become, so you can see if it mirrors how accepting you are, how tolerant you are, how kind you are, how willing you are to embrace things, and I, I suppose for me, I feel that dementia provides that mirror and helps us to build community in the broader sense* ***Rhiannon Davies****, Brecon Dementia Friendly Community*

> *it's become something which I don't think even two years ago I couldn't have imagined, when you're trying to do stuff to make the world a better place for people…it's become much more about giving representation to voices which are concerned about equality and inclusion, which it wasn't two years ago* ***Steve Huxton****, co-ordinator Dementia Supportive Communities in Wales strand at OPC.*

> *Do we want dementia friendly communities or dementia enabling communities? We don't need dementia friends; we need dementia allies.* ***Nigel Hullah****, dementia activist*

This First Touchstone will explore the theme of dementia activism in two ways. Firstly, I describe and analyse some of the encounters with various forms of activism over the period of research, focussing on some of the events I've been able to witness, highlighting and attempting to give voice to one of the main dementia activists that I have encountered, spent time with and interviewed over the last few years, Nigel.

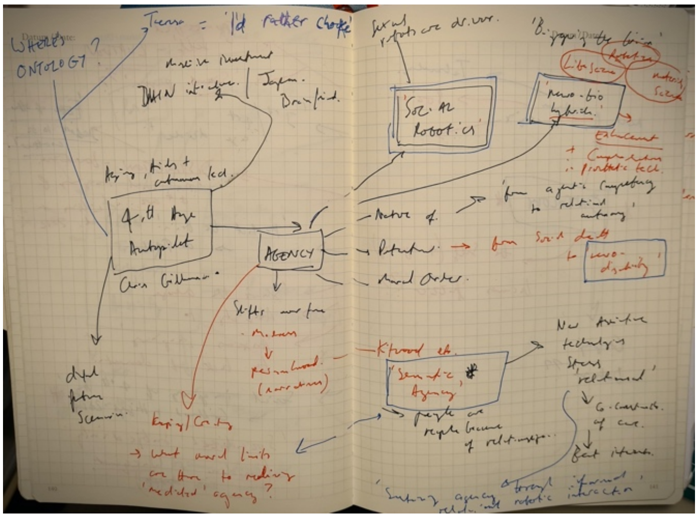
Secondly, I analyse this activity in terms of a critical-counter conduct, situated in both the macro and micropolitical acts of the activists. By activism here, I mean something more radical than 'active citizenship', which can sometimes be reified in gerontological thinking as some sort of positive health outcome for those affected by dementia, even though of course is not undesirable (Wilkinson et al, 2019). Bartlett (2012) was to an extent prescient in her analysis of moments and movements which suggest a ‘culture of resistance’ (p.18) developing among some of those affected by dementia, but there has been some interest in how, as in other movements which also claim ‘nothing about us without us’ in the name of a type of empowerment (Charlton, 1998), a new shared identity can develop for those with dementias, especially in the early stages (Clare et al, 2008) . More recent work by Hillman et al. (2018) also identifies how complex narratives can emerge from PWD who take positions of being a voice of or for people with dementia, how this can lead to types of biographical reinforcement, whilst also leading to forms of responsibilization and resistance. To an extent, it is the latter that I’ve been able to document here, in its different forms: from whispered objections and muttered lines of disapproval, especially with some of the sharper practices of larger charities, to bigger more public proclamations during various types of events.

However, it is at the level of the event - the interview in an arts centre, the academic symposium on a shiny new campus, the dementia networking event in a converted school – that I’ve also tried developing a sense of openness and be conscious of the temptation of veering towards predetermined ideological structures or codings, trying to pay attention to the immediacy of the present. Massumi (2015) highlights that often there are surpluses of un-acted out potential in even the most controlled situations, things which are collectively felt: ‘Micropolitics, affective politics, seeks the degrees of openness in any situation, in hopes of priming an alter-accomplishment. Just modulating a situation in a way that amplifies a previously unfelt potential to the point of perceptibility is an alter-accomplishment’ (p.58). As I’ve highlighted previously, it was probably my gradual awareness of how such modulations can reverberate through events – for example, the often-tactical uses of ‘we’re all in this together’, or the sudden irruptive qualities of publicly proclaimed ‘lived experience’ – that has been developed during the period of this thesis. Before this, I had an awareness of *something* going on in the room but was too quick to code and ascribe; my instinct now is to accept the *something* and try to examine each instance with the different tools of learning acquired through this process.

This includes the vicissitudes and dangers of co-optation, and in particular for those with early-onset dementias, much as those with mental health conditions, the continual pressures of doubt and qualification that accompany any display of coherence, of challenging those who are still the arbiters of that moral economy: medical authorities, governments or academics, for example. The struggle for recognition lies at the heart of this, but as we shall see in the latter section, there are several sometimes painful paradoxes and ambivalences in these moment that overlay the 'powerful insubstantiality' of the state (Taussig, 1992). As noted arguments developed in the work of Golder (2015) and Brown (2016, 2017) in particular, and building on the earlier work of Bartlett & O'Connor(2010), Bartlett (2012) I will attempt to highlight a tactical, critical form of counter-conduct in Foucauldian terms that I have come across over the preceding years; though the demand for the rights of those with dementias are often direct, Nigel and others are aware of the often contingent nature of these rights, and the ambivalence of positions which can be simultaneously liberating and subjectifying.

The fragments here include observations that lead on from the above, how different modes and acts of citizenship were deployed in the teeth of various forms of governance, and also try to give an account of the affective forces that seemed to swirl around in particular encounters.

34. Darla and the robots



The human heart is the only thing in the world that will take upon itself the burden that the divine gift of action, of being a beginning and therefore being able to make a beginning, has placed upon us (Arendt, 2005, p.322)

[For me] the concept of micropolitics is closely akin to the anarchist insistence that the politics practised in the present should pre-figure the relational field to come: that the job of political activism is to make the futurity in the present already actionable…Micro-politics is the politics of making-matter. It is not just any making-matter, but one oriented towards joy (Massumi, 2017, p.63)

'I don't want to hear Vera Lynn, I want Led Zeppelin' Darla, dementia activist

Day two of a prestigious three-day conference hosted by my department, on the brand spanking new second campus of the University, a sunny day in July. Academics and other punters had been variously running on a nearby beach, pawing the latest books from specialised presses and gulping down free coffee while wondering whose eye to catch, or avoid. This being a peripatetic annual event, a group of us had decided, because of previous experience, that it wouldn't be good enough to have people talking about dementia, there needed to be more engagement, more 'lived experience'. All too often, going to such conferences had left us with thick heads of ideas and jottings, but the sense that the endeavour of academia – to describe the world? to measure? to create networks of knowledge? to change things for some notion of a better world? – had left us with a certain hollowness.

I wrote this fieldnote after the first session of the day:

> *We sit in the lecture hall, day two, our first session hellos said and eyes locked caffeinated zing of consciousness but already the lights are too bright this session promises surveillance robots GPS braintraining and neuro gaze and first speaker runs through arguments about quantified selves various anxious imaginaries of dementia - just behind me I clock Darla day two bleary eyed down from North Wales to take part - because we tried to make sure people with dementias could - she sits with colleague from Bangor – we smile, we met before through Nigel & the air begins to thicken with concepts, lines of thought and speculation & I spider map things out on paper: social robotics, neuro-bio hybrids, co-constructing care through assistive technology, nuance of agency, autonomy, fuzzy ontologies, Japanese sex robots as drivers of change – the professor in front in full flow speculates the role of a robot in detecting and preventing the common cause of death for those with advanced dementias choking on food & there's a flurry behind me & Darla's hand goes up, before the end of the talk, it stays up, it stays & stays & stays there until the professor notices & asks her if she has a question, and she replies, a slight pause 'No not really, I'd just like to say something…my name's Darla and I've got early onset dementia…if I understand what you're saying, when the time comes A ROBOT would stop me from dying? I just like you to know, I'd rather CHOKE' the professor stares back, tries to re-phrase, contextualise, re-formulate argument, vaguely implying that she hadn't got his argument & a plane of disruption opens out, pens to the side, heads turn from one to the other. 'Yes, I'm quite sure I'd rather CHOKE than have some robot above me, that's all' & Darla finishes; there's a shift then, a subtle buzz to worry and pierce the thickening air crests falling and rising.*

Darla's comment, which seemed to come out without any particular anger or point to make beyond how she felt, seemed like a way of making-matter (Massumi, 2017, p.63) that questioned what was admittedly only one possible future outlined by the academic. The company of robots for those affected by dementia is slowly becoming a reality, even the subject of buddy films such as Robot & Frank (2012) and raises several interesting questions around future care (Frennert et al., 2020, Laitinen et al, 2019, Kamphof, 2015); Darla's intervention brought something new to this because it suddenly took away the abstraction.

I'd met Darla previously and had helped secure some funding so she could attend the conference for free. Together with Nigel, Jim, Paul and others mentioned in these pages, they are, at the time of writing, people who live in Wales and live with their dementias but feel sufficiently strongly to be prepared to act in the name of their condition, to organise and to show solidarity with each other. With others beyond Wales, they have organised themselves into largely heterogeneous networks, with varying views and ideological/political leanings individually, but have in common a desire to demand their rights as citizens, and to be allowed to scrutinize and critique their lot when these rights aren't respected. Or at least, as Nigel tirelessly points out, try to make sure that legal rights under, for example, the 1998 Human Rights Act, the 2004 Disability Discrimination Act and the 2010 Equality Act, are respected.

As noted, Bartlett (2012) foreshadows a 'culture of resistance' that has grown with some of these figures: many are affiliated to the DEEP network (see In DEEP), by its nature a self-organising network but one that is more radically oriented towards the voice of those affected by dementia. As dementia activists, the common goal would seem to be to resist all kinds of exclusionary processes, campaign for equality and aim to lead the debates around dementia (Stodd, 2016), to varying degrees; this is not a new phenomenon in the UK, with Scottish dementia activism having a long history, for example (Hare, 2020), and the costs and benefits of such activism increasingly being recognised (Wilkinson et al., 2019). There are parallels also with the disability rights movement (Shakespeare et al.,2017); Nigel, for example, is keenly aware of this and argues that more solidarity with disability rights should be a key strategic direction for future dementia activism.

During the timeframe of this thesis, different forms of activism had some success in Wales, with Nigel, Jim, Darla, Paul and others regularly turning up, participating, often leading on stages, and sometimes questioning large networking events, conferences, consultations – but also supporting smaller events and gathering, including online. The DEEP network very often has had a hand in encouraging and facilitating this, as have some academics or people more used to community organising. Many more such voices beyond Wales are to be found on social media, Twitter in particular, but also heard through blogs, memoirs, academic papers, tv broadcasts e.g. Swaffer, 2015, Mitchell 2018, Saunders, 2018.

Darla's intervention above created a frisson of something maybe not quite worked out, brewing up between a possible future for her and others, and that moment in that lecture theatre. It gave a certain density or texture to other issues: the brute biopolitics of an ageing society where there aren't enough people to care, or even inclined to care at the tricky ends of life; the techno answer dreamed up (but now an incremental reality), the cultural and religious flows between 'east' and 'west', productive circuits in which Shinto, Buddhism, actor-network thinking can relocate the human and robot; the nature of a moral order when thinking about agentic competency and relational autonomy (Pirhonen et al, 2019) in old age.

Even though I appreciated the esteemed professor's work, what started as a 'rustle at the periphery of [my] vision' (Massumi, 2015, p.53) skilfully diverted the customary rhythm and flow of such an event, teasing out the sometimes hidden layer of power, expertise and authority in academic encounters, as much as the legitimate and ultimately interesting content about agency and autonomy in old age. Furthermore, this raised other questions. If there's a moral economy centred around this idea of dementia – one that produces, circulates, appropriates and contests values and affects around this particular object or 'problem' (Fassin, 2018, p.4) - what then is the 'purchase' of lived experience? Does it disrupt, if at all, forms of subjectivation which are produced and emergent in this field, and how far can we separate such claims to authority from power, or ideas of empowerment? In claiming more rights, or becoming subjects with rights, are those affected by dementia also becoming subjects with responsibilities (Isin & Nielsen, 2008), a move which often places them within managerial governance structures favoured by certain forms of postideological government: ‘dialogue, inclusion and consensus, rather than power, conflict and opposition’ (Walters, 2004, p.36)?

I recount other significant encounters in other sections of this thesis. Even though this solidarity and purpose seems to have made some differences in Wales, for some such as Nigel, there are no illusions that co-optation, with its attendant compromises, has been part of that process (see Nigel). However, Darla’s public comments seemed to lay bare some of the unease I (and others) felt at that point with many of the seemingly stable orders of the field of dementia, of which I have also become a part: the rituals of academia, of analytical practice. The settings in which routinely an object or a problem or a social fact is dissected and shorn of any meaningful engagement with actual lives. Sitting there on an American-style campus, it felt briefly un-comfortable, exposed; I’m not quite sure for whom. Equally, it felt like a small moment of liberation from a discourse which, however well-intentioned or speculative, maybe needed to be *made-to-matter*, even if only, *at that moment*. It also felt like a dangerous moment, ontologically, one pointing to the heart of a regime of truth around ‘dementia’, an edge to which those who are ‘activist’ often find themselves: by questioning the regime, and the norms, do they deny its (and to a certain extent their own) existence? The ‘I’ in ‘I’d rather choke’ rejected the frequently abject image offered of dementia, but maybe also presents the dilemma in which many with dementias find themselves: what does agency and autonomy mean to you, when the broader expectations of society are still largely those of dependency, decline?

But there was perceptible movement of *something* in the theatre, an intensification in the air of the early morning symposium, still sleepy enough despite the coffee. The violence of “I’d rather choke” briefly hijacked time’s flow in such events with its force; no abstraction, no as yet imaginary robots, just a visceral reclaiming of choice in the face of death or lack of agency in the hands of said imaginary robots, embedded as they are in imaginaries of dementia, but also increasingly, the realities of care in some parts of the world, such as Japan. Around the same time as Darla’s intervention I’d recently been to see an exhibition which showed some of the latest care robots, and had been at another event in Cardiff which was showcasing robotic companions for older people. For a brief instance, it held up a mirror to the easy assumptions of the posited emergence of a world in which those with dementia would be somehow *routinely* cared for by non-human actors, perhaps regardless of their wishes. My observation (sometimes first-hand) has been that many dementia activists embrace the liberation offered by certain types of technology, from using Alexa (Coleman, 2020) to constantly blogging with an iPad to keep track of things (Mitchell, 2020), to being early adopters of Zoom - but this is on their terms, using technology as a means of supporting what Bartlett et al. (2019) would characterise as 'everyday citizenship practice[s]…the opportunity to participate, to be involved and to have influence in issues that matter concerning their daily lives' (Nedlund, Bartlett & Clarke, 2019, p.7), from the mundane to political acts of resistance.

The illocutionary baldness of "I'd rather choke" maybe shone a light on other ways of being political (Closs-Stephens et al., 2017), how those affected by dementia, and willing and able to comment, often bring something quite different in terms of their 'acts of citizenship': 'collective or individual deeds that rupture social-historical patterns' (Isin, 2008, p.2). For me, this public comment by Darla felt like that. This was only a few months, after all, that I'd heard how Chris Roberts, a prominent advocate for dementia rights from North Wales who, together with his wife and principal carer, had been featured in a Panorama programme about his way of coping with dementia, had 'mic dropped' in frustration and protest at one of the consultation events for a draft Welsh Government programme to help those with dementias. In other meetings using such governmental technologies (see 'A Consultation'), I'd witnessed how another advocate, Jim, lay bare the foundations of 'the bundling together of agency and blame' (Brown, 2016, p.10) often at the heart of neo-liberal governance with a few words about his own condition and status in the world.

Unquestionably, most present in the lecture theatre on that sunny day would have been very sympathetic to people living with dementia. Not far from where I sat were those who had developed the some of the very concepts around 'social' and 'everyday' citizenship in dementia. The focus of the 46th annual conference was to explore 'a good old age' after all:

but Darla's 'lived experience', the biological and biographical facts of her condition, seemed to burst through the 'fourth wall' of academic discourse. By 'fourth wall' I draw attention to the fact that much as in a 'theatrical' theatre, the lecture theatre often merrily assumes a separation between performer, performance and audience; an unscripted comment of such force – and in its own way, joyfully made - midway through the performance, not bothering with 'polite' conventions of Q and As at the end had, in its minor micropolitical moment a major macropolitical point to make, one that echoes across many other activist movements: 'nothing about us without us'.

35. Piece of Cake

"Back before there was nothing at all, not when my husband had it, all they offered me was a CPN back in the day, but I volunteered for six years after he went, mind…."

Lunchtime, 'networking', a strangely a-temporal churchlike conversion of a building, used to be a school and now, on top of a remote hill, is a community space, whitewashed, all bleached wood and polite bilingual notices. Having talked conspiratorially about reminiscence, the smell of changing rooms and leather balls ("the old boys like 'em, gets 'em going….") with someone who has a degree in sports performance, the disorientation of three hours of powerpoint beginning to wear off with the strong tea, he turned back to this familiar face, from some other networking event, somewhere else, some time ago. Nevertheless, a friendly face, from the Down-Belows.

"….but I don't do it anymore, they took us for granted, they're too top down, none of the money stayed local in the end"

She whispered the last bit.

And as they both bite into overly generous home baked brownies, she says, arching an eyebrow:

“and I CAN’T STAND the smell of cakes, we had to make them ALL THE TIME to raise money, I hate them”

36. The Consultation, part 1

Figure 5: A consultation

> *the State itself appears as the overall effect or result of a series of interacting wheels or structures which are located at a completely different level and which constitute a “microphysics of power”. Not only private systems but explicit part of the machinery of state have an origin, a behaviour and a function which the state ratifies, controls or is even content to cover rather than institute (Deleuze 2006, p23)*

> *the role of charitable bodies and non-profits has shifted in the last decade, as dementia and ageing has gained all the attention and at its most crude, advocacy groups and charitable groups have become an extension of the government, happy to legitimise policies to access the funding...**NH***

> *Every story is a travel story- a spatial practice (De Certeau, 1988, p115)*

> *I've done a lot of different things, I qualified as a pharmacist but after I qualified as a pharmacist I decided that I wanted to work within the Arts that I would set up quite large -scale community arts initiatives so I knew what the Arts could do in terms of communicating with people in terms of building confidence building community, so I had that experience **RD***

In this section, I will begin to tell the story of on an event which took place early on in the research - namely the consultation process for the first proper dementia strategy for Wales, a drawn out and interesting process. This event took place in a particular place and space in the South Wales valleys, and was part of the second round of a Welsh Government consultation for a new dementia friendly strategy for Wales. Looking back on this, I would observe how such events have by now become ever more enmeshed in a newer kinds of 'political *machine[s]*' (Thrift, 2006, p.553): in a time when Zoom meetings are becoming a norm, and our awareness of how 'tracking and tracing' for opinion and intention operates through surveillance of massive data-gathering systems such as Facebook or twitter, looking back on such an event feels almost like an act of nostalgia, an analogue dream, though it too was cocooned in emails, social media callouts and jumpy departmental moves.

However, this nostalgia is rooted in a reflection that being in the kinds of spaces that are frequently used by now with this kind of technology of governance - arts centres, church halls, hotel conference rooms and the like – can sometimes give an overall sense that 'things refuse to march in step; [that] the present [is] not as an epoch, or an age , or answerable to a singular logic or zeitgeist, but as a pluralised entanglement of many times'(Walters, 2012, p.113). Although Steve Huxton form the OPC lamented in our interview:

> *We've just had phases of disengagement with wider politics, not just party politics, we've had that as well but also with traditional social constructs, whether that be church or chapel, working men's clubs*

Ironically enough, it was often those spaces which were 'traditional' – old churches, chapels, schools – where forms of engagement were still being acted out. I found that these entanglements with other times and spaces could include a sense of the future, even the use of Zoom, but as I write this, the pandemic of 2020 seems to make the process of 'consulting' in spaces which aren't virtual almost exotic; the digital, informational, behavioural and the governmental seemed to have hastened their entwining, in part because of COVID-19.

Nevertheless, now as then in 2017, ‘consultation’ seems to be a favoured method of garnering the views of the public, experts and what are often referred to as ‘stakeholders’ in Wales, as well as the other nations and regions of the UK, and further afield. In Wales, the stated intention is to help understand how a law or policy might affect the population, elicit ideas and suggestions, with the aim of improving and shaping the work of government, and making policies more effective (Welsh Government, 2017). In part, this is how ‘empowerment’, and its more modern cousin, ‘participation’, have become part of frameworks of governance also; how there is a promiscuous, never-ending loop of ‘best practice’ and ‘benchmarking’ (Brown, 2015, p.135) between government officials, researchers of all types, charities, families (hard-working or not), agencies, health services, policing. As ‘empowerment’ has been institutionalised, it also raises the spectre of new forms of control. ‘Too often, empowerment means reconciling people to being powerless’ (Langan, 1998, p.214), but the event described here and some of the accounts in this section seemed to suggest that there is more to it than this. Cruikshank (1999) gives perhaps one of the more elegant defintions of how such technologies of citizenship are bound up in the fundamentally Foucauldian view of the productiveness of biopower in particular:

> *Instead of excluding participation or repressing subjectivity, bio-power operates to invest the citizen with a set of goals and self-understandings, and gives the citizen-subject an investment in participating voluntarily in programs, projects, and institutions set up to “help” them. (Cruikshank, 1999, p.41)*

In addition, as indicated in other sections of this thesis, my period of research seemed to coincide – not just in Wales – with a shifting discourse around dementia. People affected by the condition are increasingly challenging long-held portrayals of deficit and death, while a more active sort of (social) citizenship comes to the fore (Birt et al,2017), one which increasingly ‘involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level’ (Bartlett & O’Connor, 2010, p.37).

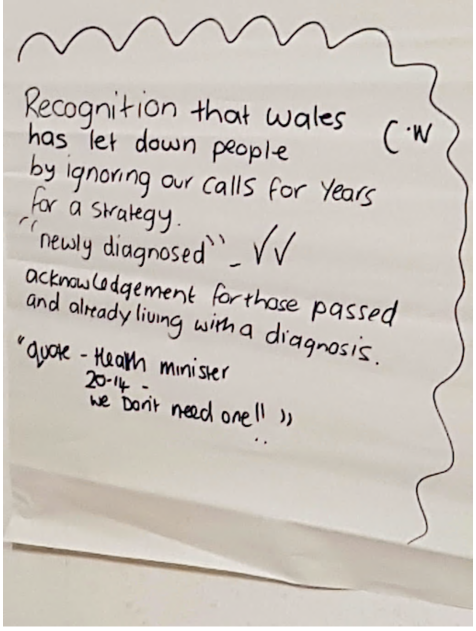
To this I would add that another emerging form of activism which, as suggested in my quote from Nigel at the start of this section, seems to challenge a perceived comfortable corporate orthodoxy which can seep through the workings of larger charities, as they become increasingly bound to the 'pastorate'. This form of resistance, gently but firmly instigated by Nigel and others in Wales, could be characterised as a critical counter-conduct (Golder, 2015) (see Foucault). The basic Foucauldian trope is that where there is power, there is always resistance, and that groups in society use forms of critique to ensure an 'art of not being governed quite so much' (Foucault, 1997, p.29). Beyond any actual theoretical justification for this view, as we shall see, my own more historical interpretation of the space where the consultation event took place also had echoes of this.

Following this particular consultation process, which included protests by many other activists, it was rumoured and whispered that the length of time taken for the final draft to come out, meant that it had to be extensively re-written: there are some indications that this is what happened from exchanges at the Senedd in Hansard. In fact, the finished document seemed to have shifted emphasis towards not only a more rights-based approach, but also listening more to people with lived experience of the condition and who, like Nigel, are self-organising around different agendas to the larger charities perhaps. Many had heard of the resistance to the original document, and as Emma, my interviewee in North Wales commented: *"In a way, maybe it was a good thing that there was such a negative response to the first draft of the consultation, because it meant that they had to stand up and take notice and listen."*

But how far does the indignation felt and displayed during such consultations end up being effectively neutered, a by-product of the very process which claims to redress, as 'stakeholders' are integrated into what is a technically defined problem for government, namely that of an ageing and increasingly demented population (Brown, 2016)? Does the concept of citizenship itself, be it biological, affective or social, become both a way of 'empowering' and normalizing subjects, 'to [simultaneously] enable and constrain political practice' (Nyers, 2004), through a set of 'voluntary and coercive practices' (Cruikshank, 1999, p.4)?

To recap and foreshadow: as much as the substance of what was discussed in relation to the new strategy, my account here seeks to place the dynamics and interplay of some of the participants involved in the broader context of emerging dementia subjectivities. Some, though by no means all, are more focussed on types of activist practice. The often contradictory expectations of the state and governmental strategies seemed designed, simultaneously, to both stimulate and punish people living with dementia, often through a process of responsibilization, while they are at times subject to the punitive gaze of the welfare system, especially during this period of fiscal austerity. This underlying logic which 'bundles together both agency and blame' (Brown, 2016, p.10) was a theme heard in the narratives of those present and living with dementia at this particular event, but is also one which I have heard in several other places.

37. The Consultation, part 2, 'the art of not being governed quite so much'



Recognition that Wales
has let down people
by ignoring our Calls for Years
for a Strategy.
C·W
"newly diagnosed" – ✓✓
acknowledgement for those passed
and already living with a diagnosis.
"quote - Health minister
20-14 -
we Don't need one!! "

Figure 6: Flipchart

> *Places are fragmentary and inward-turning histories, pasts that others are not allowed to read, accumulated times that can be unfolded but like stories held in reserve, remaining in an enigmatic state, symbolizations encysted in the pain or pleasure of the body. (De Certeau, 1984,*
>
> *Confession frees, power reduces to silence (Foucault, 1981, p60)*

In this section, I'll sketch out the observations which were made during the day, based on my own journal notes and photographs. This includes everything from a description of the building to the format of the meeting and some of the accounts heard. These notes were then analysed with further reflexions added, over the course of the following months. I had heard about the event through my own network and social media and had been signposted there also through my regular meetings with the Dementia Matters in Powys Initiative Group. For the sake of curiosity as much as mitigating too much familiarity at that early stage, I made the conscious decision to seek out a venue which would not be local to the group. Even though this was a public meeting, I contacted the organisers from DEEP and the Alzheimer's Society, both of whom I'd met previously at an event in Cardiff the previous summer, to ask them for permission to attend as part of my research, and they were happy for me to do so.

No audio recording took place, so everything was sketched out in notes and in a few photographs that I took of the building. Pseudonyms have been used to refer to any individuals apart from Nigel, who I'd met earlier and have met several times since, including to record an interview for this thesis. In a continuous process of consent, he has been happy for me to use his name in this research. Apart from the individuals who were taking part, there were at least two members of the appropriate Welsh Government department present also.

The building in which the consultation took place had seen is a large, a converted Wesleyan Methodist chapel, dated from the end of the 19th Century and in a late-Victorian Gothic style, with a three stacked steeple at one end. It is situated in the heart of a town, along with two other similar buildings nearby. It passed from being a Wesleyan chapel sometime in the sixties, and became a municipal hall, then an arts centre. However, it had recently been closed (2014), because of local authority cuts, but had since been reopened at the time of the consultation. The building according to a leaflet picked up on the day was dedicated to the following aims to 'establish a truly community driven centre for the promotion, participation and celebration of local culture, arts, creativity and language whilst also pursuing individual, community and economic development'. The name of the building – the Muni Arts Centre - attests to the municipal hall phase of the building when it was owned and operated by the local authority.

Deleuze and Guattari's concept of smooth and striated space (Deleuze & Guattari, 2013, p. 551) was also useful in thinking about such spaces and what happened in them: a smooth space is nomadic, rhizomatic and anarchic, while a striated space is sedentary, arbolic and hierarchical; Deleuze and Guattari were interested in how these spaces could co-exist: 'that the two spaces in fact only exist in mixture' (Deleuze & Guattari, 2013, p.552). Almost by definition, a 'church space' (Wesleyan Methodist originally) such as this which had become at various stages a 'state space' (Municipally owned for a period) as well as an 'arts space' (now an arts charity) would seem to suggest such a mixture. This particular event – a consultation by Welsh Government, led by two dementia charities, with radically different visions of advocacy, publics who were extremely unhappy with all – also suggested the ebb and flow, or deterritorialization and reterritorialization, between such spaces.

However, the object here is to illustrate some of the themes to which I've alluded to previously: the use of the consultation as a technology of governance, but also a technology of citizenship, one which promotes a type of autonomy, self-sufficiency and political engagement on the one hand, but to an extent also works 'upon and through the capacities of citizens to act on their own' (Cruickshank, 1999, p.4) , and in a sense instils and shapes them as citizens.

A passage from Foucault's essay, The Birth of Social Medicine, also seemed relevant in this respect, as he traced the origins of welfare and medical systems across Europe:

> *….in the second half of the nineteenth century….English medical control …provoked violent popular reactions and resistances, small scale anti-medical insurrections…I think it would be interesting to analyse how this medicine, organised in a form of control of a needy population, incurred such reactions…..For example, it is curious to observe that the dissident religious groups, so numerous in the English-speaking Protestant countries, has the primary goal in the seventeenth and eighteenth centuries of opposing state religion and interference by the state in religious affairs, whereas those groups which reappeared in the course of the nineteenth century were concerned with combating medicalization, with asserting the right to life, the right to get sick, to care for oneself and to die in the manner one wished. This desire to escape from the compulsory medicalization was one of the characteristics of one of these numerous apparently religious groups that were intensely active at the end of the nineteenth century, as they still are today (Foucault, 2000, p.154-55)*

The Wesleyan Methodists were noted as being one of these groupings. It should be noted that at least one of organisations which was charged with the day's proceedings also has its charitable origins elsewhere. DEEP was initiated by the Joseph Rowntree Foundation, which has Quaker roots; as I sat in the hall, I noted how these echoes of non-conformity resonated through the ages – the emphasis on individual, inner voice and light, this asserting of a right to life beyond the label set out by others. Could the strong calls for the need to listen to those living with dementia, to give them voice, the organised (but autonomous – each group is different) indignation of those who are organised into DEEP groups across the UK be part of a more radical tradition? Did this critical counter conduct have ghostly antecedents here?

Internally, the chapel had been converted into a series of rooms and spaces, including a coffee shop and a small hall. The coffee shop itself was quite gloomy, and the corridors were warren-like, with several off-limits spaces, mainly offices, before opening out to the main conference room, which appeared to be a suspended floor, perhaps the converted loft space; it had been stripped bare and painted white, divided from the rest of the building. The arching beams which held up the roof of the building were exposed but also painted white, with a large round window, which had plain glass, but was in a round religious pattern, which gave natural light to the internal space. It was a constant reminder of the origins of this space, throughout the day, as the light brightened and faded. Even though the effect of the whitewashing was surely intended to neutralise the space, the beams, and in particular the round window, were indelible reminders of the origins of this space. I noted down how the effect of being led through this very complicated set of corridors into this space was slightly disconcerting, a muted start to the day's proceedings somehow.

If 'space is a practiced place' (De Certeau, 1988, p.117), then what practices over the years had made this place into a space for the religious, the arts? Having been a researcher for a number of years, I'd found that by now much of the business of government often takes place in nondescript offices, often on cheap land or even industrial estates, where you will find the administrative end of health boards, county planning offices and the like. I'd already noticed that many of the meetings I was having around DFCs were in different types of building, often actively religious (certainly in Brecon), or civic/religious buildings such as this one which had been converted into arts centres, for example. In my discussions with Rhiannon, she'd also made clear that her projects over the years had involved using Arts Centres as venues for different forms of social action.

Apart from those who were organising the day's events, and those who were observing, such as myself and the officials from Welsh Government, the majority of those attending were those who had some form of lived experience of being affected by dementia: either they were currently living with the condition, or they were carers of those living with the condition (either present at the day's proceedings or not), or they were people who had lost someone close through the disease. Though I met several interesting people on the day, I have chosen to concentrate here mainly on three people in particular: Nigel, Jim and Sandra (whose husband, John, was not present, but who I spoke to over the phone), though I also refer to other things that were said.

Over coffee, and before entering the main space where the consultation took place, I sat down at a table to talk to a couple of participants, having said hello to the organisers. As we waited for things to begin, there was the slight tension of strangers (for the most part – some already knew each other) shuffling paper printouts or looking at their phones, waiting for something to happen. I had decided not to pay too much attention to the paperwork, having looked at the draft strategy with colleagues earlier that week. Having been impressed with the outside of this building, I was trying to tune into the space and was open to conversation.

I sat down in one of the few spaces left in the cramped café, coffee in hand, and soon got talking to Sandra who was a prominent member of a carer's charity and said that she was involved with many local fora in her part of South Wales, including some which covered the Swansea University area. Her husband, John, wasn't present, but was busy at home: even though he had dementia, he could look after himself for short periods, and she explained the kind of support that they did and didn't have in their situation (of which more below). Also, at the table was someone who had come along from the Welsh Government department responsible for the draft, though she didn't disclose this until later. I was open with everybody about my own research and made sure they were comfortable with any questions I might have, though for the most part I just let the conversations flow, without any questions in mind beforehand.

What was said

The most striking thing about that event was how the atmosphere seemed to get more heightened as the day wore on. Many of those present contributed accounts of their experiences to date: the losses, the multiple difficulties of being carers or trying to find support, the emotional toll, the gradual or continual sense of being ignored. At the same time, there were accounts of feeling under constant surveillance by the welfare system, especially for Personal Independence Payments assessments, which routinely classified those with dementias as being fit for work. This problem was highlighted to me throughout the research process, by various PWD and carers.

As we shall see, fundamental questions cropped up about the expectations of those who were attending to be 'active citizens', and the vulnerabilities and confusions that that such a shaping can bring. At the same time, it became apparent that such vulnerability could be mobilized here into a form of resistance, that 'it can be a way of being exposed and agentic at the same time' (Butler, 2016, p.24). By the end of the afternoon, as the January afternoon was darkening, I noted even the government officials were drawn into communal acts of clapping, laughing, even flushed tears, whereas at the beginning they seemed to remain impassive.

Once in the main space where the talking took place, there were short breaks for coffee and lunch in which we were able to strike up conversations about the day. Copies of the draft strategy were available, but there was also a synopsis of the main themes. Discussions about the draft strategy were themed and comments written out on flipcharts. From my perspective, there were many similarities in this basic format to focus group work, of which I have experience: the group wasn't too big, and there were two facilitators, though no recording equipment was being used.

I noted quite early on in my jottings that both the initial themes and perhaps the space itself recalled the notion of pastoral power, the 'confessional' as a mode of practice, working on two levels: practices which were mentioned as part of the consultation and which might be desirable as part of the strategy, and the quasi-liturgical aspects of the consultation itself. The 'confession' has a history, as we've explored elsewhere in the thesis: 'the (historical) emergence of the obligation to discover the truth *of* ourselves *in* ourselves, as well as to manifest it through a discourse of *avowal*, is nothing but the effect of a series of techniques of power'(Lorenzini, 2016, p.66). Such techniques do not confine themselves to religious practices (including here those of Protestants), and that they migrate into many different spheres, from the government of oneself, to the state, to medical practices. In an age of continuous digital connectivity and algorithmic surveillance, of 'constructed visibility' (Bucher, 2012), 'pastoralism continues to operate in the algorithmic register' (Cooper, 2019, p48), but here we were in a non-digital realm.

Indeed, one of the first topics discussed were around the idea of emotional support, a theme which by common consensus was seen as lacking in the draft strategy; this criticism, one in which there was a sense in which people had felt that they were not being heard by those in power, in medical and social institutions, was repeated throughout the day in various guises. The idea that there was a need for emotional support in the form of more counselling services, preferably ‘on tap’ as one contributor asked for, was a recurring theme throughout the day, something which was felt that was needed for both those with the actual condition and their carers. There was criticism about the lack of such services (with one exception given of a person who felt they had a particularly sympathetic GP). At one point also there came first of several comments about the Alzheimer’s Society *(‘once the person’s gone, the Alzheimer’s Society drop you like a stone*’).

What also struck me was the almost liturgical aspects of the ‘consultation process’: the reading and discussion of the text, the confessional narratives (with stories of redemption) and the catharsis, replete with emotional pleas:

> *After the diagnosis, I just ate and drank, I was killing myself, then I got myself together….now I don’t live with dementia, dementia lives with me and I keep him in the cupboard !* (Nigel)
>
> *Initially, I just sat in front of the television, I did nothing* (‘Jim’)

At several points during the day, people were either clapped after giving their ‘confessional’ testimonies, or there were many displays of emotion – from tears to laughter and back again – through the discussions. Having been present at other such consultations and having experience as a researcher of running focus groups, for example, the almost ritualistic nature of the encounter (heightened by the surroundings maybe, despite the layers of secularization brought about by conversion into an ‘art centre’) was something that struck me as significant. There was also a sense that others in the room had also been part of such consultative gatherings before: they knew the drill.

Another emotion that I noted present was that of indignation: one of the strongest shows of appreciation and clapping came after the call for any new Welsh Government Strategy to have a prominent apology for the *lack* of strategy there had been over the years, point to a type of thanatopolitics. For some this had meant, quite literally, until the point of death of a loved one, and they had felt utterly unsupported, and for all that was happening now, they and others felt they had been ignored when they most needed help. Undoubtedly, in comparison with some of the other devolved administrations, it is true that Welsh Government has lacked 'strategy' in this area: the Scottish Government is on its second such strategy, for instance.

Such a direct expression of indignation towards the government was very powerful on the day, though I noted no particular discomfort on the part of the officials present. Several things were of interest here: the overt politics of citizens participating in the public sphere, but given the setting and, as I've signalled, the liturgical/ritual feel of the day, how that citizenship in some respects is bound up in acts of piety (Turner, 2008), but also, how such acts as 'calling out' government – in its broadest sense – develops any sense of social movement (Jasper & Owens, 2014):

> *Forms of indignation may be regarded as emotional expressions of a meta-ethical anchorage, and concern infringements that are believed, at least implicitly, to affect people's possibilities of realizing their humanity (Boltanski & Chiapello, 2007, p.491)*

I noted that there was a sense of shared injustice by those present that the government had taken so long to actually start thinking about dementia, and those feeling were rooted in multiple examples, past and present, given by those attending the consultation living with dementia. These even included some who felt that they had been ignored at a recent launch for a new 'development framework' which they had contributed to. As one contributor commented:

> *Communities are only hard to reach if you sit behind a desk*

In the following section, I've picked some of the more prominent voices, and what was said.

'Sandra' (and 'John')

As noted previously, 'Sandra' was a carer, prominent also as a representative of a carer's organisation. In my initial conversation with her over coffee, she explained her husband position as someone who was getting on with living with dementia, but she was also in contact through her voluntary work with many others who were in the same position as herself. Not for the first time that day, I heard some criticism of the support offered by the Alzheimer's Society *('once the person's gone they drop you like a stone'*), even though the Society was partly responsible for the consultation taking place. This is a theme that I'd heard, often whispered, sometimes indicating palpable tensions, in many other fora and meetings also: an appreciation of some of the work that the Alzheimer's Society offers, but a criticism of some of the attitudes and very strict, prescriptive and often inflexible nature of that help. In my involvement with the Brecon volunteers, for example, there had been several incidents in which these kinds of tensions seemed to surface, especially in the planning phases of the next steps (see Tea Towel Micropolitics)

Apart from her other comments, 'Sandra' also mentioned types of help which were available to both her and her husband online, and which she considered to be a lifeline. As such, these could be seen as communities which are formed in a different social or cyber 'space', that utilized different technologies such as online forums, or cheap video conferencing. I managed to have a quick conversation with 'John' over the phone during lunchtime, as I'd shown interest in this video conferencing support. This was the first time I came across Zoom, for example, with which he would talk to several friends (many of who had Alzheimer's) from all over the world; it was important to him that he could see their faces as well as hear what was said. This was a regular feature of his life, every Monday morning. He cheerily described how many of his friends lived in Australia, for instance, and they would be comparing treatments for the condition. 'Sandra' would also use other online forums dedicated to carers: because of her involvement with a caring charity, she seemed to be well informed about not only what was available online, but also locally in her area.

'Sandra' had also mentioned that they lived in quite a small village, without many local services. Nonetheless, she said that many of the older men in the village had taken to going out and meeting informally, and that ironically enough, this seemed to be happening more frequently after 'John' had been diagnosed. At one point, she also said that she was tired of being involved in so many 'consultations' but felt that even she couldn't access all the services needed locally, and she was beginning to feel a bit exploited.

Nigel

Nigel was a key person who I met that day. Having lived with his condition for around six years ('*I don't live with dementia, dementia lives with me, and I keep him in the cupboard*') he is an active member of the DEEP network, and it became apparent that he also had background not only in the military but also as a political speechwriter, and he came across as being very confident of his own politics, as we'll see later on in this Touchstone

Through my own contacts with DEEP, I have met him on several occasions after that day, and he has been actively campaigning to ensure that there is recognition of the rights of those living with dementia. Nigel said '*nothing about us without us'* several times that day. A key part of the argument in terms of how government should be looking at dementia, according to him was that notwithstanding the error rates or difficulty of getting a diagnosis, to claim that it was only 45,000 people who were affected by dementia should be roundly ridiculed – it was pointed out that the figures could be 10 times that amount, if you take into account how dementia affects everybody around the person with a diagnosis also.

At one point, all those in the room were asked if they were aware that there is a national Dementia Helpline for Wales, funded by the Welsh Government, and hardly anybody new about this at all. Nigel's own story was that of sinking into despair once he'd received his diagnosis, and he claimed that he'd tried to effectively kill himself through overeating and drinking too much:

> *…but once I had the right support in place, I lost ten stone, and here I am today. We need a proper national pathway of support…people are beginning to be wary of the lip service paid by calling yourself 'dementia friendly'…a 45-minute session does not make*

> *people 'dementia' aware necessarily. Some institutions think that if staff have had dementia friends training, then that's good enough.*
>
> *Involving people in shaping services is essential.*

'Jim'

'Jim' was another notable voice heard on that day who seemed to enter a 'confessional' mode:

> *I just sat in front of the television, I did nothing*

But of all there, he gave the best account of the conflicting expectations of government:

> *They're telling me to live as well as possible – but then if you do, they take away your benefits*

At one point he expressed the fact that he was quite literally confused by this, and that he had even felt conflicted about coming to the consultation that day: he was currently fighting a recent decision about some welfare support that had been removed, because he was deemed 'fit'. Unlike a physical disability, someone living with early onset dementia such as himself, outwardly (at the moment), did not display the signs of the disease, though in fact he needed the constant support of his wife to get through the day. This was a very poignant moment in the afternoon; there was silence and recognition and despair in the room.

Later, I reflected in my notes, and for some time afterwards, how the experience of attending such an event, in such a place, can mark out many possible directions of enquiry, how being physically present and hearing some very powerful histories and narratives, both present through the people there but also somehow inscribed in the setting, can open up new avenues of thought. Nigel closed the day by saying:

> *you mark my words, it's time for dementia to come out of psychiatry and into society, they won't know what's hit them over the next few years*

and this perhaps epitomises the point at which activists such as he and others see themselves, very much in opposition to the excessive medicalization of their condition. But in this setting, and as an active member of DEEP, it subsequently brought to mind the Foucault quote about religious groups at the end of the 19 century, also railing against the medicalization being used as a form of social control. The other striking call that came loudly and clearly was the need for the authorities – government, health boards, all involved – to recognise the perceived injustice of their tardiness, the lack of provision and care which had caused pain to some of those in the room, and countless others.

Of particular interest to me was hearing the accounts given above which suggested a fundamental conflict in the way that people with dementia are perceived by the governance arrangements that span both from Cardiff to Westminster. 'Jim's account was the clearest example of this: on the one hand, the emphasis is on encouraging active participation in all spheres, as much as possible, encouraging 'voice and choice' as it is often characterised. This lies at the heart of the ideas of well-being and the encouragement through responsibilisation which permeate much of present advanced liberal thinking; the state does not row any more, it only steers, as the well-worn phrase goes.

However, on the other hand, we also heard of the punitive gaze of the state, contradicting itself: 'Jim', and others present, felt they were under constant threat of losing state support, for being deemed 'fit' and capable of work. I would also argue that there was a constant negotiation taking place between their sense of biological citizenship, entrepreneurial strategies of self-care and their increasing sense of social citizenship, where this group was finding ways of resisting and demanding new rights, a sense that there are boundaries to be pushed. This was the clearest example in my research up until that point of 'the bundling together of agency and blame' (Brown, 2016, p.10), the conflicting logic that insits on forms of active citizenry on the one hand , but has a punitive gaze on the other – that was the source of Jim's confusion.

His account pointed to the precariousness of many who are living with life-changing conditions and who are often reliant on support provided by the state in it's different forms, be that Welsh government, local authority or Westminster. The erosion of this support came in part due to discourses, very much encouraged around this period and during austerity, that demonise many who seek such support, as the deserving and undeserving. Taken to its logical conclusion, this was a form of bio-power which potentially 'lets die'; the cuts to welfare and changes in status of those in Jim's position is increasingly leaving a trail of death. The cuts to social care and the erosion to services has meant that according to Danny Dorling and others, we are witnessing a spike in mortality (the largest in 50 years) in part due to the excess deaths of older women living with dementia (Hiam et al, 2017).

But Jim's account also highlights the marginalization felt by those who are living with the condition, and to the very liminal nature of the condition itself: often people wait a long time for diagnosis (which was one of the key demands that all present felt needed to be addressed), unsure of what their status might be (and what rights they might then have, or potentially might even lose) (Birt et al, 2017). These struggles around status and categorization – the real very consequences of classification (Bowker & Star, 2008)- are played out in several different ways; it is not only the state or medical authorities who define what can and cannot be given to help those living with memory loss, this happens also in the workings of local and national charities. As we shall see in the Third Touchstone for instance, with quite heated debates about the differences between memory loss and what could be described as a diagnosed 'dementia': this could mean the difference between a service being funded or not.

Despite 'Jim's words however, there was a nagging feeling that the technology of citizenship being used here in the consultation were being implemented as a means of facilitating a type of consensus which might not shift the very technical approach – risk management for example – which had been at the heart of this version of the strategy. Such technologies of citizenship even - where participation is encouraged and the perceived deficiencies of citizens are examined, if not corrected, often emphasising autonomy, self-sufficiency and engagement - in themselves 'do not cancel out the autonomy and independence of citizens, but are modes of governance that work upon and through the capacities of citizens to act on their own' (Cruikshank, 1999, p.4). In this respect, it could be seen as analogous to or an adjunct of, dementia friendly schemes in general: the whole 'movement', mainly voluntary in character (though perhaps increasingly coercive as it becomes 'normalised' within various sectors and institutions) sits as a mode of governance. In addition, though there were clear calls by Jim and others to respect and in some senses extend their rights, the very issue of 'rights' themselves can be seen as a classic political technology which operates within the governmental limits of advanced liberalism (Golder, 2015).

The physical space of the arts centre was also a reminder of all these transitions, the layers of history which seemed in some ways connected: the non-conformist space of debate, sermons, in a time when community and citizenship were limited in terms of suffrage, but not in terms of religious identity, when religion, charity and class would have been part of the governing frameworks, and the involvement of the state ultimately quite limited, but there would have been strong community ties based around denomination, workplace, burgeoning class consciousness.

The very architecture and layout of the building had obviously gone through several changes. I noted the gothic pretensions of the late Victorian period, inspired in many public buildings from the mid-Nineteenth century onwards, by commentators such as Ruskin and architects such as Pugin: the arches symbolising the soul's heavenwards trajectory (Lefebvre, 1991), echoing the nomadism and craft of the journeyman labourer of the medieval period, in a time (late 19th Century) when arguably the 'social' was coming into being, when the moral order which reflected ideas around idleness and sin gave way to the socio-economic phenomenon of unemployment, when the contingent and precarious nature of work 'would be captured and located in a circuit of flows amenable to individual and collective social government' (Rose, 1999) .

As we have seen, the realities of debates around 'being fit for work' – in both a physical and moral sense, are still an everyday part of the lives of some of those who took part in the consultation. The late-Nineteenth century would also have been the same period when union membership and other forms of collectivisation would have emerged and risen as the influence of charity and religion would have waned – the union ballot, universal suffrage, the socialization of health risk through the foundation of the NHS would play its part in this phase, with local ownership passing into secular, municipal hands. Post-1979, with mass unemployment as the mines were closed, the collectivisation of the union, the 'social', mutates into the 'community' (Miller & Rose, 2008), a space of less collectivisation where individuals and families are the focus; as the 'social' continues to retreat, new forms of governance appear, and at present, the building is owned by a social or 'community' enterprise. That said, and at the risk of conflating too many arguments, in a sense the building that had once physically produced a culture and a community (Wesleyan Methodist) within it was perhaps once more witnessing the creation of another type of 'community' one that could be characterised as being, once more, a 'counter conduct' in a Foucauldian sense.

This also brought to mind further reflections of the echoes of present of other technologies of citizenship, other rituals and practices which perhaps were not too dissimilar in terms of shaping conduct; how a hundred years ago, a congregation of non-conformists would have been presented with a text to discuss and interpret, how testimony would have been given and solidarity and belonging expressed through public rituals. Though in some ways out of context in terms of the Wesleyan tradition, the confessional and cathartic nature of some of the 'testimonies', the crying and the clapping which swept through us as a 'consultees', brought to mind a range of religious traditions.

The symbolic distance between those organisation charged with the proceedings could also be seen in a similar light: DEEP, with its Quaker roots, emphasises the de-centralisation of power, the importance of voice and experience, whereas the Alzheimer's Society has a more centralised grip on the organisation; a consistent feature of my research was to hear many complaints about the rigidity and tendency to impose their values – the Dementia Friends scheme itself seemed to exist in a branded world that invites an audit and tick-box culture.

38. Further interview with Nigel

Figure 7: 'his manner of appearing'

> *his absence is very real: henceforward it is his manner of appearing. (Weil, 2008, p23)*

The last time I met up in person with Nigel was at yet another conference which featured dementia in the north of England, one of the very last I attended as part of fieldwork, where I was also presenting a poster on aspects of this thesis. By this time, we've got to know each other quite well, and as we walked around trying to find his buddies, he half-jokingly referred to the venue being a *'trade fair for dementia, isn't it?'*. He's a large man, ex-army, ex-Labour party enforcer (worked for the Whip's Office during the Blair years), ex-national media officer for the Citizens Advice Bureaux; educated at a Jesuit school, with a background in law, he had left-leaning parents and memories of meeting Tony Benn, both as a youngster at his local miner's Institute, and later on when there were regular open discussions at Benn's house in Notting Hill, and though the politics of his bosses – and his own at the time – didn't chime with the author of Arguments for Democracy, he said *'had I been religious, he would have converted me, he was not for the war, and some of his stuff insane, but his belief system was there'*. As we found people and sat down in between sessions (we were at the conference rooms of a racecourse), he said, 'I've got something for you' and handed me a 'Yes Cymru' badge, referencing my Welsh speaking. We laughed.

He is probably one of the keenest and most fearless of the many dementia activists I've met over the last few years. My interview with him, after getting to know him through many events, lays out the terrain for many of the arguments which one could have about 'dementia friendly communities': its inception, provenance in austerity-led social policy, resistance, it's future. It was tempting in this section to just lay out our interview and other correspondence verbatim, such is the force and clarity of his arguments (and writing), but instead I offer a synopsis with a critical commentary, as with other interviews featured in this thesis.

Nigel has been at the centre of creating and maintaining several different dementia networks, and is the co-chair of the 3 Nations Dementia Working Group, modelled on the Scottish Dementia Working Group (which has been in existence since 2001). He also sits on the Dementia Oversight of Implementation and Impact Group: this was set up after the introduction of the Wales Dementia Action Plan 2018-22 and was in part the result of the intense criticism of the original draft strategy, the successful campaign of resistance mounted by him and others, as I've outlined in the Consultation. This scrutinising role is there to ensure that the voice of those with dementia is heard as the strategy is implemented. When we met for the interview, he'd represented some fifty appeal cases against Personal

Independence Payments being denied to many with dementias in that period. Though he is by no means the only dementia activist I've talked to, for me some of his actions and broader outlook shine a particular light on how the ideas around dementia friendly communities have not been critiqued much, but he also has a keen awareness of the contingent and precarious position in which activism and advocacy often finds itself. As mentioned, I was familiar with some of these phenomena from my own experience as a trustee of a small charity concerned with advocacy for those with drug related problems; to survive, particularly post-2008, there was a fine line to walk between co-optation and the lurch into audit culture, pastoral power.

For our interview, at his request, we met on campus at the café of the Taliesin Arts Centre. It was busier than I'd hoped for recording purposes, but the café can be cosy enough, and Nigel was fine with being there. He would have told me otherwise.

Listening to the recording, the interference of background sounds and voices give a sense of the bustle – common to many of the other interviews – of being somewhere with hissing coffee machines, people popping in to meet, like ourselves, aromas of coffee and baking. Everyday things, but with the busy billowing sense of a space awakening to new student life, as it was recorded in late September. A small, stained-glass relief can be found in the corner window of the arts centre, made of either plastic or glass, with the words quoted above, by the Catholic Marxist Simone Weil, sometimes described as a mystic, who 'philosophized on thresholds…margins and paradoxes…the patron saint of all outsiders' (Rozelle-Stone & Davis, 2020) , a nod to one of the founders of the Arts Centre from the university, Swansea-born philosopher Dewi Zephaniah Phillips, who wrote about her work. It is a corner for contemplation, even when the café is busy.

He handed me the text from a speech he'd give the day before, at a meeting in London which had been attended by various CEOs and CFOs of charities, such as the Alzheimer's Society. Whatever he'd thought this interview would be about, this seemed to go straight to the core of the themes in this thesis:

> *....so what I said was yesterday was that the role of charitable bodies and non-profits has shifted in the last decade, as dementia and ageing has gained all the attention and at its most crude, advocacy groups and charitable groups have become an extension of the government, happy to legitimise policies to access the funding...as I said that, the whole room...*
>
> *A: Did they? Why is that such a surprise...?*
>
> *N: Well, it's because, in the audience, Aelwyn bach, the majority of the audience were CEOs, CFOs, who's main job is to keep the lights on...and their main argument is, if not us, who? And they have a point, they have a point, you can't argue with that, but they're not beyond criticism. Now I've said that, you know I think charities and advocacy groups, and I include DEEP in this, cos DEEP will tell you we don't take government money, well they take Big Lottery funding, that comes from the Department of Sport and Culture, so they do take government money, we all take government money, and I'm just wondering if where they they are, not in their own view but in the view of the people they're supposed to be advocating for supporting...*

But he was also acutely aware of his own position of power now, with his various roles:

> *yeah I know why I'm with the Three Nations Group, better to be inside the tent rather than outside, I get it, I absolutely get it.*

Nigel is one of the very few who I've met who's queried the numbers, those which are often mobilised for political effect and fundraising purposes for further research (Lock, 2013), and at the same time recognised the contingent nature of some of the arguments about the contested nature of dementia itself, as either localization (clearly neuropathological) or entanglement (emergent and dependent on life experience and lifestyle):

> *there are three great myths about dementia: first, it's unforeseen, it's not - everybody knew it was coming, we knew it was happening, you know we keep medical records, we keep diagnostic records, we knew it was there. We didn't know the scale of what was there because we only diagnosed ...percent of people in Wales. Secondly, it's a massive numbers game for the future, is massively untrue, cos we don't know, we don't know. Three things that could've changed, take Wales as a example, a thing that we know: industrial habits in Wales have changed, the industrial landscape in Wales has changed, no heavy industry, no mines, no steelworks , no factory working - it doesn't exist anymore, all which have been contributory factors*

> *to the health of the people of Wales. People are eating differently, people are drinking I saw a quote yesterday which said that 45% of people under the age of 25 don't drink at all, which is massive, smoking is on the decline, massively, so to turn and around and say that we're going to have two and a half million people in Wales with dementia in 2050 is absolutely untrue, because they don't know.*
>
> *A: so who do you think that serves?*
>
> *N: Them…'because look we can't do anything about what's in front of us now, because look what's coming, we've got to be planning for the future...' Bollocks. Literally, that's bollocks, because how can you plan for something you don't know is going to happen? You know in front of me you've got 45,000+ of people, and I think it's probably in the region of 60,000, so in Wales, plan your services for that; you can't...that's the other guy's problem, but to keep on saying you know, 'here's a massive problem, and we have to do something about it through health education' all very well and good yes, but it will not get there [in terms of what's needed]*

His core argument here is not only a critique of the present failures, echoing also the criticisms heard at the consultations, but of the great shift that has happened towards the idea of prevention – this is evident from much of the material gathered during research, including the Dementia Action Plan (2018) and leaflets used in one of the cut-ups (Change4Life, 2015). The longitudinal project, a large population-based cohort study on which I was a researcher prior to this thesis (CFAS, 2016), raised similar questions to Nigel: how much of what we see as dementia is based on external, environmental and lifestyle factors, which are continuously changing, and who could possibly predict he world of 2050.

As we've seen in previous sections, many of the most pressing issues for people with a diagnosis of dementia involves the support they can get from the welfare system. To this day, this remains a pressing problem for those who, like Nigel, have young onset dementias, and are unable to work (Mayrhofer et al, 2021), beyond the apparent contradictions witnessed that 'bundles together both agency and blame' (Brown, 2016, p10); Nigel had been part of a wider movement which had campaigned on this, as well as personally getting involved in over fifty appeals. But his point was that such action sometimes happens despite the large charities:

> *let's take the issue of Personal Independence Payments, which should be the huge thing, now I was part of a group with public law fund which actually took on the government for the legality of the changes , and we won, without any help from any charities in fact, the major charities weren't allowed , we won, turned them over, for the 285, 000 people who....and there was people like myself..[....] there were people from the national autistic society, who are quite small [A: so a cross section....]yeah*
>
> *we did that without the large advocacy groups, these highly paid professional groups, who sometimes, because of the nature of what they do, screw up the nature of compensation anyway, and legitimise what the government is doing by sharing platforms with them – if you can't have a large conference without the politicians being there and you've got to ask yourself 'whooah, now..'…I think that people have stuck their hands up and that there's a great deal of social action going on, a great deal of direct action, like Disability Rights UK who've said enough's enough, we don't need to pay someone £150,000 a year, we know what to do…*

We talked more generally about the atmosphere in which the drive to create DFCs had come about:

> *State funding and donated funds are getting harder and harder to come by, simply because of the effects of austerity and you've got to ask yourself - are we are where we are because people are interested .... or are we are where we are because of government policy? And I think it's the latter, government policy, I think it's a deliberate attempt to push back the cost on to the consumer, I think it's a deliberate attempt to make the carers, for the carers 'here you are, at the same time there's nothing we can do to help you"...the importance of the notion of dementia friendly communities, they say 'we'll have that, sounds like a good idea' [A: it was Jeremy Hunt..] yes, Jeremy Hunt, and another Jeremy was responsible, he took it on board, uhhh Jeremy Hughes of the Alzheimer's society, without doing any background. Had he done the background, he would have seen that the dementia friendly communities in Japan had been a failure, simply because the derivation [?] of different types…how will you know whether a community is dementia friendly? There's been no proper evaluation*

This built on the speech he'd given the previous day:

> *Dementia friendly communities have got wings by being part of the package of solutions endorsed by the state. They are rarely a spontaneous or genuine response by families and communities themselves. As the*

> *austerity agenda has become more prevalent in the UK, dementia-friendly communities are becoming a way of gathering local forces to cover the cracks in provision and thinking. Where they are done well they can provide some short-term focus on practical change. But there's no evidence that dementia friendly communities are becoming vehicles for more active, political change. (Hullah, personal communication, 2017)*

Since this interview, more systematic efforts have been made to evaluate (see Buckner et al, 2019), but his comments echo many other voices from this period (Rahman & Swaffer, 2018) while recognising:

> *what they have done is...it's raising awareness, it's putting it out there, which is probably the one thing that you have to give the dementia friendly movement, it's raising the awareness,*
>
> *but I don't know if all these political and celebrity endorsements which we get on a regular basis you know, you know footballers coming on telly and saying we'll donate ten quid...why don't you donate a week's wages, you know? That kind of hypocrisy that we see from politicians, who come in on Alzheimer's Society conferences and 'we support fully dementia' and then have voted down or voted up ESA, which makes people's lives with disabilities a lot more difficult…what I think Dementia Friends doesn't do, it doesn't form a political challenge, a real challenge. What it does is, sitting in an urban area usually, saying you should be doing this or that...*
>
> *I think that Dementia Friendly Communities started to act like: ' Look what we're doing for you, without Dementia Friends programme every police officer in Swansea is now a Dementia Friend'. Yes, but most of them don't know what the Herbert Protocol is, that's more important to me than doing your 45 minute online course.*

Another point made repeatedly by Nigel, in this interview, publicly and at other times we've talked, is that the whole issue of rights for people with dementia is not one of claiming new rights, but of enforcing rights which are there already:

> *everyone approaches this with the wrong attitude. It's not something we should be given, it's something we're entitled to, the law says it, the 2010 Equality Act says it, the 2004 Disability Discrimination Act says it, the 1998 Human Rights Act says it, we may not be marginalised, discriminated, for any illness or disability, visible or otherwise, it's there in law*

> *A: already, yeah, so the rights are there in law, and therefore - where is the enforcement?*
>
> *N: well the enforcement is...it's because we've now jingoed the legal system to such an extent that legal aid is hard to come by*

As someone with a legal background, during our interview, he gave many examples – some of them local, some further afield – of how PWD were regularly the victims of discrimination and their rights not being repected under provision which already covered them. At the time of our interview, this was pertinent also because:

> *Can you believe, this is the only country ever to be sanctioned by the UN because of its treatment of disabled people, we're the only one ever, you know I gave evidence to that UN panel*

This had happened earlier on that year (Butler, 2017), but in a period when so many headlines around Brexit and other issues were prominent, the impact (or outrage) hadn't registered so much, even though as Nigel pointed out:

> *we've got some actual bastions of virtue in there: China, Saudi Arabia, Pakistan, you know these great...torch-holders for human rights. But we're the only country ever to be sanctioned, ever…*

The broader point for Nigel, however, has been that there needed to be more social solidarity, that the work was one of building a movement of some sort. I was aware that with DEEP, for example, Nigel and others had managed to organise and use the Welsh Government Consultation process to secure something more meaningful, with more oversight, a critical counter-conduct move. However, he had hoped for a continuation of that process:

> *I had high hopes for DEEP you see, I thought DEEP was going to ...a social movement, I really did, the consultation work went really brilliant, the report changed Welsh Government's mind, I did an awful lot of lobbying, you know I had twelve AMs on speed dial, had people visibly sigh when they saw me, because they knew I was coming after them, and my view was, once you play the game, cos nothing changes anywhere, whether you're in Swansea or....nothing changes political will, you have to get the politicians*

> *on your side, you don't necessarily have to agree with what they say, and they don't necessarily have to agree with you, but you have to make it so that the consequences of not agreeing with you is dire and my attitude was that we knew who to talk to....*

Experiences from his previous working life had helped here, knowing how to act politically and how to challenge, but also to recognise that there were alliances to be made with others who are equally marginalised, but have a longer history of mobilisation (Shakespeare et al, 2017):

> *We must ally ourselves with other disability groups, groups like DPAC* [Disabled People Against Cuts]*, Disability Rights UK, who looked at us in Strasbourg and said 'where have you been?', you know, and they're right, I mean I do a little bit with DPAC, it's bit like being with a gang of [...] and ruffians, you know, but they're disruptors, and I think that what we should become, we should become politically aware and [...]and I don't think dementia friendly communities do any of that, they're not disruptive, they're compliant, you know it's "please, please, please will you make your shop dementia friendly?" not "you've got to make your shop dementia friendly - it's the law", cos they're too afraid that we...and then when somebody turn around and say tell you what we'll put a sign up it's all 'thank you, thank you', you know putting a badge on isn't...*

There were frustrations here for Nigel, because he had realised:

> *That's what it's all about, it's not about these high falutin deep ideas and high falutin about social interaction, activism at its most visceral level, what the hell does that mean? I don't want to spend all my life banging a drum for human rights, I do it because it seems to be the one thing that we're not able to grasp…I believe this, I believe it's going to take 200 people affected with dementia to chain themselves to the front gates of the Houses of Parliament, I think we're getting there, I can think of 50 people who would do that, and I can think of another 50 people who would join, and then there's a 100 people who would think 'well I'll go along for the ride.*

What I had noticed in my trek around the different networking events, conferences, and the like was that among activists such as Nigel, Chris and others, there is a genuine sense of camaraderie and support, a collective identity (Bobel, 2007) which seemed to give confidence to take active part in many fora, and to ask questions of those in positions of power. To an extent, Nigel already had the skillset from his previous life, and was prepared to use it but in a social leadership role that involved ‘sense making, adding value and crafting meaningful stories that serve as calls to action and sharing them wisely’ (Stodd, 2016); I’ve heard Nigel deploy his stories about what living with dementia means to him several times, often tactically and with a careful point to make. Darla and others do not come from that same background, but nevertheless have also managed to find a voices and leadership roles within the movement towards recognising the rights of PWD, and my observations of this activist scene in Wales suggested something more than it being an ‘emergent’ (Bartlett, 2012), that a type of collective struggle based on a ‘situated knowledge which draws on personal experience’ (Allsop, Jones & Baggott, 2004, p. 752) was in a sense beginning to mature into political action, with PWD getting involved in for a at all levels of government, local, national and international.

Towards the end of our wide-ranging discussion, Nigel summed up how he felt on that day:

> *I honestly believe that two things need to happen in the next five years...One is to dispute, challenge and move away from the medical model, to a social model. Second, not throw our lot in with the latest glib government, charity-based bullshit, now it's this side by side, speaking as one voice. I don't speak as one voice with anybody, never have done in my life, and I'm not going to start now. I appreciate the support of people, but I think that supports got to be earned*

39. A New Deal

There had been murmurings all morning. Would he turn up? People were still mad at him for the funding cuts, the promising project cut short, without much explanation beyond some corporate responsibility talk. In a full room, all beige and blue, there were people huddled around tables, some weary from journeys far away, name-badges drooping delivering their pitches over a third cup.

In the end he turned up, as advertised. Helicoptered in, said one. Dovetailed by a professor who talked about silent epidemics and worked in private practice, he stood forward, no notes, hands aloft, all trained earnestness.

‘This is about community looking after itself, but we have a civic responsibility to look after each other’ he said, ‘The NHS model is broken, we need a new deal on dementia’

He looked around; all silent, taking in his message.

‘We’ll get the data centres talking to each other, joined up, and get the national rhetoric to translate locally, we’ll look at what works, it’s the right thing to do’

There was more, of course, a ten-minute list of achievement, contexts, warnings. Then, warming to his theme, a crescendo:

‘We’ll pump prime and pioneer new forms of support, for a rights-based environment!’

He stood back and looked around, hands down, the face a slight reddish flush, the revivalist preacher within satisfied. And as the clapping came in waves, someone leaned over, whispered, “we’ve seen all this before, those hands, that smile….”

40. A trip north

Figure 8: Bywyd da / Good life

On a rainy day in Porthmadog, I catch up with Emma at the local leisure centre. Leisure centres, are a prime spot which fit into the DFCs broad aims of raising awareness, bringing together local organisations and services, engaging and normalising the experience of living with dementia (Buckner et al. 2019). As such they are also sites of the ‘everyday’, both in terms of participation (Delrieu & Gibson, 2017) and as a focus of mundane routines and practices (Neal & Murji, 2015). For PWD and their carers, the mundane and everyday can throw up many challenges, because the familiar has often become strange, and so attending a local leisure centre can be seen as a practice of ‘everyday’ citizenship – a matter of rights, access and belonging (Nedlund, Bartlett & Clarke, 2019), and a way of asserting agency. In my conversations with people in Brecon, both the Meeting Centre group and the activities of Brecon and District Dementia Friendly Communities had in part centred on using the facilities of the leisure centre there also, the inclusion of physical activity for both those with the condition and their carers. Sporting activities, both the physical memories they evoked and the actual competitive playing during sessions of table tennis, or versions of indoor rugby and cricket invented by the group, formed an important part of the activities at the Meeting Centre, but I also heard of other schemes during my networking visits across Wales which encouraged physical activity and the recollection of sporting memories for those with dementias, activity which is being recognised as worthwhile for PWD (Russell et al, 2019).

By now, in common with lots of other local authority services, leisure centres are often operated by large commercial groups on behalf of local authorities, as is the case in Brecon, though many seem to be open to dementia friendly sessions, including there. Overall, however, investment in such places has been cut by a third over the last decade, another consequence of fiscal austerity (LGA, 2020), when difficult decisions have to be made about all sorts of local provision.

The Glaslyn Centre, where Emma works, is still owned by the local authority in a part of Wales which is predominantly Welsh speaking. My interview with her was in Welsh. She used to be the manager of the Leisure Centre but hated the bureaucracy – her roots there were in cardiac rehab and exercise referral. I had met her before through various networking events, and was aware that she had been very busy setting things up in Porthmadog, both at the leisure centre and more generally, trying to make the area more dementia-friendly, as a ‘dementia champion’ - giving ‘dementia friends’ sessions – and setting up various committees. Her contribution to DFCs was also centred around a scheme called Dementia Go which she had developed from the chronic conditions exercise programme, bolted on as she noticed some of those who came to the programme had cognitive difficulties. Like many others I had come across, she also had personal family experience of dementia.

As I walked in the large building, it was obvious that the place was thriving and busy. Emma had been responsible for the artwork and other aspects of the leisure centre (‘I wanted a sense of anything goes’, she said) and had wanted to change it into a more community hub – this had happened, and the local library had also been co-located there. We sat down for a coffee in the large open café space, which served locally roasted Dwyfor coffee: *Now that* *they've brought the library in here, yes! It works well. I've made sure it's dementia friendly and given them the training.*

I noted that the bilingual menu, up on the wall, seemed to have healthy food with vegetarian and vegan options, which was not my experience of such places at home.

I'm giving a class today, but people come in here with their books, then come to my class and then have lunch, so they spend a good couple of hours. She said hello to some of the people at a nearby table. During the interview, she was constantly saying hello to people who came in and out of the space.

I looked around and noticed how different this space was from a lot of the others I'd frequented looking for the *tylwyth teg*. Behind me, the open library was busy-ish for a Wednesday morning. We talked in general about how things had been going.

> *Best thing I ever did, was giving the dementia friends training to the councillors. I look back over the last two years, and I'm proud of what we've achieved with Dementia Go…*

But she also noted that:

> *DFC has been a real battle…Porthmadog has got the status, we got it, and we did a lot of work but I was a bit of a lone ranger, I'd go out and give the dementia friends training, then we had a lull, and woah…realised this just wasn't working, you know? I needed help with it, so I had a refresh, I scrapped everything and invited more people along…the councillors were on the steering group, I know them and they're influential, we had the police, we had someone form the royal mail, but most of them were going through the motions, without much experience of dementia…*
>
> *we got a lot of things through the Dementia Go scheme, but mainly I just got some more dynamic people on board, from a new councillor, to someone from the local model railway, we re-ignited I all through an action plan – got more people involved in delivering dementia friends , created pledges locally….people think that this place is quite close-knit, but it isn't really, it's like a lot of other places I suppose*

She had a very good relationship with the regional Alzheimer’s Society, and used a lot of their material, but had had to translate everything into Welsh, there wasn’t enough provision in the language, it had taken a lot of voluntary effort to do that as well as everything else. This relationship with the Society in Gwynedd seems good and positive – compared to other part – so there’s an UNEVEN-Ness to those relationships then. Emma claims that they’re actually very flexible with them, hence no need to fundraise independently; Alzheimer’s Society and Carer’s Trust would seem to be involved in local service delivery, as they are in other parts of Wales. Continuing on the theme of making Porthmadog a DFC, she continued:

> *We had a lot of “well it doesn’t affect us’ kind of attitudes…but also positivity, we concentrated on those who were keen*
>
> *We got Beti George up last week to celebrate our achievements…she spoke so openly*

Beti is a well-known radio broadcaster in Welsh, and she had used her high profile to tell the story of her husband, who had dementia – she has raised a lot of awareness among Welsh speakers about the condition. During the fieldwork, I came across her quite a few times: she was a guest of honour at a large conference organised by our department, had funded some further research and had been involved with raising further awareness around the difficulties that are more acute for Welsh-speakers in getting timely diagnosis and support (Welsh Language Commissioner, 2018). Language can be an issue at all levels, from the assessments being in English only, to the care available then -this affects people’s outcomes quite dramatically and reflected the concerns I’d heard over many years. This had been the theme of the play Belonging/Perthyn, that I had just seen at that point, by the same company who had worked with PWD and given the performance at the church networking event, years before. We talked about how stigma had lessened around dementia for Welsh-speakers, because of exposure in the media, but also the work of colleagues at Bangor University, engaging with the networks of Welsh speakers such as Merched y Wawr, an organisation similar to the W.I. Emma had also worked with them.

She recounted how in the previous week's celebration, in the Q&A, a man who was with dementia got up and walked towards the stage – could barely speak – so Emma went to help him and he whispered to her how much he wanted everyone to know how much his wife had helped him. Everybody crying and cheering. Post-interview, I reflected again how this confessional mode seemed integral to how this works.

She continued:

> *Another woman stood up and said 'well I'm so glad I got the diagnosis because I could then go and get the support' …so she felt that there was support out there for her from the get-go, which was a good moment for us*

I then mentioned the consultation events for the draft Welsh Government Dementia Strategy, and what had happened at the consultation events I'd seen, but also all the rumours of mic drops by activists, and how it took another year before the strategy was finally agreed. As I spoke, I could smell the café becoming ever busier, the sounds of coffee machines and smell of baking potatoes.

> *There was uproar, wasn't there? Revolution, with that first draft…it's still not perfect but it's a starting point.*

She explained that her approach was based on ultimately wanting to get everyone into a room and have a one stop shop kind of approach: memory clinics, carer support, all in one place.

> *There are too many pathways – you can't always see the pattern, how things connect – it's all very tentative, let's hope the strategy helps with this, bring things together…at the moment, because it isn't explicit enough in the various strategies, we still have to shout a bit so that people can see what we're doing*

She went on to say:

> *In a way, maybe it was a good thing that there was such a negative response to the first draft of the consultation, because it meant that they had to stand up and take notice and listen.*
>
> *I've been given a lot of support from the council here to pursue my vision if you like, but I'm still a bit out on a limb because I'm working for leisure.*

I'd noted that in the new strategy, mention of 'dementia friendly communities' had been minimised, but this didn't seem to phase her.

> *What's good about DFCs in Porth is that I created it off my own back, but now others want to do it too locally, I can just go and share my experience and pass some of the knowledge on*

There was a pause, and I asked her more about the classes – she had begun to look at her watch as she had another one coming up.

> *when you see people's faces when they leave the class, you can feel what they feel, that's what wellbeing is, that's it....they've had the physical, the mental and the social"*
>
> *With Dementia Go, it's completely up to the carers if they want to take part or not, but we feel that they also can do with the exercise too, it benefits them – but if they want a break, they can go. But what we're finding is that carers who might have lost someone or who have a loved one in a home, continue to come to the sessions and become very supportive of others, peer to peer...*

I reflected later that in some ways, the leisure centre is a kind of hub the way that Joan in Brecon had imagined the Meeting Centre to be. Emma sounds like the 'go to' person in her area for dementia matters – just like Joan or Rhiannon have been. She is, that was my first impression of her years ago – and because she has that reputation, the council is prepared to come back to her time and time again, she gave examples of doing everything from giving Dementia Friends sessions to the Trading Standards division, to taking Dementia Go into the local authority care homes in the area.

> *I think that fundamentally what we've been able to do through our work here in the classes and elsewhere is create a sense of closeness which then*

becomes a trust, and I think that's then led to people feeling that they can be more open and confident…when we had our awards ceremony the other night there was something very special about it, and that was it, people felt they could talk freely about their experiences…"

"I mean when I go to speak publicly about dementia friendly communities, but in the back of my mind, what we're really talking about is how to be good neighbours to people, that's all it is…as Chris Roberts [another dementia activist] says, get it right for people with dementia and you get it right for everyone.

41. Collage: Robots! Protest!

Figure 9: Collage - Robots! Protest!

In this collage, inspired by Darla's intervention at an academic conference where she challenged us to think about advancing robot care of those with dementia and what this means in terms of human autonomy (she would rather choke than be resuscitated by a robot, when the time comes), I juxtapose some of the general atmospheric unease which has been present over the last few years: Brexit, the unravelling of the welfare system, long-term socio-economic injustice resulting in catastrophic, housing policy; the hidden horizon of death behind social and health policies that produce inequality (Fassin, 2009). I also cut-up three phrases common to the research: 'we're all in this together', 'nothing about us without us' and 'making the familiar strange' and have arranged them as three discreet 'cut-up poems'. As in other collages I've made for this research, there is the solidity of the Brecon Beacons, Zulu shields and spears in the background, but also spaces and places in Brecon: the Zulu shields are from the famous battle of Rorke's Drift, and form part of the regimental Brecon's regimental museum in Brecon; as well as being a market town, it is a barrack town, with military presence going back to Roman times. The Himal Spices are used mainly by the large Nepali presence there, with the Ghurka regiment stationed close by. Though this is market town in a large rural county, there are layers of involvement here with colonisation, with empire. Weaving bunting with my group of PWD, there were reminiscences of the twentieth century wars, never too far away – shared stories of relatives who had died or had lucky escapes were never far away. But here also are assistance and communication robots featured, from an exhibition attended in 2017[9], together with an object I picked up around the same time – a chocolate egg wrapped in a flannel which was being sold to raise money for a dementia charity in mid-Wales. A line of flight also formed from this as I began to

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[9] https://www.sciencemuseum.org.uk/about-us/press-office/science-museum-reveal-remarkable-500-year-history-robots-new-exhibition

speculate if, in future, such robots will also develop dementia like symptoms: clogged lines of code, future CPUs slowing, memory degradation through too much feedback with human interactions. This was also inspired by the Beat poet Gary Snyder's poem 'Why I Take Good Care of My Macintosh' (Snyder, 2016) which points to more-than-human representation via a deep appreciation of Japanese cultural traditions.

50. Newspaper Cut-up: Spectacular Fish Control Elderly!

> *The word of course is one of the most powerful instruments of control as exercised by the newspaper and images as well, there are both words and images in newspapers….Now if you start cutting these up and rearranging them you are breaking down the control system*

(Odier & Burroughs, 2008, p33)

During this research, I made a habit of collecting the headlines in British newspapers that referred to dementia directly, whenever I came across them, usually while shopping or walking about doing everyday things. Though this list, compiled over three years, is by no means exhaustive, I felt that it might give some indication of a background 'hum' to dementia matters: undoubtedly the rise of electronic media means that many people are more exposed to digital sources in their daily lives by now, but walking around any town centre or supermarket would indicate that newsstands are still prominent, corner-of-the-eye messengers, even if many of us are increasingly stooped over glowing clumps of crystal and electronics.

In this section, I will explore what can happen when we apply a creative approach such as Burroughs and Gysin's cut-up method to such headlines. It would be pertinent to think here again of '*how* we document creativity and *how* we document creatively, but also *how* and *why* these methodologies are valuable' (Veal and Hawkins 2020, p.359). In reality, this was a long process of noticing, documenting and thinking about such headlines, before applying the cut-up method as a means of questioning some of the strident and directive language that emerges from time to time in such headlines, specifically about dementia in this case.

That said, it was not an attempt to ‘take back control’, to use one of the phrases that peppered this period, rather the value was often in trying a technique which might help get beyond the kinds of impasse that can happen in research (Collaging as a practice can do the same). It also highlights a move away in the thesis from an idea that knowledge creation is about the tidy re-presentation of one medium in another: this photo proves this or those words prove that (about DFCs). By randomised cutting up, for example, something new potentially emerges every time: the newspaper headlines become a form of poetry, and once cut off from their directive nature, submerged hidden meanings appear, can be performed even if read out loud with sufficient gusto – and can change every time we cut again. Re-presentation in this way can really be a form of transformation (Doel, 2010).

Other studies have also looked more systematically at how dementia is framed through various media discourses (Bailey et al., 2019, Cuijpers & Van Lente, 2015, Peel, 2014, Van Gorp & Verycruysse, 2012, Kirkman, 2006), but my reading of these themes over the period of research commonly found that the words used were often those of crisis, national or otherwise, of war, and of a ‘master illness[…]used to propose new critical standards of individual health, and to express a sense of dissatisfaction with society as such’ (Sontag, 2005, p74), one that often inspires dread (Zeilig, 2013) and a somewhat apocalyptic demography, as much as ideas of progress or successful ageing (Cuijpers & Van Lente, 2015). Equally, strong references to biomedical solutions, responsibilization, consumerism, and of hope, tentative political action, and increasingly, celebrity are all to be found often in these headlines around dementia (Peel, 2014). Despite the decline of print media, it still plays a role both in awareness of a range of health, social and political issues. This period was particularly febrile because of Brexit, the number of general elections, and the attendant sense of national crisis and division; but in the headlines around dementia, and for all the talk of dementia friendly communities, often much of the discourse focussed on individual responsibility, or the magic bullets of science, regardless of environmental or societal or structural factors which may contribute to the prevalence of the condition.

Inspired once more by a line of flight produced by the image of Burroughs in Brecon, I decided to experiment using cut-ups with these headlines, to see whether there was any other productive way of using the words around dementia used, whether other meanings could be generated from such a set of headlines. I was aware that this was a step towards blurring some of the lines between 'social science investigation' and a type of creative practice, but felt that it was another way of asking "why this 'problematization'?" (Foucault, 1992, p10) of ageing and dementia that was evident in these headlines. As explored in other part of this thesis, I've been trying to develop a more mobile subjectivity as the 'author' of this thesis to explore these issues in the writing process (Shapiro, 2013), for example by extensive use of anecdote and a fictocritical writing. I saw this as a good opportunity to think things through in a manner which 'invent[s] and appl[ies] conceptual frames and create[s] juxtapositions that disrupt and/or render historically contingent accepted knowledge practices' (Shapiro, 2013, xv), such as the 'scientific/technological progress', or 'successful ageing', or 'the aging society', as presented in the newspapers. Others have done this in perhaps a more conventional way using corpus linguistics, Critical Discourse Analysis and other forms of coding and labelling, with interesting results (Bailey et al. 2019, Cuijpers & Van Lente, 2015, Peel, 2014). For me, I wanted a cut-up approach to act as a 'fictioning against fiction or spectacle machines', (Burrows and O'Sullivan 2019, p42), spectacle machines being newspapers in this instance. In such Deleuzian terms, some argue that the cut-up becomes a 'war machine', undermining the 'fantasies of realism' (Lyotard 1984, 74) conjured up by syntax and the particular sequencing of images.

As Lupton (1999, p.260) observes:

> *For many lay people, the mass media constitute one of the most important sources of information about health and medicine. Mass media portrayals contribute to the creation or reproduction of knowledges about illness and disease … they work to portray ill people in certain lights (for example, as 'innocent victims' or 'deserving of their fate')*

I suspect the coverage of dementia and DFCs is generally different in local newspapers, and those involved in dementia matters in Brecon, for example, had a good relationship with their local paper, The Brecon & Radnor Express, where I witnessed journalists turning up for networking events or giving positive coverage about the Meeting Centres. All of the headlines used here are from mass media, and a particular newspaper (The Daily Express), noted for its strident headlines, which often cover health issues affecting its mainly older readership – 83% of which is over 55, for example (Hurst Media, 2019). Peel (2014) explored the discourse used in this paper and another, The Daily Mail, with a group of carers affected by dementia, and observed that whereas the latter tended towards the catastrophising of dementia, the Express emphasised a discourse of 'living well' with the condition: this has not changed since Peel's article, as can be seen below. During my period of research this paper had a repertoire of headlines which seemed to revolve around a particular set of subjects: Brexit, dementia, immigration. In framing these subjects, I noticed that language was often directive and commanding when it came to dementia ('Eat/drink this, do that') – but with other subjects, Brexit being the most obvious, there was often a shift to the first person plural ('we' or 'us' – for example, 'You Can't Bully us Mr Barnier' or 'Do or Die, We Will Quit the EU by October 31st'), thereby shifting between positions of responsibilization and solidarity. The Express was by no means the only paper which did this, but it seemed to stick to a particular formula in terms of their headline writing, and is quite well known for this style of revolving headlines (Press Gazette, 2013).

Here are the headlines used:

Eat curry to beat dementia

Drink coffee to fight dementia

Dementia crisis as deaths soar

Dementia risk from diabetes

Dementia crisis out of control

Snoring raises dementia risk

Stay married to halt dementia

Sugar speeds up dementia

New dementia breakthrough

Drink tea to fight dementia

Dame Babs’ plea to end dementia agony

Favourite songs will help you beat dementia

Arthritis drug will fight off dementia

Millions snub check to spot dementia

Busy roads can cause dementia

Dementia care delays causing elderly £15 billion

Eat mushrooms to fight dementia

Study proves you can fight off dementia

Dementia cure hit by lack of funds

Oily fish can beat dementia

New drugs to beat dementia

Dementia cure within a decade

Spectacular Alzheimer’s breakthrough

Sir Jackie’s F1 boost for dementia cure

Six rules to fight dementia

Stay off booze to fight dementia

Keep fit to beat dementia

Eat salads to beat dementia

We must act now to beat dementia

Dementia runs in the family

Statins fight Alzheimer's

Alzheimer's cure hope

Having collected these onto single word document, I followed the first procedure as outlined in Appendix 3, and this was the resulting cut-up:

Spectacular fish control elderly!

Dementia songs care for Alzheimer's

Stay to drugs, dementia

married out roads

spot dementia, you

dementia cure

Oily coffee study

dementia

Alzheimer's raises fight

of check off,
beat lack risk
dementia to cure off
delays prove boost within beat,

Drink up by plea
fit soar family
dementia hit
drink,
‘…eat dementia funds,
Alzheimer’s will….’

Dementia -
spectacular fish control elderly,
snub now, rules favourite
can a salad cure, beat?
As we,
new of the cause,
will dementia

causing millions fight

Dementia, dementia
beat beat
beat deaths, you speed,
I
Eat, act,
halt.

Dementia, dementia -
crisis statins must run
to fight off curry, tea
Eat to beat
Stay cure booze,
dementia crisis mushrooms:
to fight dementia
can fight dementia breakthrough?

Dementia, dementia -

Snoring diabetes,
a busy fight

Dementia, dementia, dementia -
end dementia!
Arthritis fight, decade hope
keep new billion,
help sugar breakthrough.

My initial reaction to this piece as I finished working on it was to think of it having a ‘stuttering’ (Deleuze, 1997) quality, with the immediate effect of disrupting the very linear logic of grammar and syntax in the directive headlines. It breaks, jumps and repeats, producing some different images: ‘sugar breakthroughs’, ‘snoring diabetes’, ‘to fight off curry’, ‘spectacular fish control elderly’. It has ‘a friction, foreignness, a murmur of other possibilities, extends routine and thought in a new direction’ (Gunaratnam, 2015, p129), and it is that ‘murmur’ of poetry which produces a different kind of narrative, yet one which also falls together with common ‘truths’: ‘eat dementia, Alzheimer’s will’, ‘can a salad cure, beat?’ ‘As we, new of the cause, will causing millions, fight’. For me, the piece also has a quality of lamentation – a bit like Beat poet Allen Ginsberg’s early poetry[10] – so the repetition of ‘dementia, dementia’, and then the word/homophone soundplay of lines like ‘fit soar family’

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[10] For example, ‘Kaddish’, written for his dead mother, a form of Jewish mourning poetry for close relatives.

as ‘dementia…. fit SORE family’, plead with the reader, and reminded me of the many carers I’ve met – the soreness, the jangled nerves, crying and often lack of sleep that can affect people getting used to the condition. Equally, there is the surreal quality of ‘spectacular fish control elderly’, which sounds like a subverted headline in its own right. The piece has a performative quality: the more you read, especially out loud, the more it stimulates new ideas that might lie beyond the slightly hectoring tone of the original headlines. The tone itself has changed completely: instead of instructions for ‘living well with dementia’, we have ‘brief bursts’ of fragments, ruining the construction of such schema (Davis, 2019, Barthes,2010b), and inviting the reader to think again. It gently challenges a certain type of biomedical discourse that ‘serves to reinforce the power of medicine and pharmaceuticals as the appropriate and benign instrument of social control’ (Clarke, 2006, p 274), and cuts through the cumulative effect of such a discourse. Single headlines or news articles probably seem quite insignificant, but by assembling them together here we can see the concentrated, accretive power of such a discourse that positions and represents various interests (Fairclough, 2015): cutting up the text to create something new may be a way of questioning this.

I’m conscious that by turning to these more unusual methods, taken from literature, it is perhaps a way of ‘doing and making that intervene[s] in the general distribution of ways of doing and making’ (Rancière, 2004, p13), and as such are more experiments in ‘making the familiar strange’. As noted, the headlines here could very easily be cut-up again and again, with different effects each time, and I would invite readers of this thesis to do so.

51. Second touchstone – Sidelong glances

This touchstone contains several anecdotes, vignettes, cut-ups and a list. To an extent, it’s an archive of incidents which aren’t that remarkable, but are somehow relatable to dementia, community, to neighbourhood, to going about everyday business, where exchanges can be compassionate, jocular, occasionally contain hidden violence or sadness. They are sidelong glances (Perec, 2008) at the field. Quite early on, it became apparent that to understand what a 'dementia friendly community' might be, beyond the formally prescribed tenets of 'doing participative observation' or 'doing in-depth interviews' or even 'taking photographs', that a way of acknowledging the affective, the randomness of encounters, the conversations in and around this subject would also become necessary. Not doing so would be to ignore the richness of what was to be found in the immediate vicinity: my own neighbourhood, in shops, on buses, in markets, train stations, where the *tylwyth teg* are sometimes found. There is a strong academic literature about neighbourhoods and dementia (Keady et al, 2012), but that's not point here. The fragments are in a sense more concerned about 'being a neighbour', a figure often overlooked, sometimes distrusted, but one which might have daily interactions and attachments in a given space, grounded in proximity and ideas of hospitality (Painter, 2010).

I was alerted to Georges Perec's work during the same fateful seminar in which we discussed a piece by Kathleen Stewart (2013), and after which a colleague alerted me to the picture of Burroughs, though I'd picked up a copy of Species of Spaces (2008) many years previously, had it on my bookshelf somewhere. We discussed ways of writing about place, looked at a paper which attempted to 'exhaust' a space (Riding, 2017), which reminded me slightly of Kerouac's spontaneous approach, though they're different; the point was how do we experiment with writing to convey what might be happening, or attempt to give some sense of place, or a space - physical, emotional, dynamic state of being?

Perec's work often grapples with the urge to classify and categorise, but also uses descriptive methods, approaches, even stylistic devices, which are relevant to ethnography (Becker, 2001), more non-representational methods of approaching research and fieldwork generally (Phillips, 2016). 'The eccentric bard of the mundane' (Back, 2020, xv), his writing is characterised by trying to capture the whole range of experience, from that very mundane to the specific, from background to foreground, the 'infra-ordinary', 'the background noise, the habitual, the stuff that is looked over, missed when gazing at a place' (Riding, 2017). He saw his own work as having four ‘modes of interrogation’ (Perec, 2008, p.141): the sociological, or ‘how to look at the everyday’, the autobiographical, the ludic/playful and the fictive – or a combination of all four. In a time before computers were commonplace, he was disconcerted at the idea of being perceived as a ‘machine producing texts’, but rather thought of himself, metaphorically, as a peasant cultivating these fields of interrogation.

In Species of Spaces (2008), Perec experiments with several forms of writing, ranging from autobiography, essays on memory, to notes on classification, lists. One essay is entitled 12 Sidelong Glances (p. 156), in which he takes a particular subject of interest, in this case ‘fashion’, and then proceeds to give twelve sometimes quite oblique pieces of writing/text, that for him have meaning in the context of thinking around ‘fashion’. This chapter is an homage to that approach, presenting different ways of looking at DFCs.

Often, once people had an inkling of what I was doing, or sometimes even quite unprompted, (such is the pervasiveness of the *tylwyth teg*) I would encounter something about ‘dementia’, ‘friendliness’ or ‘community’ and feel the need to capture it somehow. These fragmentary illustrative exchanges, fired by what surely must be a core tenet of research - to pay attention, even to ‘the contradictions and ambivalences of our projects and attachments’ (Berlant, 2017, p13) -would stick with me, and sometimes become ever more entangled with the questions at hand, make me even more conscious, anxious even, to record some of the background ‘hum’ of this research experience. Something found or overheard or said in conversation could become a relay or line of flight, illustrating, even if for only a second or two, the problems or questions brought in the wake of the *tylwyth teg*, ‘emergent in disparate scenes and incommensurate forms and registers; a tangle of potential connections’ (Stewart, 2007, p4).

52. A short history of dementia in Welsh

One July evening, sitting on a friend’s patio for some tea and posh biscuits but on our way out to eat, I met their neighbour, a tall man in his late eighties in front of the ripening gooseberries, a lord and retired judge no less. It was a warm evening, and I'd heard a lot about him over the years: *un o'i filltir sgwar*, as we say, rooted in his local square mile. He'd always lived in this part of the world, near these hills, as had his ancestors, by all accounts. This was despite weekly sojourns down to the Lords in later years, and for a period in the late sixties and early seventies, the Commons. A yellowing caravan in his driveway had also seen many years of local jaunts, as a perennial temporary home at the Royal Welsh or the Eisteddfod.

After ritual pleasantries over cooling Lady Grey, we got talking, and I explained my interest in dementia and communities, to which he observed almost immediately: *'Wrth gwrs, i ni beidio anghofio tarddiad y gair gwallgof , un sydd yn llythrennol gyda cof gwallus ac felly yn lloerig o'r herwydd'* ['of course, let's not forget the origin of the word in Welsh, gwallgof, quite literally someone with a faulty memory, and maddened because of it']. *Lloerig* in Welsh has the additional meaning of 'lunacy'.

He peered at me under kindly, bushy brows. We could have talked about this for a long time, I think, of the pure movement of mind, the perpetual flight that stops memory from forming, as I was reading at the time (Foucault, 2009a). But here was an everyday linguistic intrigue, overlooked, suddenly obvious: *'dwi o fy ngho gyda fo'* – 'I'm mad at him' is literally 'I'm out of memory with him'. This is not 'the' dementia of course, which by now in my mother tongue is rather prosaically called *dementia*. In previous times, and still with relevance as descriptions of symptoms, it could have been, among other terms, *musgrell*, *ffwndrus* or *dryslyd* each with slight variations on frailty, fumbling or confusion.

The knotted, tuberous history of 'dementia' still remains slippery at this point, and as Foucault observed, it's something which refuses to crystallise: 'a madness, minus the specific forms of any particular madness [which]…is anything unreasonable in the ordinary mechanics or fibres of a well-ordered brain' (Foucault, 2009a, p.255). I could only wonder how an ex-judge, a lord, a politician would unearth more meanings to this word, could have watched the intimate impacts of its force as it circulated (Stewart, 2007) across the decades, across his square mile, his courtroom even, or as whispers in tea-rooms of the elected and privileged, the weaknesses of princely bloodlines. How of all cognition, memory – so much of it outsourced to the shiny device and the far-off server farm to which I ran after our conversation – must have been the most prized of skills, upholding kinship, laws, transmitting meaning, shared collective myths and stories in paperless times. To lose it, a disaster: King Lear (or *Llyr*, as he is in Welsh) on the heath with his Lewy Body dementia, as they would have it these days (Jones, 2014).

The neighbour’s memory is legendary, however: vast chunks of law and Shakespeare and Welsh verse intact, according to our friends. But we kept things short and talked of other things, drinking tea and occasionally listening to the songs of berry-thieves all around, hills behind mottled green from sun.

53. Mid-afternoon motor engineers

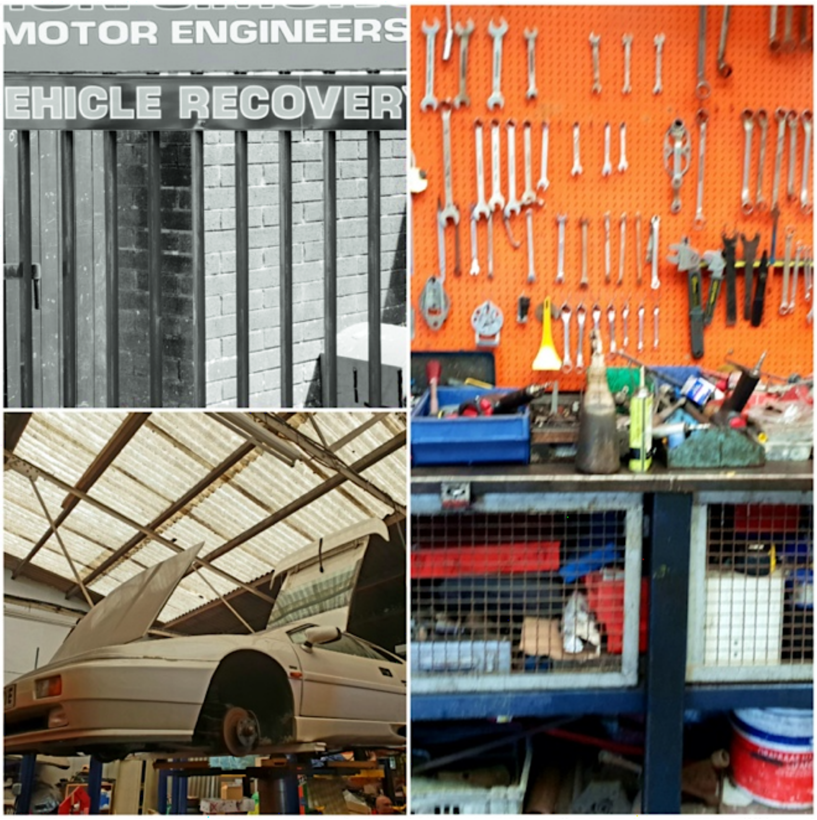


Figure 10: Motor engineers

“You’re lucky you’ve got a bumhole, mine’s gone cos of the bowel cancer, sewn up, don’t really need it anymore” said Roy, whilst finishing off his choc-ice in his little office, talking to his friend with a white pencil thin moustache and pressed chinos, also tucking into a choc-ice. It was a hot day in mid-May, and the friend was about to undergo radiotherapy for his prostate. The delicate matter of bums being probed in prostate treatment had been the reason for Roy’s reflections.

“You don’t want to be old, son, I was as fit as a fly before Christmas” said Roy’s friend, looking at me, some white ice cream on his lower lip.

He’d come in to settle up, an overdue bill for busted suspension springs, thanks to post-snow City potholes. Jerry, Roy’s brother, was outside sweeping up under the pearlescent white body of a Lotus Esprit, which had occupied one of the trolley jacks for a good few years, and Roy’s wife Glenys sat there, also finishing off a choc-ice, and talking to Jerry.

Roy looked up at him, his olive-green eyes still and calm under his baseball cap, in his immaculate overalls.

“Thing is see, I’m handing it all over to Jerry, I haven’t really worked here properly for two years now”

“Is that so Roy?” He said, handing over his card. End of an era stuff this, the great picture of Roy and Jerry working on Formula cars in the seventies, pictures of power boats, the hours we’d spent talking caravans, camshafts, the Lotus, inspecting the various falling off bits of various falling apart cars I’d been unlucky enough to own over the years. He looked out at Jerry still sweeping away, Glenys staring out into the middle distance. Roy’s friend got up to go to the garage, for a quick word with Jerry. He asked about Glenys, after a chance conversation a few weeks earlier when, Roy struggling with trolleys outside a shop.

“Well….it’s getting more difficult to cope…she, she doesn’t know” he nodded towards the friend “….but I think he’s probably guessed by now. Last night I made steak, new potatoes, broccoli, but she didn’t eat it, threw it all away, she knows there’s something up and it’s getting her down. I’m not used to this cooking and cleaning, but we’ve got a good carer mind, she came the other night and helped put her to bed, stayed with her. I phoned the company to let them know how good she is. But it’s getting harder.”

He looked nervously, through the door.

“She can’t judge what to put on her fork, I’ve got to cut everything up. But last night she wouldn’t eat a thing…..” he paused “….and I can’t let her go to the toilet on her own these days, she’s forgotten what to do once she’s there. She can’t write or use the phone no more”. He looked down. “But my daughter will be up this weekend, and I take her to things, just pretend it’s got nothing to do with dementia. Funny thing is, her sister has it too, but she’s gone all aggressive, but she can still use the phone. But because their mum had it, she’d hate to think that she had it too, she’d hate it…”

“If I hear of anything local, Roy, I’ll let you know…”

The friend came back, they changed tack.

“I’ve got to go and get my son now Roy” He handed over the receipt. “But pop over anytime for a coffee, you know where I am, plenty of time for that at the moment what with…” He rolled his eyes and raised an eyebrow, laughed.

Ducking out, he waved goodbye to Jerry and Glenys. She used to do the books here and they used to be neighbours; still are really, just he’d moved to an adjacent street. Roy still drives a big Mercedes with personalised plates, driving gloves, immaculate.

Jerry was still under the Lotus, someone's expensive hobby, though not Jerry's; a saga of spare parts and rusted suspension. He smiled again, she smiled again and waved goodbye, then left.

54. Boiler resilience

Working on the boiler, looking up, over his moustache. “I pick and choose these days”.

Sips tea, fetches the Phillips.

“My business partner, had been off the booze for twenty years, but he had that....Korsakoffs or something....”

“He didn't think that he was an alcoholic, 'he only drank beer''. Slight shake of the head, sad smile, looks over.

“He actually got involved with AA, but he would be asking the same questions about the old boys from the area, people we'd known since we were kids - but they were all dead....”

“He'd wake up at three am and go out in the van, afraid that he'd made a mess of a boiler. But he would go off for a sharpner and that would be it...”

Looks away, out of the window.

“His body gave up in the end: his belly got all bloated, and they had him in with a tube to feed through the nose, they'd tell him to not play with it - but he'd forget within five minutes and pull it out.”

A sudden gush of valves, copper tubes filling, and the boiler comes to life; he pulls back, satisfied.

55. The cultural front

> *Well, we touched on humanity, all of us collected, and that was what was so powerful...what the purpose, um I ...The Older People's Commission, and it was Gweneira Rees, hey they were brilliant, because I'd done so much 3with them before they were out to support and they were, I tell you what, they worked bloody hard so we had, really we were given. I remember going and saying 'could we have Re-Live theatre?', because I'd only just seen them at Chapter, they said "yes we can do that", so open and receptive it was wonderful...that's what you saw, so what we did in that day is we brought in the Health Board, do you remember?... ...Someone from social services, from voluntary organisation, we brought them all in to be accountable really. What we did, I believe that day, is that we touched their humanity as well as their professional roles, and it really helped I believe to move some things* ***RD***

Memoria / Re-Live, November 2015, Brecon networking event. This started it all off.

Belonging / Re-Live , April 2017, Taliesin Arts centre, on the Singleton Campus, Swansea University – watched with student nurses, it's about how a North Walian, living in South Wales, develops dementia and loses ability to speak English, and the struggles for this family. Very moving, muted snuffles of audience, and I think about my own fate. **Do Not Go Gentle** / Everyman Theatre, Chapter Ars, Cardiff, September 2017 – Autralian/ Welsh production - dementia, disorientation and the South Pole, and Aled Singleton, friend and colleague, does part of the Q & A as trustee of Chapter. Earlier that year in the same venue: **Tinted Lens: A Festival of Mind, Memory and Ageing**, May 2017 **Y Tad [The Father**]/ Theatr Genedlaethol Cymru – at Sherman Theater, Cardiff, February 2018, Welsh language adaptation of Florian Zeller's play. A friend of mine acting in it: complicated, clever staging of disorientation. Somehow, somewhere Beckettian. I read Frantzen's **The Corrections** (Frantzen, 2002) at last. That father, his Parkinsonian struggle, hallucinatory fragmentation of mind, but much more, fantastic and moving. **Wy, chips a nain [Egg, chips and my gran]**/ Theatr Fran Wen, Chapter Arts Centre, Cardiff, a play for children about granny developing dementia. Missed out on getting tickets but heard good things. **Still Alice** (2014), watched at home, June, 2018. Hmm not sure and not convinced. I recall other Hollywood attempts at portraying cognitive disturbance: Eternal Sunshine of a Spotless Mind (2004), Memento (2000). Meet with Gwion

Hallam at a friend's wedding, May 2018; a poet (and tv producer, mostly….), he won the Crown at the National Eisteddfod, 2017, for a longish poem – **Trwy Ddrych/ Through a Mirror** – about getting to know somebody with dementia in a care home. It's playful and tender and poignant. He felt it had captured something, so did I. It reminded me of Rhiannon's words: *I would say that dementia is like a mirror, it's like a mirror on our society, how are and accepting are we of things that we perceive as being different form, in inverted commas, "the norm"? Umm it's a mirror of our communities again, how accepting are we of people in our own communities, who might need more understanding, more kindness, how accepting are we of that? Umm it also mirrors back to us.* I'd just interviewed, in April. Two biographies during 2019: I read **Somebody I Used to Know**, by Wendy Mitchell (Mitchell, 2018)- I then meet Wendy in Brecon in October, with Darla, for the launch of a new group for those with young onset dementias. Everybody there. She is delightful, we talk: my blog is my memory, typing is my memory, the whirlpool in York, nature never stops, dementia is about time, about enjoying the special now, dementia has brought a gift of friendship. Also, **Memory's Last Breath: Fieldnotes from my Dementia** (Saunders, 2018), recommended during the RGS conference, written by Gerda Saunders, an unflinching, thoughtful memoir, which – like Wendy's book – makes me feel that, we are now in the time of the long 'dementia boom', culturally, with all its ambivalences, reductions, distortions, but also spaces for alternative, 'critical counter-discourses'(Swinnen & Schweda, 2015, p.10), questioning our 'hypercognitive society' (Post, 2000). I re-write part of this section at the end of August, 2021, I pick up a Sunday newspaper, a review of seven recent films about, or related to dementia: **The Father** (Anthony Hopkins, Oscar-winning film), **Dick Johnson is Dead** on Netflix, **Relic** (a horror film, another genre-defying offshoot for dementia), **Falling**, **The Roads not Taken**, **Away from Her**, **Amour.**

56. On the bus, Swansea

We listened in on the conversation behind, a lovely sunny, cold morning in late October.

“they’ve just moved me onto Universal Credit, my ESA stopped last week…” pause “…so I’m skint, though I’m working” his voice got louder, stress levels. Oversized fluorescent jacket, thick dark hair and beard, late twenties.

The bus passed down the high street with its Escape Rooms, advice centres, Jesus is Alive posters, charity shops for every possible ailment and condition (including your dog’s ailments). Half the people have eyes down, on phones. As he got off, we looked at each other,

“Poor guy, he was so stressed” a kindly smile as she changed her glasses, the bus taking on more people on its way to the hospital which is a campus, a life-science hub and an old priory, all at once.

“don’t blame him, things are getting hard these days, I hear the same things all the time at the practice I go to. But everything’s so stretched, and the systems, well you’d think they’d have sorted them out by now, all this technology and I still have to go to one place for a blood test and another for the results” a slight rolling of the eyes, but the kindly smile remained, neat white hair, as she adjusted a pale blue fleece.

I agree with her.

“Sometimes they make us older one feel guilty for living, terrible thing” and the smile broadened as she invited a tut.

“Well, that’s terrible’ I tutted “people shouldn’t have to feel that way.” I said.

“Well, my poor sister is going through it at the moment, she’s 74, she had terrible trouble with her son, who was meant to be her carer, but he just took her money see. She’s got the early stages of dementia, but she won’t admit to it”

“Oh, has she……? I work with people who have dementia sometimes”

“Well it’s been rife in my family, both my parents, my cousin and now my sister, but she won’t hear none of it”

“One of the people I talk to says its life changing, not life ending, especially early on, there’s a lot of groups round here…..”

“But she won’t….. I go with her a few times a week, we go places and have a nice time, but then she forgets, and she’s having trouble getting her words out. It’s in the front part of the brain, I used to nurse many years ago.”

“Does she have friends? Keeping quite active with other people seems to help a lot of people I’ve got to know”

“Just neighbours really they all know about it…. I’d like her to phone more or text, she won’t touch facebook or things like that, that’s where I get my news these days and keep in with old friends. The thing with her son has been difficult, we’ve had to change the locks and things in the house. And because, even though she’d had a diagnosis, she doesn’t accept it, it makes it more difficult. We’ve got her a place in the day centre, a couple of times a week, all paid for, but she won’t go…”

A pause.

“…but that might be because that’s where mum used to go”

“Do you mind me asking, how old was your mum…?”

“Well she was 94 when she went, a good innings…dad was 86, both had it at the end mind…”

“Well, I hope she’s able to get out a bit more, there’s support out there….”

The bus sped along the beach side, low, golden shine of the sun picking out some skiffs in the bay, quite a scene. We both looked out at the shimmer of it all, the bus turning now toward the hospital campus.

“I’ve got my retinopathy today, so blurry vision time for a while” as if it was an easy thing. “and I’m waiting on a corneal transplant, they do a thousand per year here they say, amazing…” She smiles again, “Nice to talk”

“Well I hope you have a good day” I say, as she gets up to get off the bus.

57. Easter bunny

Figure 11: Cream egg bunny

Sometime in Spring 2018, my mother-in-law gave me this object: an Easter bunny made of flannel, rubber bands, stick-on plastic eyes, and a cream egg. She had brought it at a stall in the local village outside of Aberystwyth, a 17-year-old student was making them and selling them to raise money for a dementia charity. Her grandfather had the condition, and she was determined to help in some way, was the story told. To me, this object became somehow totemic as I pondered the forces at play here. Its materiality: an assemblage of cotton, plastic, rubber, cocoa, milk – and all the processes and geographies involved – but also the rhythms and energies of family, health, ageing, desperation, hope. Something 'altogether more lively and heterogenous' (Michael, 2012, p.167). As a 'a temporary and changing arrangement of multiple parts' (Coleman, 2018, p.62), it was soon eaten by my eight-year-old.

58. Car park

There was a slight kerfuffle at the checkout. She stood there patiently for a while her beige, a faint floral skirt and mauve raincoat. They'd put through the cleaning stuff, the couple of ready meals, the cans of lager, but the wispy bearded check out man was trying to figure out some savings for them; he'd spotted that the till hadn't registered some offer and had called his supervisor to work out how it went. She smiled faintly at him, tension at the edges of her mouth, the large transparent frames of her glasses accentuating the dark circles round her eyes.

"My husband will be along in a bit, he has the money for this"

She looked over, and nodded in the direction of the figure slowly coming towards her, behind the other cashiers, his gait unsteady but a headful of shiny thick white hair above smiling eyes,

"I'm here dear, sorry to keep you waiting"

Shoppers behind were drifting in an out of the queue, eyes beginning to glaze or harden, other immersed in phones, some watching, the early February murk outside making neon lights all the brighter. A song drifted in the background, not loud enough to drown out the child who had been screaming somewhere at the back of the store for ten minutes or so. He reached slowly into his pockets for an envelope full of notes.

The cashier, happy with helping out, smiled: “It’s ok, we’ve saved you some money” he said, “that’ll be twenty-seven pounds fifty”.

Reaching into the envelope, thirty pounds are carefully counted out. There’s a tremor there, the cashier sees it and is patient, others see it too, a woman looks away and tells her boy not to stare under her breath. He smiles, mumbles an apology to those behind them. Change given, he gets hold of the bags and carefully puts them in the trolley, on which he leans for some support, steering a course towards the door on well-worn heels, shoes which belong in some other era, frayed dark trousers falling over them from under his mac. She walks beside him, expressionless, yet holds his arm as they push the trolley towards a small yellow car.

Careful of their steps, this takes a few minutes.

And as she opens her car door, driver’s side, and he takes the shopping to the boot, she shouts

“You fucking old cunt, you useless piece, piss pot alcoholic you fucking shit, didn’t have a pot to piss in they told me not to marry you, I regret the very day, you old bastard what the hell do you think” she gets in the car, slams the door and keeps shouting, facing forward, spitting rage but somehow motionless, while he fills the boot, slowly, expressionless by now, then gets into the passenger seat, as if he hadn’t heard a thing.

59. Two conversations, sunny May morning

> *I mean when I go to speak publicly about dementia friendly communities, but in the back of my mind, what we’re really talking about is how to be good neighbours to people, that’s all it is.* ***EQ***

> *…a place is a story, and stories are geography, and empathy is first of all an act of imagination, a storyteller's art, and then a way of travelling from here to there. (Solnit, 2013, p.3)*

Awake for a couple of hours before getting up, the birds outside the window give a gentle call on the city breeze. An election morning, the drumbeat of Brexit somewhere in the distance. I have to get my bloods tested, routine, so post-coffee cycle over to the surgery for a date with the phlebotomist. A no-phone five-minute wait, the first of the day through the door, some in school uniforms, a screen with educational intent, health through walking, gardening, becoming expert on your own disease in 6-week programmes. Feeling stressed? (technically, I am) Then we can walk it out! Beatles pop up briefly somewhere behind my eyes as the adjoining pharmacy opens for the day's trade.

Called in, the sunny phlebotomist has a couple of students in, do I mind? Course not, a student myself for now I say. Strap goes on and I look away as she pats for veins. 'Sharp scratch' in it goes, but nothing flows out. "It usually ….' I say, and she reaches for another needle, 'Lets' try this one' "is that juicy enough?' I say, we laugh, I look away once more as the scratch strum of vein and metal settles into a red tubular flow.

So what do you study? I'm trying to finish a PhD looking at dementia friendly communities, I trail off, waiting to see whether this would be a lost gambit between the day's skin-pricks, but no, there's interest, 'oh we had some training with that a while ago, the woman explained that if you imagine the brain as a bunch of fairy lights, then dementia is a bit like those lights flickering and going off over time, or like a couple of bookshelves, intact but with the odd book falling off: there's still a lot there, and sometimes they're re-arranged….' She smiles, and I say "sounds like you had some Dementia Friends training…?" "Yes, that's what it was" "Did it help?" The other two students in the room pay attention: an actual conversation taking place. We can all learn something. We exchange factoids around different types, young onset needs; she has always had a kindly face, she's been at this surgery a while.

“It must be difficult taking blood from those affected…?”

“Yes, it can, usually they’re with carers, it’s getting them to understand that this is nothing bad happening…but we usually get there”. She smiles and I believe her, feeling the cotton wool and plaster, by now beneath denim.

May in a city near the sea is a great time for seagull shit. Great dollops pile on cars in crusty mottled splashes, and as he cycles home, a neighbour with a far grander car is doing the daily brush off. He stops to say hello and sympathise, and his neighbour frets and reminds me that this all eats into paintwork. ‘Not another thing to add to my daily list….’ He shrugs in mock horror, they chortle their ‘have a good day’ as he gets the bike through the door. The neighbour has a point, he thinks, and boils the kettle, fumbles for an old brush from the garage, a clear-out of its plenitude of accumulated crap perpetually on that list also.

As he scrubs and scrapes with boiling water, his kindly neighbour from across the road is out in front of her house, and comments politely on the excesses of the feathered residents of our street. They are forever sentinel on chimney stacks, clacking snail morsels on dormer rooves and ready to swoop on the slightest remnant from ripped recycling bags.

“What can we do?”

“Live with them I suppose”, she said

They shrug, and not having seen each other for a while, he asks, “how are you anyway…?” and crosses over, kettle and brush in hand.

“Oh…not bad” she glances back at her window. Silence is never empty.

“And how’s your husband?” he said. He has a warm smile, always friendly, always on his way to the temple at the end of the street, a red hat on his head whatever the weather. But he’d noticed something wasn’t quite right.

“Well, he had another heart attack a bit ago….” They look at each other; her bindi is that bond between them, her brow slightly furrowed, but she wants to talk. “He has all these tablets now, and of course there’s the dementia…they’re coming this morning to help with some forms”

“I thought that maybe he had something going on, I’m so sorry to hear this” he said. Pausing for a second, he said “I work with people with dementia sometimes”

“Ahhh, so you know…?”

“Well, I try to look at how this works in a community” he added. There is a moment of relief and of recognition, a shared ground, the possibilities understanding and empathy. He’d lived here for thirteen years, they’d always been friendly, their sons also live further down the street, have children the same age as his, show gentle care. They’d grown greyer together, petition by petition or in snatched conversations about the latest council ineptitude or greedy development, nimble around their nimby-ness, the great joys of Diwali, Halloween and Christmas marking the years here, festivals of light.

The kettle and brush are a bit awkward in his hands now. They carry on.

“They did some confusing things with his tablets, and we had to get the ambulance out. But he’s not bad” She looks over her shoulder at the window, and sure enough behind the vertical blinds standing, smiling and waving, is her husband. He then steps back from the window. “He needs to be with me all the time”

“It must be quite tiring” he said, “does he sleep at night?”. He thinks of others in similar predicaments, how the partner waking three or four times a night, but able to sleep during the day is a slow torture of care and patience.

“He’s not bad….” She looks over her shoulder again, but he’s gone “there’s a lady coming today to help with the forms for a wheelchair, he can’t walk that far, and we need to get some air, get out of the house. My sons are good, but still I need to go places with him”

“Is she from the Alzheimer’s Society?”

“Yes, I think so. These days, we go to the temple and as we have to separate, men and women, he doesn’t like it, so Sanjay has to come more often. But we still go”

“It’s important” He said, trying not to sound like he knew it all, but eager to reassure “from what I see, keep all those social things going, for both of you, but that you also have time for yourself”

The kettle getting heavier, they smiled at each other.

“Oh I’m lucky” she said “the family, the temple, it’s all very near. But going back to India will be difficult this year, we’ll go for less…but when he’s there, he remembers everything, my sons will help I know, but it’ll have to be for less. When we go to the garden, both here and there, he used to just do things with me, but now he asks me to tell him what to do. He watches more. But we still enjoy this together”

There’s a pause, but no sadness; above them, seagulls stand and wait.

60. Waiting for the 10.04

Figure 12: On an adventure before dementia

Get into the station, buy ticket, get coffee, sip, slurp, look up at the board, a bright morning. Head craned, I hear someone sighing a long sigh next to me. She says out loud:

“They just cancelled the London train, can’t for the life of me understand when the next one is….”

Unsure of whether this was directed to me or to herself, I volunteered:

“There should be one soon” We were both wearing Ray-Bans, mine smudged so I hooked them up to have a clearer view of the board. Truth be told, it was a bit confusing, and the words ‘Service Cancelled’ always seem to be rather cruel and final when applied to train travel. “Why don’t you ask him over there?” I nodded towards one of the ticket inspectors.

Off she went as I tried to find my own train, platform still not up. She came back.

“That’s A BIT better. It’s crazy – they cancelled the 9.47, there’s none for another hour.... but I bet my reservation will be worth NOTHING on that one” she bristled.

“Sure, there’ll be plenty of room this time of day, though I’m heading the other direction” I volunteered. Unsure whether she wanted to maintain the exchange I try quipping away her unease “Don’t worry, pretty soon they’ll track us all so well…” I held up my phone “..we won’t have to worry about a thing, you’ll be told everything before it happens…”

“You mean like one of those” she gestured to her ankle, which didn’t have a tag on it – it would have been kind of unexpected if she had - but at least we’d understood each other, phew.

“Well we carry these around all the time” I said, gesturing to the phone “it already tells me what to do almost to the minute these days, if I were to let it...”

“Well I’m just waiting for my dementia to kick in” she said lightly, “that’ll be great”

Hmm. “Do you mind me asking, what do you mean? I’m a researcher interested in dementia, it kind of intrigues me why people might say that.”

Through the sunglasses, I felt the gaze sharpening.

“Look I’m seventy” she said, raising her glasses momentarily, a slight pause “and this is the bit where you’re meant to look at me in disbelief…” She smiled thinly and put her glasses back down “…. honestly, it’s just that my family lives far away, and that aspect of Big Brother is fine by me, wouldn’t want to be found naked on Queen St now, would I? It’d be good to know my family can track me.”

There was another pause as we looked at each other, one that I decided not to fill with any comment.

“My first husband died quite young…. you see, I was left looking after his mother, who had dementia, and she used to escape in her nightie, you know how they can get, they go wandering about…. I just wouldn’t want to be that vulnerable, it was difficult…”

She trailed off in fleeting memory, snapped back. We both had glasses down by now, could feel the moment slipping away. We looked up at the boards again, my platform there by now.

“Hey, take care, hope you have a good journey” I said.

She’d half turned, distracted, by then. “You too.”

61. Cut-Up: ‘Resilient Boiler’

In this cut-up, there are two radically different perspectives/texts where I take one of the fictocritical anecdotes in this section (Boiler Resilience) - a personal story about a particular type of (usually) alcohol-related dementia - and fold it into another short official text from the Well-being of Future Generations Act, one of the official, national ‘well-being’ goals. (Future Generations Commissioner, 2015, p. 4)

From Well-being of Future Generations Act (2015):

Support social, economic and ecological resilience and the capacity to adapt to change (for example climate change). A society in which people’s physical and mental well-being is maximised and in which choices and behaviours that benefit future health are understood. A society that enables people to fulfil their potential no matter what their background or circumstances (including their socio-economic background and circumstances). Attractive, viable, safe and well- connected communities. A society that promotes and protects culture, heritage and the Welsh language, and which encourages people to participate in the arts, and sports and recreation. A nation which, when doing anything to improve the economic, social, environmental and cultural well-being of Wales, takes account of whether doing such a thing may make a positive contribution to global well-being.

Cut up:

Resilient Boiler

Future health understood. A people to participate in the arts choose, these days!

Sips tea, connected communities.

A society that ….

Korasakoff's

"he didn't their background or circumstances for twenty years, but he had think he was an alcoholic 'he improve the economic, social, the area, people we'd known since, which when doing anything to (including their socio-economic,

attractive, viable, safe and well- play with it

– but he'd forget within culture, heritage and the Welsh dead….

He'd wake up at three am, environmental and cultural

His body gave up in the end: his fetches Phillips.

'My business, well-being of Wales, takes account of their potential no matter what'

He would go off for a sharpner, physical and mental. He'd made a mess of a boiler. But partner, had been off the booze. Climate change. A society in which well-being is maximised and in which enables people to belly got all bloated, and they had whether doing such a thing may. Working on the boiler, looking up, him in with a tube to feed through and sport and recreation.

A nation questions about the old boys.

From sudden gush of valves copper and go out in the van, afraid that that promotes, and protects over his moustache.

“I pick ecological resilience and capacity, actually got involved with AA, make a positive contribution to tubes filling ….”

and the boiler comes to background and circumstances, global well-being.

The head, sad smile, looks over. ‘The nose, they’d tell him not to and that would be it…’

Looks away.

‘Life;’ he pulls back, satisfied. Adapt to change - for example only drank beer”.

Slight shake of support social,

economic choices and behaviours that benefit, we were kids

– but they were all five minutes and pull it out.

Language, which encourages, but he would be asking the same.

62. Third touchstone

> *Land, labour, and history. It can be cold standing there. The winds sweep those ridges. You go back down into the settled valleys, with their medley of map names. Different views, different lives. But occasionally, laying your right hand, palm downward, on the deep layered sandstone, you know a whole intricate, distinct place. The Black Mountains. Ewyas. (Williams, 1981, p.222)*
>
> *With DFCs, we're looking at a phase two now aren't we, or even a phase three…the recent events that we've done are about 'what's next?' for DFCs, they've done the black mats and the cheap window sticker stuff but now they are involved, they're asking bigger wider questions.* SH

In a sense, it was all over by the time I got there. This touchtone could be described as largely about the aftermath of Dementia Friendly Communities in my main case study, Brecon, as I chose to spend time with one of the main achievements of that earlier phase, the establishment of a Meeting Centre. Of all the stories here, it is the one of which I find myself part of the most, spending a lot of time going up and down the A470 from Cardiff over the years, often relishing my time there, which was always worthwhile, even on the most routine of visits. Around this touchtone, I've arranged strolls around Brecon, some dancing in daylight, smells, sounds and glimpses of community in the name of dementia. In accordance with my growing interest in non-representational methods, it was the work of being beside Brecon, its place and people which gave me the opportunity to think and feel my way around the *tylwyth teg*. McCormack (2008) makes the following point that:

> *Humans do not always consciously reflect upon external representations – signs, symbols, etc – when they make sense of the world; that thinking does not necessarily involve the internal manipulation of picture-like representations; that intelligence is a distributed and relational process, in which a range of actors (bodies, texts, devices, objects) are lively participants (p. 1824)*

This touchstone perhaps more than any other tries to give the sense of a key piece of learning in this thesis overall: the distributed and relational *process* which can be found in the everyday, in movement, embodiment, in events that are ongoing and, in a sense, never-ending. There are several stories to be to be told here of a place where ‘the politics seems mobile, fluid and dynamic’ (Dean & Villadsen, 2016, p.45), where the aftermath forks off in different directions with different people.

Even if some ‘endings’ are portrayed in this section, by interacting with this text in this moment, the process continues anew, will hopefully spark. This has also led me to think about how the Meeting Centres, which bring together and create ‘community’, can help us to re-think the idea of ‘selfhood’. Taylor (2008), in considering her own mother who had dementia, concluded that 'selfhood' is distributed among networks, sustained by supportive environments, emergent within practices of care’ (p.326).

63. Border country, finding Brecon

Figure 13: Food truck, near Pen y Fan

> *At the top, you shift down a gear as you pass the youth hostel, the road bends and the light changes, with Pen-y-fan with its snaking multitudes of part-time hikers and military men receding in the mirror behind your right shoulder, the layby full of motorbikes come into view at the bend- a sullen tribe in colourful leathers eating fast food - but before you, a region, a plain, flat land which bends light differently, looking out onto the Marcher lands and beyond. The incline is slight as you descend. Sometimes I stop to take a look, find a spot among the immaculate bikes of that generation just before mine; this route is so familiar it’s easy to forget, to not notice this shift. Post-industry, the Valleys, other types of living, the bareness of long-ago stripped forests – these lie behind and to the west of you now, and as you reach the*

> *level, going up through gears, there's a different greenery, a flat patchwork of farming, farmsteads, market towns and national parks ahead.* ***Fieldnote 5.9.17***

To reach Brecon, I take a familiar drive north of Cardiff, the A470. This road begins within a mile of my home in Cardiff, and ends, 130 miles later, in Llandudno, at the top of the Conwy Valley, where I was brought up, where my father still lives. On it, you trace a crooked spine through Wales, ticking off a stage at a time: Merthyr, Brecon, Builth, Rhayader, Llanidloes, Commins Coch, Dolgellau, Blaenau Ffestiniog, or branch off to Aberystwyth, Porthmadog, roughly five hours of mountains, farmland, forests, watersheds, lakes and changing light, varying degrees of patient concentration while driving, depending on weather, each stage of the journey a scene, a shift in bio-regionality, accents, dialects, shading of the stone, vernacular dwelling, county boundaries, bilingual signage, *communities*. But reaching Brecon, in my internal cartography of Wales, represents a first step from home, roughly time enough to listen to Ziggy Stardust and the Spiders from Mars (with bonus tracks, currently my son's favourite) on the CD player, beyond the Beacons hump and the quick, dual-carriageway post-industry of Pontypridd, Merthyr, which often seem darker, occasionally glum. But even on a dark day in winter, getting past that bend near the youth hostel marks the beginning of a new regional territory, 'an edgy composite of trees and grasses, barns and steeples, commons, colors, noumena, haircuts, performed socialites…a robustness in cold weather, a hyperactive sense of practicality' (Stewart, 2013, p.281). To the East, borderlands with England, edged by the Black Mountains.

64. A backstory

Figure 14: Medical practice options

'Canmol dy fro a thrig yno' ('Praise your area and dwell there')

Brecon Town Motto

A: do you think there's a failure of politics, going on here?

R: yes I do, I think that we have... one of the big things when we first set up Brecon Dementia Friendly community I would always say that this is about doing things with people not for them, ok, so by doing things with them we actually see what is needed... I think that we have um um some people have devolved...community within to do with government whatever 'we just see it as over there, and we're here, and the two are separate', we've forgotten somehow, that actually, we're all part of that together, so we have to take responsibility, we have to take responsibility for vote, to take responsibility to find out what it is that we feel strongly about that we need to look for...and I think that we've become, some of us have become quite complacent with it

A: It's almost as if ....

R:... and de-motivated, and so, so how do you motivate people, to become more involved, then? And that's the key to it really, how do you motivate people to take more responsibility...people get...we feel as if... we feel as

> though it's our....that we can't that we can't affect the status quo, that it's always going to be done for us, and that's not right...**RD**
>
> *Went to a meeting intending just to suss it out, next thing you know, you're co-chair, you know the way it is....*JB

In June 2013, a group of like-minded individuals, with Brecon Town Council and Alzheimer's Society Cymru, held a public meeting which explored the idea of making Brecon a 'dementia-friendly community'. Rhiannon Davies was one of the instigators, someone who had trained as a pharmacist but had worked both at a strategic level in the local health board and also had a background in working with a large, successful art-based regeneration scheme based in the nearby Valleys, back in the early 90s, arguably around the time 'a new multiplicity of territorialities around the notion of community were coming into view' (Dean & Villadsen, 2016, p.33). This was a time when the lines between public and private investment, civil society in the shape of the South East Wales Arts Association, and community based action on regenerating the post-industrial areas was a concern for pre-devolution, central Government (Welsh Government, 2016, p.19). This had meant setting up and funding the type of arts centre that had been the venue for the dementia consultation, for example: Rhiannon remembered being involved in such schemes, and I met people during fieldwork who knew her from this period.

But it was her background as a pharmacist working for Public Health Wales, reading the Bannerjee Report (Bannerjee, 2009) - which stated quite bluntly that thousands of people with dementia were dying early because of the use of anti-psychotic drugs in care homes – which had been a real call to action for her, as she'd helped to implement the reduction of their use. The recommendations from that report were clear: early diagnosis, support and training for carers in the community, giving people options about their own care, raising awareness (p.53-54), all these measures would reduce or delay the need for such medication. By her own admission, this was a lightbulb moment. Beyond the general raising of awareness through something like Dementia Friends, and a sense of some higher calling which she gave when we sat down to talk, these basic ideas around care and inclusion were what seemed to motivate Rhiannon most of all. By hook and crook, she and her friend had got themselves onto Dementia Champions training in London (because the scheme wasn't available in Wales, they'd had to give a London address to get onto it):

> *I was in a fortunate position where I had had some experience where I could see the gaps that I found really difficult to reconcile within the support that was being offered and there was a lot of talk, very little action, certainly from the statutory bodies and I just felt that we needed, I needed to come outside because I worked with the health board that time and I needed to come out and we would actually find another way of pushing from the outside*

Before starting the PhD, I had seen her talk in public numerous times in different venues across Wales about setting up BADDFC, as part of a 'roadshow' for Dementia Supportive Communities, sponsored by the Older People's Commissioner. By that point, she had given up her job working for the local health board to concentrate on developing Dementia Friendly Brecon, 'a calling' she said. A community-led steering group was formed, made up of carers, committed individuals, health and social care professionals and a range of other community and voluntary organisations, which was eventually constituted as a not-for-profit organisation by April 2014. This enabled them to enrol members and raise funds. They also established a local Brecon Dementia Action Alliance bringing together regional and local members to improve the lives of people with dementia. This included Brecon Medical Practice, Powys Health Board, Brecon Library Service, Dyfed-Powys Police, Brecon Mountain Rescue, Brecon Beacons National Park Authority, the local Fire Service, Barclays Bank, Lloyds Bank, a local mental health charity (Mind) and Brecon Theatre.

> *R: yes, motivation and I believe intention is really important for what you put into action… during early 2013 there was a lot of going out and speaking to people bringing together kind of action groups creating a constitution and a vision statement. What then happened was I think that this ireally started the ball rolling, was that in June 2013 we had the public meeting, and that was at the Guildhall and we invited the man who'd inspired me from the Alzheimer's Society someone called Ian Jones speaking about setting up a dementia friendly... We invited him to come and speak at the Guildhall and we also invited some carers, local carers, to speak about what difference it would make to them for it to become a dementia friendly community. So that was a public meeting and it was there that we had*

> *about 60 people who came, representatives from the medical practice fire station Health Board loads of people came, and it was that then really that was the catalyst to be able to uuumm eh involved people in what they could do and set up for dementia friends champion training. So there was a lot of work going on in between to deal with lobbying networking, I was going out and finding out about good working practice, I was trying to bring that back so hints and tips, all this type of thing, so I was out there in other places, just like a little squirrel picking stuff up 'that was good, that was good' , so bringing it all back, so it was finding those examples, so then it was April and July we did the first dementia friends champion training and so by that time we built the relationship with the Alzheimer's Society, then a year later, exactly to the day we had an official launch of dementia friendly Brecon, and that...er...what....er... What we did then was involve those who had become dementia friends champions before and were now in their different organisations and agencies doing dementia friends, we invited them to speak about the benefits it had had for their area of work or whatever, so they were kind of like the pioneers, those people, they then spoke about the benefits of becoming dementia friendly organisations, and that then encouraged others to get involved, so it was putting in those building blocks.*

My first visits to Brecon in my capacity as researcher, albeit on a different project, were the ones which fired my imagination about DFCs and what was going on, and I witnessed what was already quite a well-established set up. What Rhiannon and others had created felt, from that first day when I heard “we’re all in this together”, like a well-organised, established, professional operation, which brought together some of the skills which Rhiannon could bring from other projects:

> *all of us encouraging and supporting each other and showing what was possible, and I think one of the reasons why it did so well was because we were absolutely really tight about it, so visually we had logos, we had pictures, we really we had a very good visual Impact, and we were consistent and we were professional, [...] , and there was a lot of heart in there, a lot of heart*

If there has been a high water point for DFCs on a policy level, then arguably it was in this period, just prior to work on this thesis.

In another interview, Donna, one of the volunteers, recounted how, as one of the first volunteers for BADDFC and subsequently the Meeting Centres, Dementia Friends training, the main strategy for creating DFCs offered by the Alzheimer's Society was rolled out locally:

> *Rhiannon and Joan - having instigated the need to bring dementia champion training to Brecon [the first such training in Wales] ...there were probably about sixteen in the room. I came from a training background [as a former Metropolitan Police trainer],so to me this was absolutely simple, they just said right this is the input, what we need you to do now is to plan the lesson and redirect it back to us, and of course it was like bread and butter [laugh], so I just went, 'right I'll do it like this' , whacked back a lesson and they went 'ohhhh...you can teach can you...? So yeah, from there on in…*

The practice where she works is the only one in Brecon and for the surrounding area, with around 20,000 patients on the books*: just to raise that awareness… Rhiannon and I often ran sessions here at lunch time, which was just raising the profile again for the GPs.*

The ripple effect of this activity was what then could build up a kind of critical mass, though Rhiannon and Donna, through their networks, were able to influence within their own organisations:

> *right from the word go because they then became champions and they went back, so the policeman who was quite high up in the police force went back and did dementia friends champions...uhh friends sessions, so he was raising awareness, the fire, fire people were raising awareness, so what happened was it was sending out the word which was what was... And what I thought was really really important, what we had was we then had about 14 dementia friends champions who could go out and run these sessions and who absolutely could influence that change*
>
> *Yeah, a critical mass really, and it was about building partnerships and it was about creating the networks as well, so we all began to link in with each other. Then, it was bringing people together but also bringing organisations together with a common purpose, and it wasn't difficult to do, we were pushing against an open door really because there were so many people who had relatives, or family members or knew someone…*

The accounts of Rhiannon, Joan, Donna and Steve tell a very similar story from this period of rapid growth in awareness and activity around Brecon. When Rhiannon stood up to say 'we're all in this together' at the networking day organised with Steve and others from the OPC, the one that initially got my interest, pre-PhD, everything had been carefully engineered to *find another way of pushing from the outside*, including the lived-experience theatre performance:

> *The Older People's Commission… were brilliant, because I'd done so much with them before they were out to support and they were, I tell you what, they worked bloody hard so we had, really we were given...[A: I was with Steve Huxton yesterday...], I remember going and saying 'could we have Re-Live theatre?', because I'd only just seen them at Chapter, they said "yes we can do that", so open and receptive it was wonderful...that's what you saw, so what we did in that day is we brought in the Health Board, do you remember?... ...Someone from social services, from voluntary organisation, we brought them all in to be accountable really. What we did, I believe that day, is that we touched their humanity as well as their professional roles, and it really helped, I believe, to move some things…*

Between that meeting and starting the work for this thesis, I was invited to other meetings by Rhiannon and Joan, kept in touch. One was at a school where the assembled local services were given a detailed plan of what the next steps would be the establishment of a Meeting Centre in Brecon. Some thirty or more people turned up, representatives of all sectors locally, people with dementias and their carers, CPNs, faces which I was now becoming familiar with, and to whom Rhiannon introduced me when she had the time.

65. Collage: Odds and Ends

Figure 15: Collage - Odds and Ends

Burroughs passed through this space, which I've grown to know well, in 1960. Over two years, I took several pictures of that particular corner, between Bethel Square and the Guild Hall. This was the original line of flight which led me into thinking about how we create knowledge about phenomena such as dementia, and that knowledge is often elusive, but sometimes may be found in the odds and ends of the research process. Anne Carson's words: "Corners are what make a grid different from a line, a plaid shirt different to a striped one…corners make personality out of persons, maps out of surveillance" (The Graduate Centre, 2018). My interaction with the picture of Burroughs, and immersion in research around DFCs – a kind of surveillance of meetings, events, spaces - creates a map of diverse objects: newspaper headlines, postcards used in DFC meetings which say 'I want to speak please', noticeboards as readymade fragments of voluntary civic action, or moving through the surrounding landscape of the Brecon Beacons. Each element has a story of repetition, difference, disorientation at times: we can all feel these states. Perhaps this corner of Brecon, this portal to a square is an invitation into thinking about different ways of being with dementia, of living with change in physical and mental spaces over time, as community ebbs and flows through us.

66. Tea towel micropolitics

Figure 16: Guild hall

> *That we're all in it together...many a time I've said you know, we're all in it together, it doesn't matter how big or little the thing that you do, every contribution is part of it, some of us are called on to, you know, do bigger tasks perhaps...but it's no less important when someone does something else, it's all part of the whole* RD

> *Sitting here, a sense of old power and connection drips from the old portraits on the walls, gold heavy wood, stuccoed ceilings, heavy dark curtains which makes the late afternoon light cling and clash with the artificial fluorescent inside, picks up a warm glow in the golden strips, the polished wood. All in good repair, well-painted & maintained, the solidity of the chairs and the square tables, a small kitchen to the side. Trade & twinning – flags and ships and old stern-eyed burgher types – Gouesnou in Brittany, Saline, Michigan, Weert in the Netherlands – but what stories here to be told? So far, cups of tea and some tension at times*. **Fieldnote, 13.2.17**

To set up a Meeting Centre, there are steps to follow, things to do (Brooker, Evans et al, 2017). Having had the open meeting with as many community partners as possible, BADDFC set up the Initiative Group, one of the first stages on the road to establishing a Meeting Centre, to which I was invited as an observer. I ended up going to about six such meetings. Two centres had already been set up over just over the border in Leominster and Droitwich, under the guidance of the University of Worcester, as part of an international research project to test the viability of the scheme, and during these months I also attended the launch of the evaluation report for that project at Worcester University. This was a period when Rhiannon described as:

> *there was a lot of work going on in between dealing with lobbying and networking, I was going out and finding out about good working practice, trying to bring that back so hints and tips, all this type of thing, so I was out there in other places, just like a little squirrel picking stuff up*

There were many plans deliberated and put in place during this period, including establishing Dementia Matters in Powys, an important step which meant that Rhiannon and others had ambitions beyond Brecon, but was also the vehicle for a Big Lottery bid to fund the Meeting Centres – there had already been meeting with the Lottery to discuss these possibilities, which had gone well. In contrast to many of the other meetings and events that I attended during fieldwork, these were more straightforwardly about the nuts and bolts of what was being created in part because of the *tylwyth teg*. These were also the least confessional of meetings – though there were stories, they did not have that confessional element which so many other meetings either produced or even demanded.

Usually, it was a group of about between six and twelve that people that turned up for each meeting. Having been invited by the Mayoress of Brecon to hold the meetings in the Town Council chambers, we sat in the grand Guild Hall, which had been used for some 700 years for similar purposes. I would come across a similar space in Leominster, about eighteen months later, Grange Court, with a shared history of the same architect (John Abel) dating back to the 1620s, at another DFC networking event just over the border. To the side of Bethel Square, the Guild Hall space spoke of order, solidity, steady progress, historical time, but here again, as in other situations looking for the *tylwyth teg*, how would 'sense and significance emerge from such ongoing practical action' (Anderson & Harrison, 2010, p. 23)?

In a situation which seemed inherently relational and fluid, as things were busily being set up and put into action, what could be felt in that space, in each event?

There was some coming and going in the group, but it drifted with purpose because Rhiannon and Joan determined the pace of things. As always in something that depends on volunteers, not everybody could attend every time, but everything was minuted and distributed in advance, the serious routine of progress being ordered that echoes through most organisations. On this scale and in this period, this order and optimism spoke of new beginnings, energy; at the time, it was in dire contrast to my other involvements, as the precarity of charity I was involved with lurched from meeting to meeting, no matter how well minuted. I felt relieved not to be chairing, just observing in this taking-place of events, though when asked I contributed and always introduced myself, and told them what I was doing there.

Besides Rhiannon and Joan, I'd got to know some of the others through other events: Dave, the social worker turned up to a couple, Donna from the local medical practice, other voluntary organisations large and small, some councillors, including the mayoress, and those who were carers or living with dementia. This was, to an extent, the epitome of one sort of active citizenship in dementia matters (Birt et al, 2017) albeit less contestable or paradoxical than some other examples seen (eg The Consultation): the lines into local town politics were clear through the easy inclusion of the mayoress, and there was representation by carers and PWD in most meetings. Even so, the formula for setting up the centre was modified quite quickly, when it became apparent that even in Brecon, it would be difficult to set up the required sub-committees.

If 'events bring forth drama and conflict, uncertainties and ways of thinking, subjectivities, differences, and repetitions' (Vannini, 2015, p18), then in a minor way, these meetings brought many of the underlying issues that might accompany such practical action to the fore, the micropolitical rubbing itself into the emergence of something new. In my fieldnotes, I jotted down how at times there was a crackling of tensions in the air, often focussed on funding, on wordings and definitions, of what could be done, on support offered, then taken away or limited. In particular, the contingent nature of dementia itself, how it’s defined, was a recurring theme with very practical consequences: the Alzheimer’s Society would not admit anybody to their local group (Tea & Chat) who didn’t have clear diagnosis of dementia, for example, and yet because it took on average twelve months (or more) to get such a diagnosis locally, this meant that lots of people who had all the symptoms of memory loss, beyond ‘mild cognitive impairment’, had nowhere to go. This recalled another form of contestable biological citizenship: a struggle over identity, demands for recognition, access to knowledge and claims to expertise (Heath et al., 2007), a diagnostic and interpretive gaze setting out boundaries which was literally dividing people, when the tenor of the Meeting Centre was to unify.

Many of those present questioned this, as it was a gap in services in part brought about because they were overstretched, austerity cuts biting. I noted how the language used by the person there from the Society, increasingly getting involved in service provision for other local authorities in South Wales, seemed heavy-handed to some, with eyebrows raised when bald statements around ‘withdrawing funding if such and such happens, legally it would be against our charity rules’. At times it felt like different languages being spoken: the professionalised voluntary sector talk of outcomes and legalese, while many in the room were looking to simply set up supportive networks without the formalised bureaucracy (at one point, Rhiannon interjected, mischievously perhaps: *In council and health speak, it’s called early interventions…we’re going to call it early opportunities…*). Minutes were queried, irritations expressed or muttered under the breath.

This tension was compounded when it emerged that the Alzheimer’s Society was only partly helping the Meeting Centres project in Leominster for a very short time, or that they didn’t offer the same services in Brecon that they did elsewhere, even though the need was pressing and so much work had been done to raise awareness. Yet here they were, a presence on the Initiative Group. Dave also gently reminded the group of how the local authority was looking to cut provision further locally for those with dementia, with talk of closing a local day centre – there would be great interest in how the Meeting Centre model could make up for this, the implication being that responsibility for such services could be devolved to civil society groups such as this one.

However, there was also genuine progress made in working out the next steps for DFC, how a Meeting Centre in particular might sit well on top of the work already achieved: the awareness raised in banks, shops, the workings of the medical practice. Throughout, as if by quiet magic, cups of tea and coffee, home-made cakes would appear, and as discussions continued, Rhiannon smiling, chitting things along. I realised that I was beginning to get my hands dirty, literally, and that there was no other way. By the fourth meeting, I was helping with the washing up, taking orders for cups of tea: within me, I could feel how any macropolitical critique I was carrying would have to give way to something more immanent and participatory, micropolitical, to 'engage[] becoming, rather than judging what is' (Massumi, 2015, p 71). Rhiannon, in a later interview looked back on this period:

> *that's got to be the starting point for any [...] initiative really, it's motivations and intentions, and you ought to check that in yourself also, actually, it's worth...I mean it's all about the respect of individuals as well, its, well there are all those things which we could talk about, but actually it's 'can you live it'...can you? You know we all know the theory, we've all got the theory, but it's how you put that theory into practice, and that's why that mirror is so important, that mirror is so good because you look at it and you think, actually, what was that, where was I really coming from there?*
>
> *The other thing I feel really strongly about as well is that with, I needed to say with activities, one of the things is that sometimes we've become um competitive, in "I do this" "you do that" and "I'll talk to you" and we all look as if we're doing things but actually...that's a nonsense, we have to learn how to listen and to feel each other, really feel each other and find a way of working together, so it's not separate, because everything impacts on everything else and it's one of the things that I think is quite a test for Brecon as three [new?] initiatives have come to the fore, so we've got Tea & Chat and ...etc*
>
> *I think... our challenge is to make that all part of a whole, to make it all part of ..so that actually those who are involved with it are actually communicating well with each other, and it's inevitable that when you're first setting something up that you're a bit nervous, a bit tentative, but the reality of it is ....we...I suppose it's having the intention to begin with that*

> *you recognise that we need to be working all together to make things happen*

By the last couple of meetings in the Guild Hall, funding acquired, the new ‘opportunities officer’ for Meeting Centres, Yvie, was in place: she had worked for over a year setting up the Leominster centre, had a many years of community development experience, but lived locally. There was an immediate sense of someone who had a plan, could move things quietly, but was utterly dedicated to a vision of inclusion, and how that could manifest itself – she introduced herself with a poem (George & DMiP, 2018). There was still some tension there, in those meetings; a further rift, more fundamental, about whether the Meeting Centre should find a permanent home, become a ‘one-stop shop’ or ‘drop-in centre’, not just hire out community buildings. Even if there was a lot of activity going on around intergenerational work, student placements from local colleges to help out, the possibilities of integrating a lot of support and advice in the Meeting Centre practice, this became a recurring debate, on in which slow division sprang up between the founders of BADFFC. Washing up with Yvie, clearing the cups, she smiled at me: *this is just tea towel politics, it’ll pass.*

67. Brecon Stroller I: A stroll around the market

Figure 17: Notice boards

> *I am not unfamiliar with this place, I've circled around and wandered through, on my Brecon strolls and stayed at the entrance to peer in and take photos in the cold and on those days when the smell of the butcher then the fishmonger is what hits when you get close to the hall but also the ghosts of nights from many years ago, blurry August nights of Courtney Pine or some other jazz-based music, Giles Peterson once with my brother taking a selfie before they were selfies, dancing perhaps & finding some tipsy end of night groove, but in the day it feels like the off centre centre of market town, ancient enough but maybe not quite & clad in darkening stone & where all the activities of such a place are distilled not least in with town cryer jumble of paper & notice at the entrance.* ***Fieldnote, 26.6.18***

While thinking about community and what it might mean in Brecon, I have built up a collection of noticeboard photos, taken around the market town over the years I've been strolling about between meetings and interviews, trying to take things in. Despite the sometimes dull march of digitization, and the encroachment of its twittering symbols and fonts, physical noticeboards would seem to be a natural place to get some feeling for the nervous system of this market and garrison town, the background hum of lives (Anderson & Harrison, 2010): there are many of them, and they are crammed with the activity, the movements of the vicinity, patchworks of paper and contacts dotted around. A riot of fonts, photos and paper types proclaim yoga classes, militaria collectors fairs (of which more later), dial-a-rides, sound baths (see other fragment), but also choirs, county shows, dog walkers, Pilates, circus skills, historical experiences ('if gravestones could talk'), taxis, Buddhist meditation, bowls, folk clubs, slimming worlds, car boots of all description, foster carers, help with abusive relationships, councillor drop-in sessions, counsellor drop-in session, adventurers for hire, assisted living providers, life drawing, credit unions, air guitar competitions, sheep shear sharpening, pictures of feet with the promise of reflexology lymph drainage, or several offers of talking balms for troubled mental states. All put up and about, and updated from time to time by individuals, organisations of all sizes, groups, official bodies. Ready-made cut-ups, if read in a certain way, brick-à-brack bricolage. See figure 22.

But to get to the Market Hall notice board in particular, you can take several routes, though generally walking up from the river or away from the centre of town, past the guildhall and the banks, you will get you there. These panels in the entrance run the whole gamut, with ample space to do so in the long entrance into the cavernous space within, and this may well contribute to its sheer variety. Some, such as the Rotary, The Lions International Club ('Formed in 1917, the Premier Volunteer Service Organisation, with over one and a half million members worldwide') or the local hospice, have a more enhanced presence, protective wooden cabinet surrounds even - but then the Rotary has its own 'well' for donations in the nearby Bethel Square also, behind the Guild Hall. Once this became a fixed part of my method, then, I would notice just how many of these boards there were in supermarkets, the library, even coffee shops, and occasionally take a snap. The re-organisation of the local Co-op to take in more postal services meant the loss of one, but I've reasoned that if such a thing as local community exits in such places, then surely these physical boards reflect, in part, it's sinewy health. My group of people affected by dementia were a regular presence here also, among the fluttering leaves of information: Dementia Friendly Brecon, Dementia Matters in Powys, the Meeting Centre and latterly, the Like-Minded group, with a more substantial stand in the library.

However, on one particular day in June, post-interview with one of the volunteers and stalwarts of many of these dementia matters in Brecon, my feet took me beyond the collage of notices outside, and I found myself entering the market with a stereo recorder in hand to take a take a loop around the stands, with a vague idea of trying to find out if there was more to be said about community, by trying to listen differently - listening being one of the pillars of our 'methods' of course, but very often reduced to 'interviews' (which I had just completed). Twisting slightly here between what has become standard kit – the slight, discrete, apologetic mp3 recorder - and a larger machine with a shiny stereo microphone head, my intention was to paradoxically make the gadget invisible by giving it more visibility, maybe one of the few bonuses of living in an interview society (Atkinson & Silverman, 1997), with the ubiquity of such formats. Most of my fieldnotes do not rely on gadgets – surveys, recording, even the photos – rather trying my best 'to look at people, listen to them, think and feel with them, talk with them rather than at them', (Polsky, 1967) so this was trying to have, metaphorically, my methodological cake and eating it.

This impromptu sound walk seemed to be a way of observing or listening to some of the everyday in a space which had been occupied as a place of exchange, commerce and life for many hundreds of years (if not more). Though a recording was produced, it is neither a sound*scape* nor a collection 'interviews': though some of the words are 'fixed' (especially through their writing into script here) each listening - distracted by the plop of an Amazon parcel here, the yelps of pet chihuahuas there, as I write this - speaks mainly of my keenness to build an inventory of phenomenon to think about when thinking about Brecon. Listening again is also more phenomenon in this sense, and on another day one I might notice something else, but there is movement: the sounds flow 'along irregular, winding paths, and the places it describes are like eddies, formed by a circular movement *around* rather than a fixed location *within*' (Ingold, 2011, p 139). Tentatively, maybe in these eddies as described –

including the speech, and much as with the ragbag layers of leaflets - we find points of community, connection, even conviviality.

But apart from the interesting hum of sound, music, footsteps, not too busy that day, I did manage to talk to some stall holders after introducing myself and being open about what I was doing, which didn't seem to be a problem. Playing the twenty-five minutes or so of this loop back, it also still evokes some of the pleasure to be had in creating such opportunities, of engaging with 'the surface of sonic vitality' (Back, 2012, p.251). As a stereo recording, it's possible to feel the changes in space or pick up clanking, floating steps towards and away from things, or with repeated listening, wake up in the middle of the night with an earworm full of Kate Bush's wintery take on Slavic life from the mid-eighties ('Babushka') - why was that blasting out on such a sunny day in June? Either way, this stereo recording sees me as protagonist, and has sufficient acoustic detail the different resonances or *eigentone* (R Murray Schafer, 1993) of each space as I pass through and loop around the space, beginning and ending at the mouth of the market.

I hadn't really set out to do this, on that day. However, it seemed like an appropriately embodied, dynamic and multi-sensory way to explore if there were other meanings to community in Brecon, beyond my forming views around dementia and community in Brecon.

The hum

Vehicles backing up, footsteps, the echo, voices and whistling. People talk about the hot weather as I move from one space to the next, the slight incline down from the entrance a loudish radio talk host talks about palliative medicine, some laughter and it begins to echo more as I pass the butchers (who sometime supplies our group with mealtime goodies if there's a cawl to be made, or ham for sandwiches) and other assorted shops, then enter the hall. Space changes, the radio fades a bit, but there's a generator type hum in the background, as I walk forward, other waves of sound becoming clearer and I must have gestured, a conversation starts. It's quite empty, but there are people on their stalls, mishmash of antiques, records, tea-towels, militaria, old crockery.

Stall holder 1 – 'totally social'

I look towards some sort of timetable and catch the eye of one of the stallholders, who has various types of old-looking objects on his table: old tools, cutlery, old bottles, china. He indicates there's a café on Saturday, and different themes: antiques and collectibles, farmers markets, craft fair ('y'know') and 'this past week was a charity for the Brecon peace garden' 'what's that then?' 'to be honest I couldn't tell , but I think it's all to do with the Falklands war….they're trying to get benches for it, there's a guy in the corner over there who knows, he does all that, if you're interested it's well worth having a look'. A pause, I explain what I do and he says it's fine. 'Tell you what, they're all friendly here…the only reason I do this, I'm retired, I don't make any money out any of it but it's all good company y'know , there's an atmosphere, can you feel it?' another pause, and he tells me that he comes twice a week and has a look at all the other collectibles also. 'But I can't afford to buy anything, he laughs, I'm here to sell!' 'it's social for me, totally social'. There's coming and going, stallholders that is, but when someone new starts they 'become part of the family'. He comes from Leominster to do this, so over the border, and he indicates that another stallholder comes from Tredegar. 'Y'know they come from all over'. 'We all try and help each other, and I mean that guy over there runs the stall and all the profits go to charity, y'know…I'll watch his and he'll watch mine, we're a small community…I mean we'll have a bit of a sniggers every now and again, a bit of a bust-up but that's part of it'. The arpeggiated strains of Babushka by Kate Bush starts up rather loudly in the background, and I thank him and walk on.

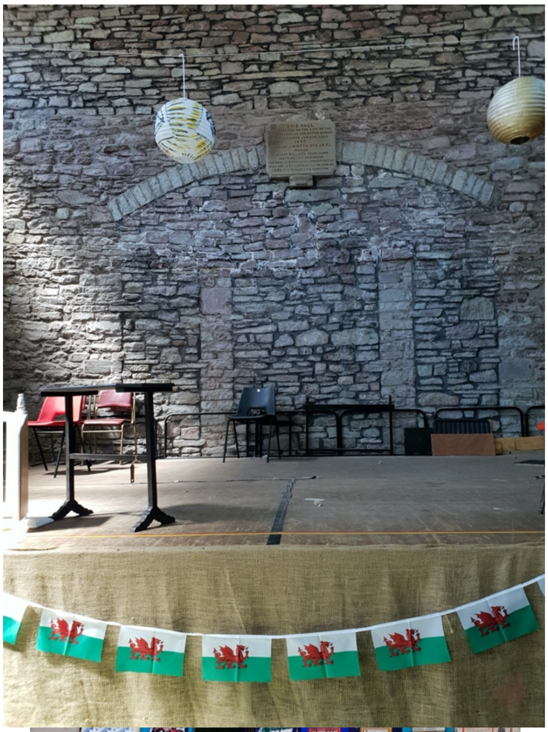
Stall holder 2

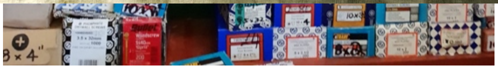
Seem to be getting closer to the source of Kate Bush, the fretless bass and drums and cod Slavic folk scales getting louder. After getting the wrong stall, get to talk to stall holder who's an ex-squaddie ('and my wife is an ex-squaddie, she's actually older than me, she was in the Falklands war, last year was the 35th anniversary and we had a bit of a memorial at the peace garden'), and I ask about the peace garden, 'which is on the way out of town on foot past Aldi's past what used to be the red dragon babushka babushka babushka ja ja takeaway if you're walkin' down the road down the hill from the museum where they're building it there's a…oh wait I've got brain damage…there's a little café, then a hairdresser then an old carpet shop…and then there's a gap, and that gap is the peace garden'. So there's the Falklands bench and the Falklands stone 'and now we've got permission to change the bit that we've weeded into a wildlife garden'. Babushka has now finished. His voice is clear. 'and we want raise money to create a sensory garden ('oh that's good' I interject) and replace the three wooden benches which were put there as part of a millennium project but have rotted, they're dangerous – one for the Great War, one for world war 2 and one for the Iraq-Gulf conflict, that's what we're trying to do'. He's the area coordinator for care after combat and tells me of upcoming fundraisers: they have the rent for the stalls paid for by the friend of the local MP and then all the money from the stalls will go to care after combat for the gardens. He launches the poppy appeal every year in October….silence… he drifts away in thought. Shows me pictures of the previous years, the small piles of poppies below big red wreaths. No one goes to the Falklands one but us, though I managed to steal sergeant major to get down there last year…shows me some big mural pictures painted on cloth that a friend of his makes ('they're all Welsh heroes') – these get displayed up on the stage in the market hall once a year. 'it's weird but next week it's Armed Forces Day, and we're a garrison town and there's nothing…the poppies that you see

on lampposts on armistice day, I had to go and repair them an put them up with a mate of mine from Builth because they don't bother'. Keeps showing me pictures on his phone, his wife, both in military garb, more of the Welsh heroes painted on large panels ' and he did a picture for me for the Falklands, which we don't look at too much because it's the Sir Galahad…my wife was on the beach watching it and her cousin was on the ship'. We move onto how they all help each other, look out for each other's stalls'. There are links to Port Stanley, and his wife – even though he's not allowed to say it – she fought throughout the war. They live eight miles north, in the middle of the firing range. His PTSD is so bad that the other stall holders look out for him. I don't do crowds and Mark over there and Ray who's ex-military look out for me, but I can live up there in the gunfire and the explosions and they don't affect me, but the low-flying jets affect the wife because as I said, she watched the Galahad get bombed lost her cousin and 54 mates, so she's scarred I'm scarred different wars. A pause. This sinks in quietly between us. Do you get any support I ask, I don't get nothing, this is my priority, I do the stall Tuesday and Fridays, and when I run 'em I struggle like hell but they seem to work out. Cos of my brain damage I have short term memory problems…I'm on lots of tablets but military charities won't touch me help for heroes are a waste of time because don't treat PTSD in Wales, they won't help half the veterans in wales…the guy at the top of our food chain gets 42 thousand a year, where the guy at the top of British legion is on half a mil… the big six have got millions of money set aside or invested, if they all put it together there wouldn't be a single homeless veteran in this country. Background music is getting louder, an insidious europop beat of some sort. I won't support a charity which puts thousands and thousands into the pockets of a ceo, even though I help launch poppy appeal in this town I'll do that because they're friends of mine and I like them, but other than that I won't give to……oK? I''ve got to sit down now sir….Thank you, thank you

Stall holder 3

Next door more or less, I wonder over to the person who's been watching us talk, a friendly face, small moustache, standing in front of some old bright boxes. I do the explanations, point at the recorder, 'oh yes no problem and we all look out for each other, I've been coming here 18 years, when there's nobody about we all talk amongst each other, don't we? You see 'em come and you see 'em go, but there are some genuinely nice people never any problems with shoplifting or abuse….' And are you from Brecon? No dear god, nobody here's from Brecon, even the sheep commute….! No I'm from Glyn neath, I live in Ystradfellte now' 'oh I know, waterfall country' yes yes " I come up here when I retired, and I come twice a week. I organise the militaria fair, which is quite big now we're in our twelfth year, started off as a little adventure… we've got a huge amount on loan to Swansea Museum for their world war one display' Is that your passion? Yes and being a mutton molester hahahaha don't care if you're recording no no I'm ex-army, joined from Neath grammar school when I was fifteen, cos you could then, did 25 years in the military police and then was a scenes of crime officer in the South Wales police, retired at fifty with the two pensions and though what do I want to do now?....that display behind you is seriously impressive, I point to the boxes, labelled with different screw sizes, bolts, nuts ' Well when I finish all these will go to St Fagans' O h my wife works there' Well they'll end up in the Gwalia Stores, some of the screws here are seriously rare… paper rustling these old lists of wood screws, sixteen by sixteen inches right..? he reaches over and shows, you can't get these ….forty years ago these were £681 per box of a thousand, seventy pence a screw…wow, that's expensive, why so? Because they were so difficult to make, they had to be such a steel that wouldn't bend….and these here, they're late Victorian, in their original packaging..of course if you're restoring or reconstructing something…I've been collecting them for years, you don't get anything like this now you see because they won't work with





electric screwdrivers or these metal cable clips….then there's things that we have to hide then like Stovo, can't show that any more because it's got black people on it oh no… now we all get on here, apart from some of the nosy buggers. Launches into filthy joke. We laugh and I walk away, see ya, take care bye now. It's busier now, more people more footsteps, soft, soft, the hum of machines in the distance as I make my way to the entrance, gushes of air picked up by the microphones as I walk out into the sun.

What did I learn? The Market Hall can be a space with layers of living performance, a nexus that takes in some of the realities of a small garrison town, which has drifting within it memories of loss, camaraderie, the ebb and flow of volunteerism, petty entrepreneurial fundraising, comings and goings, the ghosts of jazz performance and forgotten wars, of nostalgia for militarised orders, empire peeking out through the union jacks and welsh dragons on display, time passing over us in cigarette papers and bunting. Memories loom large and point to the hidden wounds, not least of hidden populations here, some no doubt at risk from dementias (Rafferty et al, 2018), ones not catered for much even here in this town. But also the civic comings and goings of gardens, the inadequacy of local government, distaste for big charities – a theme warmed to in other parts of this thesis – and *conviviality,* both in the Spanish cognate sense of 'living together', but also with the *tools for conviviality,* as in Ivan Illich's vision of those which give each person who uses them 'the greatest opportunity to enrich the environment with his or her vision' (Illich, 1973, p21). The poppy sold, the unusual screw donated - this is how the garden is built, the museum is filled - here through the tool of hand holding, petty commerce. Despite it being a huge place for the centre of town, it feels intimate, even on a cold day, even when there's not many people about. It speaks of jagged, parallel timelines; a snatch of early Eighties hovering above it all in balalaikas, bombings, shipwrecks.

68. March afternoon in the Circle

Figure 18: The circle with activities

The mountains on the way had snow on them, and when I got there we were in the circle. Breathe, relax. There are many ways to understand the stress of being with dementia. In the circle, we try to look at this, the practices that are ultimately about the self-care of us as carers or observers or how we live. ***Fieldnote 20.3.18.***

Care is a face-to-face, body-to-body encounter. It is without doubt enhanced by science and rational knowledge. The trouble with care is that it is also stubbornly non-rational. Emotions, feeling and sensibilities for all involved can ruffle the surfaces of an interaction, resisting, betraying, inflating, colliding with and burrowing under everything that has been learned in a training room or from reading. (Gunaratnam, 2013, p.113)

It's been really interesting bringing the learning from the English, from Leominster to mid Wales – there's so much of that learning from that first year that gave a good structure and an advantage in some way to what's happened for DMiP. Statistically, the Leominster meeting centre had a higher number of families staying than any other centre, so that's the member of the family staying for the day…but we had to up the game a bit in terms of how you engage the family. But when we started in Wales, we

> *came thinking that that is possible, that this has worked somewhere else, and that this is the unique difference that we offer.* YG

> *I was lucky enough to go on some excellent good training about the history of social justice and social inclusion in particular, and inclusion became a massive thing to be and then I really fixed on the work of John O'Brien which later on in my work life I was lucky enough to get to work with John, having sort of been inspired by the Five Steps to Inclusion that he wrote* YG

It was agreed by the Initiative group that we would initially call the Meeting Centre by another name, a Friendship Circle, to attract as many as possible to a 'friendly' environment, but also an approach that was rooted in Yvie's commitment to inclusion. Each session would start with sitting in a circle, and would regularly sit more than once during a session, facing each other, an important part of her practice (O'Brien & Dill, 2003), another confessional space at times. What follows here is an account written up from fieldnotes of a particular day which follows the typical rhythm of Meeting Centre practice as I got to know it.

> *Looking at the scene: I stand just outside the kitchen hatch and look over what's going on, different spaces, almost a zoned feel, small industrial style kitchen, pale blue hues but still somehow warm because of the sunlight, it's divided into four spaces, the accoutrements of religion in the shape of the cross and the font almost discrete, modular, solid movable chairs, with large cupboard space ready to spill foldable trestles, a ping pong table and the assorted accumulated objects of our circle: the outsized Jenga, the drum, skittles, soft balls of all shapes, jigsaws, games. I've been getting used to this layout now, shoulders unhunch as I pass through the doors, but all about the relaxation today,- what do we do to relax? Hear about massages, mindful colouring books, walking (A GOOD STOMPING! Says Gina, when everything gets to be too much, a STOMP ABOUT!).*

> *So in the circle, I improvise a small meditation, volunteer this, my first time of doing something like this, even though I have many years of sporadic practice on my own, many breathing meditation and some yoga. This is normally what Donna does at the end of many sessions that I've attended: we close eyes, try to feel stillness, but then Yvie puts on 'relaxing music', which for me isn't relaxing, but also aware that Gina is a bit tense because of the situation with her father who might have to go to Hampshire for good, to her sister and a home. We then get on to cook some leek and potato soup, set the table; these movements are routine, I know where things are kept, we call out the cuppas, eat and talk; plain hot soup, potato and leek, and buttered bread: it fills the room with something 'homely.'*

‘Smell always draws us into the entangled threads of memory and possibility’ (Tsing, 2015, p.45), and this is consistently important in the Meeting Centre, given the proximity of the small kitchen, but also the enthusiasm of some of the volunteers for cooking or preparing simple meals or snacks – a cawl, perhaps, or the waft of prepared muffins in all varieties at times, including gluten-free, scones at others. It can start and maintain a conversation or bring back or stimulate memories; for those affected by dementia, the decline of a sense of smell is part of the terrain (Alves, 2014), and so it’s important to spend time talking about and using it. Vast cricket teas prepared at lightning speed by a volunteer whose husband used to be in the local cricket team, piled high with carefully cut sandwiches, or sometimes just local fish and chips; I’ll do the run to Morrison with a shopping list after the first round of teas and coffees as people drift in. We tuck in together around the table, sometimes set for fifteen to twenty people, the meeting centres grew during my time there and we almost ran out of cutlery.

It’s a quiet day, not many here, but enough. A masseuse has come for the afternoon, she sets up in one of the corners near the windows and we all discuss how important it is for all to be able to relax. Piebald mountains in the distance. Snow had hit mainly in March this year, and driving over the pass, the mottled green and white of the valley below seemed to promise the beginning of the end of winter.

Post-circle and discussion, post-food, onto second or third cups of tea. Paul twirling his white topped cane, a lovely object; feet soaking in a blue plastic container full of warm water and radox, trousers rolled up over olive knees, he’s always a good colour. “Would you like a cup of tea?” I ask, and with blue-eyed twinkle, he said “Yes, with milk …..and some sugar, make sure she doesn’t see it….”. He raised a brow in half conspiracy towards his daughter, on the other side of the room, busily in conversation. I wink at this lean, straight-backed man, he turned the cane held out in front of him for support, fixing me with a slight smile. Mid-March light comes through the high, broad, well insulated windows, its strength gathering in early afternoon, with the clocks about to turn. He dwells in the space, seems at home somehow, feet soaking, taking everything in. I think he recognizes me from session to session but can’t be sure. Windsor and he are both keen on the ping-pong, quite competitive.

I step back a bit and look at everything going on in the room. Gaenor was first to the massage; she would go for one quite regularly when she could, she needed the relief of stress, of looking after Windsor, often having many nights of disturbed sleep. She sits there in the special seat now, the masseuse being as gentle as needed Windsor looks on, he’ll be next. There’s a dividing line in the kitchen – it’s a space for other types of conversations,

> *maybe not the kind you'd have in the other space, it's almost like a place to reflect a bit more as you do the washing up or cut the veg or line up the cups and talk over the sound of the urn. I catch up on the gossip in Dementia Matters in Powys in this space. Over my time at the Meeting Centre, it feels like a space that is closest to Goffman's dramaturgical observations of backstage and front stage*
>
> *A guy from the Prince's Trust just wandered in, looking for volunteers, for a trip to Uganda, some development work – wrong place we think! – but he sits down for a cup of tea anyway, Yvie keen as always to just add any momentary possibilities. She never turns anything down, just goes with the flow of the session, but at the same time moves things along, she jokes with a rather wicked gleam about taking the group on a trip to Uganda. She embraces the randomness of things that happen in these sessions. Quite an important component of what she sees as her core calling – community development work, that's where she comes from.*
>
> *So at least four things going on: massage, foots-soaking, tea-making, an impromptu talk about development work in Uganda. Catch Yvie's eye and see the satisfaction she gets from surveying this: movement, busyness but also calm. Back stories around Paul (used to be an engineer at IBM, had worked all over the world for them), Peter and Jill, used to teach in Fitzalan (still think of him reading his poetry), Yvie talks about her son who went to Oxford.*
>
> *New student help this week also, someone who's interested in going on to do psychology at Swansea; Rhiannon also popped in, but for 5 mins only – there's some tension there I think, some 'non-acknowledgement' going on between her and Yvie, seemed to keep out of each other's spaces. Getting to know T as well, who had brought the radox and spent a lot of time with Pete.*

Sitting in a circle is a very powerful start to these sessions: sometimes there was a theme, sometimes there wasn't. People vented (Gina about her sister, the new student admitted to living with anxiety and trying to control it with mindfulness, on that particular day), told their stories, read poetry, played, meditated, look at each other directly, and over time, this was how people bonded. On more than one occasion, I witnessed how couples or families would come in for the first time, often shocked and very emotional from their newly-diagnosed situation, often worn down from lack of support, unsure of how to respond to the workings of the Centre. Over time, these worries seemed to dissolve as they bonded with others in the 'circle work' in particular. Later on, when the Initiative Group dissolved and became an extended, more general, Advisory Board for DMiP and the Meeting Centres, while Yvie was still part of the proceedings, we would always start in such a circle.

Through her years of community development practice, Yvie often talked of the power of this in her person-centred practice, and now part of Meeting Centre practice, common to many indigenous methodologies and therapeutic settings (Kurtz, 2013), especially in North America. For Yvie, it is part of her 'magic' repertoire (George & DMiP, 2018, Brooker, Evans et al, 2017), she even wore a necklace with a small mushroom on it, to remind her of such magic circles. Community-making through ritual (the circle, the meditative relaxation, the food, playfulness) seemed integral to her ethos of inclusion, along with the ability to listen and improvise. It was notable that many people who attended the Meeting Centre – volunteers, carers, PWD - were not from Brecon or the surrounding area: many had retired there or built second or third chapters to their lives in the town. There were couples and individuals from the Northeast, the Midlands, London, the South coast, Cardiff, South Africa, and many had lived and worked in other countries, people who had moved to care for relatives who had themselves retired there. Gina, who started off coming to the group as a carer, then ended up volunteering, said that she's never felt more connected to Brecon than she did once she joined the group, because of her dad's dementia. She was originally from Hampshire, and like many others had lived and worked elsewhere most of her life. Many others expressed the same feeling, finding more of a sense of local connection through being part of the Friendship Circle/Meeting Centre.

Many of the activities which arose during the course of meetings would also have helped with this, including visits by the local PCSOs (Police Community Support Officers), the library service, local community choirs; there would be activities centred on helping other local activities, such as making bunting for the Jazz festival, for example. I would periodically visit the library in town, and they cosntently had material there to help PWD, or display of the help available through either BADDFC or the Meeting Centre. If 'we're all in it together' had led to this, then a gentle form of bio-sociality was clearly emerging from the group and its rituals too.

So does dementia create community, these micro practices in the DMC as part of it? Community needs some foundation, needs to be sustained (do rituals do this? Yes they do). The values are prescribed in the Adaptation/Coping model but can be interpreted through the practice – which Yvie likes to keep quite spontaneous. Something always emerges out of these rituals.

We are in Baptist surroundings, with another Baptist chapel within 500 yards, a space which has a vista looking at the mountains, and we are near where the Honddu river meets the mighty Usk: *Aber*honddu, the Welsh name, means the mouth of the river Honddu. But there are three rivers which meet here: Honddu, Wysg/Usk, Tarell. Such a meeting of rivers, according to old stories, could only mean that the *tylwyth teg* were nearby.

69. Dancing with Windsor and Gaenor

Figure 19: 70s

> *Encountering a human being means being kept awake by an enigma. (Emmanuel Lévinas, quoted in Rothe et al, 2017, p. 43)*
>
> *My spaces are fragile: time is going to wear them away, to destroy them. Nothing will any longer resemble what was, my memories will betray me, oblivion will infiltrate my memory. (Perec, 2008, p. 91)*

> *To grasp a rhythm, it is necessary to have been grasped by it; one must let oneself go, give oneself over, abandon oneself to its duration (Lefebvre, 2004, p.27)*

Windsor and Gaenor have formed an important part of my experience of being alongside dementia in the context of DFCs, and latterly the Meeting Centre. Their story fills me with a sense of connection to Brecon, the place where they've always lived, and the sometimes gentle, sometime violent elusiveness of the *tylwyth teg.* They were some of the first people I met when I walked through the doors to join the Friendship Circle, as the Meeting Centre had been billed initially, the pat pat pat pat chirrup sound of a competitive game of ping pong taking place, Windsor concentrating intently and determined to win. The cool pastel blue of the ping-pong table, full sized but easy to pack, would be a feature almost every time I visited in those initial months.

The couple are from Brecon and have lived there all their lives. There is a clear sense of attachment to the place and the surrounding countryside which came through in our conversations, both in the Meeting Centre, but also when we met for sessions outside of vestry. The 'life course' of their transitions from childhood into adulthood, parenthood and now old age are embedded in both local and national institutions, histories and places (Bengston et al, 2005). For example, one day we met up at the Beacons National Park Visitor Centre, a few miles out of Brecon, and Gaenor talked of all the happy memories of being there with their children but being there also provoked a memory of the period when Windsor did his National Service in the early sixties, stories of him hitch-hiking back from his barracks to see Gaenor, being dropped off nearby. He'd then worked for many years at Christ College, the independent school which has been in the heart of the town since the sixteenth century. He was the captain of the local rugby team in the seventies, and Yvie devised an 'indoor rugby' game in the Meeting Centre, with him in mind; gentler, perhaps, but still played with a steely determination by Windsor, from time to time.

Gaenor had worked at both the medical practice as a receptionist, and at one of the local chemists. Both have a wealth of connections locally, though their children have left the area.

There is a sense of the autobiographical ‘insideness’ of place (Peace et al, 2012) when I’ve been with them, of Brecon as a landscape of their memories, from the way streets and events are referred to (including the jazz festival, for example) to the connections made in day to day conversations about who knows who in town, or where the best fish and chips might be to feed everybody in a Meeting Centre session. However, the playfulness of playing ping pong together, or the closeness evident from the moment they’d walk into a session couldn’t hide the fact that Gaenor had become the only one capable of keeping these memories alive. Being in a space such as the Visitor Centre, which had pine décor unchanged from the Seventies, where they had frequently brought their children, underlined how such spaces could connect with both happiness and sadness, but that such spaces are also fragile. Nonetheless, the ping pong, the rugby (not to mention indoor cricket, jenga), eating together (Gaenor would ask us to make sure Windsor didn’t eat too many biscuits with his tea), and all the other experiences which I describe here, such as visits to museums or having a sound bath together suggested to me that ‘life course’ – a linear understanding of how Gaenor and Windsor’s lives were ‘progressing’ – couldn’t adequately express what was going on. Schwannen et al (2012) respond to the idea of lifecourse more as a continual folding and unfolding together - ‘entwined becomings’ (p. 1294) – of other life-courses (in this case, mine included), material and immaterial, human and non-human, a more ‘topological understanding’ (Barron, 2019) a way of connecting the more gerontological-focussed thinking with more-than-representational theory.

…

Since Windsor had his diagnosis, the couple have taken part in most of the activities that have been available locally, starting with the Tea & Chat which was run by the Alzheimer’s Society, then as members of the Friendship Circle/ Meeting Centre, but also supporting any other activities which Joan or Rhiannon, an old friend of Gaenor’s, would dream up. Windsor’s condition had taken its toll, however, on both. He had great difficulties communicating at times, and although he clearly enjoyed many of the physical activities as well as sitting down and eating, or the relaxation sessions, he was often unsure of his surroundings and who he was with – but there was always a mischievous twinkle in his eye too. Things could be quite difficult for Gaenor because Windsor's sleep was also greatly disturbed – he would often get up in the night and it would take time to bring him back to bed, after which Gaenor couldn't sleep. Over time, attending the Meeting Centre had greatly helped to give a sense of regular stimulation in a supportive environment, which helped to calm things down.

…

what kit sun streaming on two apple laptops - enormous screen half shaded behind dj pushing glasses to forehead, student L going for it as does T who dances regular on a Monday night but not with her husband who has two left feet and as marc bolan stops stomping I notice gleaming eyes, more sweat in the air and roughly twelve of us up and over the hump of looking with those lit up eyes, physical, no more staring at feet and as I look over at W a Saturday night fever jolt – back in the room with everyone – so strange dancing in this daylight – W is swaying arms up looking intently whether you're a brother or whether you're a mother I roll my arms one way, he copies then the other- he copies !- you're stayin alive, stayin alive and we smile and do it again this must be community surely watchful R beaming at the side shaking leg a leg - proud -drinking it in (Fieldnote, 22.5.18)

This fieldnote, written up as soon as possible after the event as spontaneous prose, makes me think back to that afternoon, the flows of energy which were in the Meeting Centre space, and how music and dancing opened up our bodies to the possibilities of non-verbal, intersubjective communication, to connection. Dance has its place in both non-representational theory (McCormack, 2003, Thrift, 2000) and dementia studies. In particular, the work of Kontos on embodiment and dementia (2005, 2016) and the power of dance (Kontos & Grigorovich, 2019) has highlighted the egregious bias towards cognition (as well as the purely instrumental use of creativity to improve 'behaviours') that underpins much research on dementia and dance, arguing that it 'implicitly denies that the body itself, separate and apart from cognition, could be a source of intelligibility, inventiveness and creativity in everyday life' (p.163): dance is better understood in terms of a latent knowledge or 'kinesthetic background' (Merleau-Ponty, 1962, p.116) which can produce 'moments of a unique totality' (Merleau-Ponty, 1962, p.110).

As I think back to that afternoon, there is a uniqueness in the way I can recall, time and time again, how dancing with Windsor, the intensity of his copying my clumsy moves, of our bodies finally relaxed enough to tune in in such a way to a pulsing disco beat and falsetto tone, meant communicating something about the space we'd created. We were both grasped by it. Because he had great difficulty communicating verbally, the spontaneity of this expression – he danced with others not just me, of course, as did Gaenor – pointed to all of our openness that afternoon. Everybody got up and shook something, joyously. Whether or not Windsor could remember Staying Alive, what was important was how unexceptional this moment was – it was just fun, in which our embodied self-expression seemed in tune. 'R beaming' refers to the blissful look on Rhiannon's face as she watched the scene. A highlight.

Anderson (2006, p.735) provides a description of affect as the 'transpersonal capacity which a body has to be affected (through affection) and to affect (as the result of modifications)'; two sides of a dynamic shift, that he goes on to say, quoting Massumi (2002, p. 212): 'when you affect something, you are at the same time opening yourself up to being affected in turn'. This dynamic relay, which left us all feeling animated and 'in sync', as we packed things away at the end of the afternoon, was surely part of community-making, a glimpse of the *tylwyth teg*.

70. An afternoon with Joan

Figure 20: Afternoon visit

Joan is one of the founding members of Brecon and District Dementia Friendly Communities, together with Rhiannon, and she was one of the first people I got to know in Brecon. This interview took place after we'd met quite a few times through either networking events around DFC, where she would often be the main organiser, certainly locally, or in the advisory group meetings which took place as BADDFC pondered its next steps, which led to forming DMiP and developing the first Meeting Centre in Wales. As we walked about Llanfaes, on the outskirts of Brecon, she explained the background to her continued involvement and how her work for BADDFC had evolved into primarily being about promoting intergenerational approaches to dementia, even though she still maintained other aspects of developing DFC practice, from running Dementia Friends sessions (one of the few who still did) to engaging with local businesses.

As Steve Huxton had noted in a previous interview, and should be apparent in this section, we were now talking about the post- dementia friendly communities' scene in some senses, the second or third phase, which I was witnessing through my visits to Brecon. The whole enterprise there, which had been held as an exemplar, had forked off in many different directions. We met, at her request, at the school where some two years before I had met her for the first time, invited to a BADDFC public meeting to present the idea of Meeting Centres to local councillors, the medical practice and others. A lot had happened since that meeting, including setting up DMiP, and then the first Meeting Centre opening its door some eight months before this interview.

We walked over to a local privately-run care home with some Year 6 children from the school, watched the intergenerational activity unfold, the mid-morning bustle of residents being wheeled about, tea and coffee being offered, as the children and residents became absorbed in painting activities: *bright eyes, swift old hands, Brecon rocks convivially* I wrote in my fieldnotes. Joan and I then sat down in a quiet classroom after walking the children back safely. Most of the children wore branded polo shirts with 'Making Brecon a dementia friendly community' on the back, which suggested the level of commitment to this scheme.

In the recordings, there are sounds of crunching gravel, cars passing, locks being turned, air changing as we moved from room to room or outside; a fleeting acoustic ecology which suggests movement, coming and going, transitions from space to space, before we finally settled down for the main part of the interview in a quiet classroom. The 'what's happening when nothing is happening' (Becker, 2007, p.267) gives a sense of being somewhere not quite urban, not quite rural, and as I listen to it, different sensory memories are evoked of that sunny day in June: you could smell the greenery on such a day around that part of Brecon, just as you come off the A470, mountains still clearly visible in the background, bells going off, pupils moving around the school. The small garden at the entrance of the care home was in rude June bloom: Joan's original idea had been to build a sensory garden with the residents. Nothing was recorded acoustically in the care home, and I was careful to explain my presence there, at Joan's request, to all concerned. As noted, the time spent there was convivial, the children were very much at ease as they helped, joked and painted with the residents in a sun-filled lounge area.

Afterwards, we explored what Joan had achieved so far, how she saw things. This was only one of the groups she would regularly interact with and take to nearby homes in Brecon and the surrounding district. For me, it brought back memories of having to do the same thing, back in the late seventies, early eighties at my primary school in North Wales: we also had to go over to the local council-run residential home and sing and interact with residents, though the memory is one of Christmas carols and large chairs with shrunken bodies, the smell of overcooked vegetables, being uncomfortably hot. I reflected that such interaction has recently been re-invented not just as a cognitive 'good' for all involved, for community, as 'a positive, sustainable way of drawing on the community to achieve benefits for people living with dementia, children and wider society, at very little additional cost' (Di Bona et al., 2017). During the interview, Joan illustrated this point several times:

> *It doesn't matter what we do [like the sensory garden] it's the interaction that counts. We do painting, we do games, we do colouring, use memory boxes – but it's the interaction that counts, and the kids love it*

She'd started out observing how her own grandchildren enjoyed this, but that it gave an opportunity to bring about 'education' in the broadest sense, for example as a natural way to explore themes such as death, though ironically, she added that through this activity *life had been made more tolerable* for all concerned. All kinds of connections were being created in each session. For example, in the previous visit with this group and that particular home, a pupil had brought over a photo of his father being christened by a resident's husband, a local clergyman. The pupils formed relationships with the residents, and this could then be difficult when inevitably, they would die – but this was a way of teaching the children about such things. This was the fourth cohort of Year 6 children who had taken part, and Joan was convinced that this stood them in good stead before making the transition into secondary school. But it had become an important part of how she herself was trying to make sense of dementia, even after four years of being at the heart of BADDFC:

> *You know, dementia's fascinating. I go into three different homes and everybody's different and sometimes they're different from day to day, or week to week. There's a woman I'll see in […] this afternoon, and one week she'll be laughing and into having the kids there, and the next she'll be crying and getting frustrated…it's horrible when you see people get upset, but the changeableness of it, the different effects of different types of dementia have on people…*

Many of my previous encounters with Joan had been at either networking events in Brecon, or at steering group meetings for the dementia Meeting Centre. We shared a common background in that we'd both also been active in drug and alcohol charities in South East Wales, in management positions, voluntary or otherwise. When she commented early on: *Went to a meeting intending just to suss it out, next thing you know you're co-chair, you know the way it is…*I had some sympathy with how things can happen, and having got to know Rhiannon, could imagine that she would have seen how able and experienced Joan seemed to be.

Originally from Liverpool, where she still had many connections which remained inspirational as far as being alongside dementia matters mattered for her, she'd moved to Brecon in 2009, and had joined about a year after Rhiannon had set things up. Her daughter was a town councillor in Brecon at the time, didn't want her to get bored after retiring. She did the Dementia Champions training and started to give dementia friends sessions with Rhiannon and Donna *so I've been involved for four years, I've done loads of sessions [of Dementia Friends], but I fancied getting the children involved*. She'd ended up being chair, taking over from Rhiannon when she became CEO of DMiP. *A big mistake,* she said with a mischievous smile.

> *because we were so successful in Brecon really, as far as I remember, the Big Lottery approached us, cos they were interested, so we put in the bid, got the money and PAVO also gave us some money or we got money through PAVO to set up DMiP*

We talked about common experiences of being in small charities, ups and downs, the horror of having to make people redundant, but also the beauty of being more agile, able to respond to people's demands quickly:

> *People need practical things to help, I think it's really important that people still enjoy their lives, so the activities are great. We've raised loads of money and I don't want that money sitting in the bank, so tell me what you want and we'll pay for it…*

She was also an active Labour Party member, vice chair of the local group, but saw the politics in Powys, where the Conservative Party had a *de facto* majority as being very complicated. We talked about the background to things in developing the work of BADDFC in a time of austerity. *We're saving them millions,* she said

> *I think they're a bit hopeless as a council in some respects, but I feel a bit sorry for them… services are being cut and cut and they have to make choices, but what do you cut? Everybody wants a good service for everybody don't they, but do you cut the domiciliary work or money going into homes because there was a time when we were setting up DMIP and the Meeting Centre, there was all the business of them closing down the day centres..but I felt at that point what they were trying to do was get us to pick that up.* […] *would have been a good building for a meeting centre, and we could have worked the political pressure to get that to happen, but…that would have been a great place for a meeting centre, but I don't know what's happened with that since then*

She went on:

> *we did have a good relationship with the council, we did sessions for them, they became a dementia friendly council, they made a commitment, but I'm not sure if that's been followed up really. Rhiannon was very good at that stuff, she had a good network*

She worried how much political lobbying is being done now: *that's what needs to happen, when this is what needs to be done.* Things had got complicated once DMiP had been set up. There had been some disagreements about the way ahead, and the vision for the Meeting Centre. Joan's objection had been that the idea of a Meeting Centre had just become a group which meets once or twice a week. She had wanted to see something more permanent with better infrastructure, which was partly based on her experiences of working in the drug and alcohol charity that had a more permanent base, though she acknowledged there were pros and cons:

> *With DMiP, I was involved in setting it up and I was a trustee, but I've resigned form that, partly because I've got too much to do, partly because it was just becoming a bit uncomfortable…I make no bones about the fact that they're doing great work, but don't call it a Meeting Centre, it's a group that meets twice a week, and now one that meets once a week, now how is that a meeting centre, you know what I mean? You were there at the beginning…I think you need a base, you need to be open more than once or twice a week and you need someone to oversee it. I'm not criticising it because I'm not involved in managing it , and I'm sure they're doing what they think is right, but it just feels…it jars with me, I don't think it was what we saw …I appreciate things change but I was just getting a bit uncomfortable with it.*

This was a fundamental fork in the road, but for Joan one that had created a plurality of choice and development around the idea of DFCs in Brecon, at least in theory at the time of the interview:

> *It would be foolish for people who are working limited hours in DMIP to be doing the same stuff as what BADDFC is doing…in Brecon, there's not much need for their developmental work because there's a lot of stuff going on anyway. Concentrate on other places in Powys, make sure you come to the steering group, that there's good communication, but it's stupid to all efforts into Brecon when it's happening anyway*

We went on to talk about the provision now available. Joan had been busy engaging with the Brecon Business Dementia Alliance, ongoing work with local banks, and in similar moves to Emma in North Wales, had had some success engaging with the local leisure centre, which had helped work at the Meeting Centres too. Regular activity sessions at the leisure centre had been set up, then cake and coffee with carers, then the carers can could go off to do their own activities. We talked about a couple we knew who attended all these activities, and how the parkinsonian shake which the husband's dementia induced would go immediately when he had a racquet in his hand. I mentioned how I'd seen him recite his poetry at the meeting centre once, how it left us all close to tears – an ex-teacher, he really struggled with his voice and communication because of the dementia – but it became clear as he recited his own work. Inspired by the success that Nigel and other had had with DEEP campaigning for 'slow shopping', Joan mentioned also how she was in talks with the local Morrison's for a similar scheme. We'd already spent time there some months earlier helping people to pack their bags to raise money for BADDFC, I'd come up on a Saturday morning to help out.

The Alzheimer's Society ran a session called Tea and Chat for PWD and their carers, which for a period was just before the Meeting Centre sessions, and this was Joan's test bed. As I'd witnessed though, Meeting Centres and Tea and Chat were fundamentally different in terms of how they structure the support: in the former, the ethos was that PWD and their carers did activities together, whilst in the latter, sessions were held with PWD doing things apart from their carers. Both had their plus points, including providing some respite for those carers, but the strictness with which this structure was policed was quite frustrating for Joan:

> *The Tea and Chat again is totally inflexible; the Alzheimer's society won't allow people to mix…what's that all about? Who says? They might want to mix, but they're not allowed – what's that all about? I keep quoting the DEEP group in Liverpool…you walk in the room an there's about 50 people, it's called the SURF group [https://surfdementia.org] …but you walk in and there's a buzz, there's always someone there form Mersey NHS trust, they're always there but they never interfere. They only speak when they're asked to speak, there's a psychologist there who only speaks when she's asked…but now they're so powerful, nobody in Liverpool passes a policy without it going past them, transport, housing, they've got an input. Now they all mix together…who the fuck are they in the Alzheimer's society to say they can't mix together, how dare they…how arrogant, they think they know best…can't stand that inflexibility*

She spoke fondly of her connections to Liverpool, and this group in particular: it had clearly been the basis for her vision in Brecon, but more than that it held a link back to her home city. Earlier on in the day, I'd mentioned the picture of Burroughs in Brecon, and where it was leading me, and she mentioned at length a writer friend up in Liverpool who was also fascinated by all things Beat, and she had also studied English at University – my nascent ideas around cut-ups were interesting, she thought. This was a recurring theme, here and elsewhere, how larger charities can sometimes be unhelpful. I'd observed these tensions up close in some of the other meetings in Brecon, but Joan was more specific:

> *It's an odd thing really…I find them* [The Alzheimer's Society] *extremely inflexible. My idea was to get Champions in schools, so that we could spread the work, anyway…very few teachers turned up, and I'd put so much work into it because you had to meet the heads, head of education and you can only do these things if it's a non-teaching day, we planned it months ahead… but the inflexibility of the Alzheimer's Society was quite stunning, because I thought this was really innovative, and everybody want to create a dementia friendly generation, so let's get schools on board, but they wouldn't support because of the dates, which we couldn't do much about….it's that thing with huge charities, they're not flexible*

I asked in terms of shared resources locally, how much do they put in:

> *well nothing really…when I managed people, my mantra was really no volunteer should be out of pocket, but I've fallen into that…but I do think they're not very flexible or responsive, but I don't have that much to do with them really, I just use some of their resources and get on with it*

In the end our conversation drifted back to BADDFC, its future, the relationship with DMiP. There were some pauses on the way, and I could feel a sense of slowdown. Joan was retired, after all, and her daughter, in a reversal, wanted her now to slow down. She'd recently had some problems with flooding in her home also, which had delayed this interview. This had been a nightmare, and she'd only just been able to get back into her home; I'd kept up with this through the others in Brecon. But slowing down? Easier said than done:

> *I certainly don't want to give up any of the intergenerational stuff… what we were hoping for DMIP was that we could take some of the intergenerational stuff outside of Brecon…but I don't want the whole thing on my shoulders again. Two years on the run we organised concerts and stuff, god it takes over your life doesn't it, and I don't want to do that again*

She continued:

> *We've got a solid steering group now…What happened was er I was organising everything, so although there were loads of volunteers, most of it fell on me…and that in many ways my own fault, cos I'm a control freak and I like to know things and I'm an organiser, but then I had to stop because of the flood and everything , and what I'm pleased about is that things didn't just stop you know, so during dementia action week there was a bring and buy sale you know, there was a coffee morning….*
>
> [during the time I was off] *there weren't as many things going on, but there was enough. And what I'd like is that some stood and said…'I'd like to be chair now', because I don't want to end up as before….*

At this point, it struck me that her tone was similar to Rhiannon, with whom, a few years earlier she'd seemed like an unstoppable force for DFC in Brecon; their creative line of flight had marshalled businesses, schools, councillors, medical practitioners, as well as those living with dementia. But in the micropolitical tensions of forming the next stages, full of small resistances, something had changed: 'the creativity of the minor trajectory is all too brief…lines of flight get recuperated, organised, systematized, programmatized. On the other hand, there are moments of minoring, of breaking away, creating something new…' (Rose, 1999, p.280). By creating DMiP, systemising their vision into one which lay beyond Brecon, which meant Meeting Centres, employing staff, bidding for lottery money, something had changed, things had broken away, people had decided to go in different directions.

She was admitting that she felt overwhelmed and a bit tired from having to chair all this, despite the many achievements. She wouldn't go through the process of writing bids ever again as a volunteer. She pointed to others, who had actively started DFC campaigns in nearby town such as Hay, at roughly the same time, had also given up on such activities. The energy needed to maintain this idea is a lot, as a volunteer, and even though it could still be felt here on this midsummer day, there was a sense of dissipation, of how energy was now focussed differently, for Joan, but also Rhiannon and everybody else in both DMiP and BADDFC. After this interview, I still saw Joan from time to time, towards the end of my fieldwork: another lively Dementia Networking event, back at the Guild Hall, where it all started, and at the launch of another group for those with young onset dementias who wanted to meet informally in a local bookshop (see Wendy Mitchell in Brecon), but never with Rhiannon.

The fork in the road had happened, now zigzagging between dementia friendly *communities* to dementia friendly *generations*, channelling different types of spatial and temporal energy to what went before.

71. A sound bath: 'multiple realities resonating'

Figure 21: Sound bath

> *Sound, like breath, is experienced as a movement of coming and going, inspiration and expiration. If that is so, then we should say of the body, as it sings, hums, whistles and speaks, that it is* ensounded. *It is like setting sail, launching the body* into *sound like a boat on the waves or, perhaps more appropriately, like a kite in the sky. (Ingold, 2011, p139)*
>
> *It was if, for the first time, he was able to know them as himself, and this was like a change in the weight of his body, a deep flowing-back of energy. (Williams, 2006/1960, p309)*
>
> *No matter whatever you've seen happening in the MC, there's a rationale. There would always be two things going on. You could link the activity back*

> *to something discussed by the group which was of interest, but also, I could show you how it would help them to adapt to change in some way, either emotionally or practically.* YG

A crisp spring day and I make it up to the Meeting Centre, the early May mountains are bright green, slight haze rising. It's been a while, and as I park up and go in, I feel quite emotional. It's one of Yvie's last sessions, and there's a certain sadness to this, leaving what she's built, but in self-defence really. The energy needed spent, she's now looking to start in a new direction, archaeology. I walk in on a deep conversation about Hadrian's wall.

Cwtches, coffees, and people drift in some new volunteers and workers also. Geraint and family, who I speak Welsh to, and Gaenor and Windsor, so good to see them again. Others absent, and I pick up on the complications around transport and funding that are never far off. The circle has been opened out with two trestle tables in the middle; in that sense, the circle is broken, an unusual state of affairs. Music has always floated over the Meeting Centre experience, is never far away from activities; when it opened officially, it was a string quartet that brought in the crowds after all. A tea dance turned to disco. Some choral music on a foldaway keyboard. The drum. We soon chased away the Vera Lynn from the stereo, even for armistice remembrance; almost nobody here is of that age, and even though we're present alongside other people's memories, and our own, for at least part of each session.

Though Donna isn't here, the other rituals of the group are sitting in regular meditation at the end of each session, becoming present to the body, and each time we close eyes, and open them refreshed. For the carers in particular, this part of each session brings some relief. Massage, footbaths, or even just a quiet cup of tea, there are always attempts at bliss.

> *but today a sound bath hapi drums Tibetan drum chimes of all sizes a xylophone shamanic drums crystal singing bowls a kalimba gongs GONGS big GONG we sit and close our eyes and begin to journey through different states together and pretty soon we find that there's something different going on the hairs on the back of my neck begin to prick a bit but there's also a calming of front mind as we all face the same way and wait for the different waves to hit Geraint & family to my left and Gaenor and Windsor to my right Ray&Jean at the end near Yvie with Gina the other side the*

> *window to the side is open to the spring as the waves start - we tune to it all including silences as we sit there eyes closed attention expanding and it goes form crystalline highs to rumbling lows as the reiki woman goes from instrument to instrument and back again I peek to see the masks to the world around me softening through looping xylophone feedback of intoning intoning intoning & the wave hits with colours in your mind almost I hear the birds outside too - in the silences there are tears here across the circle and midway through Windsor asks for a cup of tea - hee hee - hapi drum rounded pebble sound it breaks through like a twinkling joke because Windsor stays silent usually and Geraint is laughing to himself the other side of me as I hear a dog barking sharply in the distance then at one point distant voices from other windows opened & slow DREAD strikes me with the shimmer and rumble of the GONG that passes over the top of my head but slowly and the seat is vibrating with Gwyn laughing and tears in the eyes kalimba tinkles and takes me somewhere else again quiet quiet resonate echo loop nodal wave that cancels and bliss descends in bong bong bong chime bong*

We open our eyes, what just happened? Geraint still laughing ‘that was good’, he says four times and in Welsh *‘dew, rodd hwnna’n dda’.* For over half an hour, our listening bodies had come together through this exchange with the sounds produced: bodily affects seemed at times both social and pre-cognitive (Waitt & Duffy, 2010), some ending in the emotion of muffled tears, a request for a cup of tea from nowhere, dread, goosebumps and then a type of bliss. There were delocalization effects (Augoyarde & Torgue, 2011): at one point I wasn’t quite sure if a dog barking was actually there, somewhere outside the building, then suddenly the ubiquity of voices from somewhere else. For me, there were certain synesthetic psychedelic effects too, seeing colours. It was a truly visceral experience: some of the sounds such as the gong, reverberated through the body with a surprising force.

For a moment, the visual is too much; it was a bright day before we closed our eyes, and now there’s a certain shimmer in the light, something you catch in the periphery of vision. Perceptions have shifted slightly perhaps: I feel more *in* both sound and light, there’s luminosity (Ingold, 2011, p138). Energy levels have changed and some need to get up and walk and talk, everyone animated but a blissfulness in the eyes, relaxed. The sounds seemed to have picked up ‘density and texture as they [moved]through bodies, dreams, dramas’ (Stewart, 2007, p.3)

Looking back, what I felt was the polyphony of this group in this moment, something which we seem to achieve regardless of instruments (though music and rhythm are never far away). Often, the act of listening here in the Meeting Centre forces us ‘to pick out separate, simultaneous melodies and to listen for the moments of harmony and dissonance they [create] together. This type of noticing is just what is needed to appreciate the multiple temporal rhythms and trajectories’ (Tsing, 2015, p24), as I try to grasp for ideas of dementia, friendliness and community.

72. Market Collage

Figure 22: Collage - Market Collage

This collage is made from pictures of noticeboards, mainly Brecon, taken over three years: markets, guild halls, supermarkets, theatres. Also flyers, leaflets and postcards picked up over the period: for dementia related drama productions, the Meeting Centre and other events. There are layers upon layers of paper, card and glue, it's a tangible physical object with bumps and unevenness, that changes colour according to the light – currently winter – and has multiple perspectives, repetitions. I've cannibalized some part of it by processing ready-made collages made of the images in software and adding them in layers, but allowed certain words to appear more prominently, though without putting much conscious thought into this. The original noticeboards are often (though not always) cacophonous artefacts of life in the market town, probably worthy of more attention, and ripe for further cut-ups. The collage has some geometry in parts: circles/bubbles, triangles, but also jagged edges and undulation. Looking at it, I'm reminded of different messy layers of experience which make up the research process, and by allowing the eyes to settle each time, a different sequence of words appears, sometimes with surprising results; but they always come back to Brecon, and in a sense each time help me re-imagine and re-kindle what 'community' and its connected meanings has entailed in my time there. As with cut-ups, there's a diffractive quality to this process, it means 'thinking with disjuncture; thinking about where data rubs up against data and what that exposes about how subjects and objects of research are made through the research' (Dawney, 2018, p. 110): each flyer has a life, a story of being produced and placed, rubbing up against another life, and through my process of collaging, some new connection, potentially. Incomplete and messy, it holds onto various objects of research collected (if not categorised), and paradoxically for something glued into place, 'manifest[s] the extraordinary liveliness of the world' (Barad, 2007, p. 91).

73. An ending - Where’s Ivy?

Figure 23: Cricket tea

Some of the community development work involved in something like this is to make sure that you put things in place so that it doesn’t go down that obvious road where people think that they’re disempowered…having a worked in a lot in jobs which are about self-esteem or inclusion, this has been a job where I’ve been able to bring a lot of that. **YG**

Christmas Cracker hats now at various angles, up for the last cuppa of the day and I was a bit late for the start of the session, but everyone settled after turkey sandwich and a singsong. Talk of Christmases past, children, childhood. It’s cold out there but crisp, mountains are quite clear today,

> *we're onto lining up cups when I feel someone is missing; as I do this, pile up the mince pies (home made by W), it comes to me "where's Ivy?", I look through the hatch, she isn't here today (doesn't always come) , but when she's here she'll help with the kitchen, though she has a bit of difficulty walking she'll come up and take things over to people. D and R look up, D with suds up to elbow; there's a pause, a sudden shift when someone has something say and depending on mood (mine), can be filled with momentary concern – still thinking in terms of vulnerabilities, how was she last time I saw her? Was she happy or sad? Is she ok? has something happened? Too much coffee also does this – and D breaks out into a smile "she's gone and put herself in the home, would you believe it? Tried it out a few weeks ago and loved it, loved it" D has estuary accent, second 'loved it', triumphantly emphatic. R looks on, has also stopped, and is smiling. "This all works doesn't it?" We look out of the hatch. I feel a soft glow of something, Ivy being here but not here, a milestone, marking a moment about this whole endeavour.* ***Fieldnote, 15.12.18***

I first met Ivy at one of the weekly sessions at the Meeting Centre in Brecon. Ivy and her carer were some of the first people through the door. Like many others with dementia, Ivy has had increasing difficulties communicating, but nonetheless, she could, with a bit of encouragement, take part in one of the key elements of the Meeting Centre Practice which is to sit down in a circle at least twice during each stretch of four to five hours; and in that circle of telling stories, sharing experiences, playing games – it's such a central part of the practice of Meeting Centres.

Integral to the sessions also is the lunch. After the initial cups of tea and coffee, we all eat together, often continuing the conversations started in the circle. As we explore, there also many regular relaxation sessions, almost always in the circle itself, a form of self-care that benefits everybody – volunteers, carers, the few employed staff and people with dementia - and again helps us to bond and support each other. The space where this takes place not only has a small industrial-style kitchen, but also foldaway ping-pong table and the big bright windows look out over the Brecon Beacons. If there is a god to be found here, she is definitely fond of solid pine and pastel colours.

Ivy and her carer would take as much part as they could in these sessions, and would take part in most of the activities, which as far as possible are based on ideas from the group itself; but what Ivy seemed to enjoy the most was helping out in the kitchen, making sure that people got their cups of tea and helping to plate things up. She had spent a large part of her life as a dinner lady, working in the kitchen of the nearby school. Each time I visited, for some of my time I would help out in the small kitchen space, and guaranteed Ivy would also be there.

For many with dementia, and generally as we get older, procedural memory (knowing how to do such-and-such) often persists much longer than other memory systems (Matthews, 2015, Nilsson, 2003). Even though there are some in the group who find it difficult to communicate, they often still take part in, and enjoy, activities such as walking, dancing, or singing that rely on embodied procedural memory. The table tennis has been a firm favourite from the start, and often gets to be quite competitive, but the group under the beady eye of Yvie has also managed to develop some forms of indoor rugby, even cricket at one point, all based on the interests of those in the group.

It's doubtful whether Ivy remembered who I was properly from session to session, but as time wore on, what was a look of uncertainty when I asked her how she was became a smile, even though her ability to speak was deteriorating into longer lapses of silence. But she would always help around the kitchen.

These spaces in the Meeting Centre corresponded in some way to Erving Goffman's notions of front stage and backstage (Goffman, 1959); most of the action involving volunteers, staff and those affected by dementia would happen in the main vestry, whereas the backstage was the kitchen space, which was usually mainly the volunteers and staff. Over the years I volunteered there, there I would always notice a slight shift of tone and feeling between the two, with the kitchen being a more off-guard or even confessional type space. In between the pots and pans, things were said or aired which maybe wouldn't be said in the other space. The tone was more jocular as we peeled potatoes, chopped veg or even just made scones.

Ivy has been perhaps one of the few with dementia who would always be in and out and at the threshold of these spaces in each session, quietly moving things from one space to another, and if not waiting at the hatch, then inside the kitchen drying up – until we realised that there was a dishwasher available. Then, as described in my fieldnote, having got through the snow from Cardiff for what was my second Christmas dinner with the group, which had by now grown significantly, I was busy helping in the kitchen once more, and for a while I couldn't put my finger on what was different, until it came to me: 'where's Ivy?' I said.

The other two in the kitchen, both volunteers who've been working to help support people with dementia locally from before the centre had even opened its doors, stopped what they were doing, and there was a small pause as we looked at each other. For a split second, I felt discomfort, feared something bad had happened, until one of them smiled broadly and said that Ivy had put herself into a local home and that she wouldn't be coming any more but was completely happy, a decision shed thought about with her carer.

This was a small ending really, but nevertheless it felt like a 'threshold between the known and the unknown' (Raynor,2018). Three of us in that kitchen space thinking about Ivy having made up her mind to move transition into something new, a strange kind of freedom, but also for us something significant, a hope that she'd been supported by the practice of the Meeting Centre. For me and for some of the others who'd been there longest, Ivy in some ways still lingered there, a trace of her as we still wiped the dishes from time to time, even if there was a dishwasher: if 'endings are an opportunity to take seriously the significance of the *absent* for the present' (Raynor, 2018), then it felt that that this particular absence from what was still a fledgling project in many ways, was somehow a joyous absence.

And of course, she isn't the only example of endings in this context, and not all are joyous. There are many examples in this group of people who've struggled with this very slow end of life that can happen with dementia, the undeniable grief and loss that is felt at times when close and intimate relations change and get closer to the end. Windsor for example, our most competitive ping pong player will regularly come in and ask his own wife if she’s seen his wife, or Pam who still comes a year after her husband had to go into a home because it was simply impossible to manage his symptoms.

The anthropologist Janelle Taylor, writing about her own mother who had dementia has argued that we may need to stop looking only to individuals as the bearers of "selfhood," and start looking more at how "selfhood" is distributed among networks, sustained by supportive environments, emergent within practices of care (Taylor, 2008). I argue in the conclusion of the thesis that this is one of the key strengths of the Meeting Centre as I’ve experienced it. It was an idea which emerged without prompting from the group itself: as some deteriorate, we collectively shore up each other’s experience over time. We all change in that respect. The key idea here is one of metamorphosis, a transformation from one being to another. This is at the heart of what happens as people are affected by dementia, and what the Meeting Centres try to do is to support people through this metamorphosis, as we very often have to bid farewell to previous ways of being. Ivy’s story has emerged and become part of our shared practice of care as a group in Brecon. Even though her time with came to an end, as I write this some years and months later, we changed because of her being there.

74. Brecon stroller 2: jazz, haberdashery, military, Brexit

Figure 24: August stroll

A wink. 'Don't let anyone know but the last thing I'd want to do is go to see some jazz'.

Shop owner and Brecon Jazz organiser

Individual or group, we are traversed by lines, meridians, geodesics, tropics and zones marching to different beats and differing in nature…we are composed of lines. Or rather bundles of lines. (Deleuze & Guattari, 2013, p237)

Playing jazz means learning how to reconcile differences, even when they're opposites…constant co-ordination, but in an environment that's difficult enough to challenge your equilibrium…you're always prepared to do the unexpected (Marsalis, 1995)

We are grappling here with difficulties not easily mastered. The community be it numerous or not…seems to propose itself as a tendency towards a communion, even a fusion, that is to say an effervescence assembling only to give rise to a unity (Blanchot, 1988, p. 6)

This stroll took place in August 2019, on one of my last visits to Brecon, a walk which took in an outing with the Meeting Centre group for an hour or so, but also other events on that day. I'd tagged along before when the group would leave the usual vestry surroundings, an important part of the Meeting Centre practice for several reasons, but above all, one which meant that people weren't defined by the building alone and made it easier to be part of the wider community, which had its own benefits, as Yvie had commented:

> *We don't wear uniforms. We were somewhere the other day and the staff wanted to know who we were and the y said 'it's so rare to see people of such mixed ages together – that's why I wanted to know who you were, because you're all different ages and having a laugh together' – he didn't notice the dementia, what he'd picked up on was that it was a bunch of people enjoying themselves, having fun. Where that used to be common – in whist drives, this that whatever, people of all ages coming together – well if you've got less of that now, and you've got this bunch of people out there doing that, not in a particular place with uniforms, then that changes things…it might be what brings back integration and inclusion.* YG

That day in question had the sight and sounds of an important by-election taking place. With the drumbeat of Brexit in the background, this one that had (UK) national attention beyond the febrile buffoonery of August which usually takes hold in the national newspapers[11]: an expenses scandal involving the local Conservative MP had meant a recall and by-election at a point which the arguments about what form Brexit should take were continuing to be contentious. This sketchy, ill-tempered milieu wafted through all media; I felt relief turning off the car radio as I entered Brecon. A close yet sunny day, I parked up beside the river and saw the notice outside the usual spot for meetings, explaining that the group was over at The Museum of the Royal Welsh, where I would join them.

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[11] I noted the following headlines outside various shops in the town: 'Flappy Hour – Booze-Crazed Gulls Terrorise Weatherspoons Beer Garden', 'No Deal Millions To Be Probed By MPs' and 'Army Trains Keyboard Warriors For Digital War'

As with other strolls, a layering of stories awaited. Beyond the obvious, there was something in the air, a bustle in town, even down by the river it felt like there were more people about (but then August in most picturesque towns will have tourists about). 'A point of observation describes a path' (Ingold, 2011, p12), and this was another opportunity to take advantage of a purposeful walk: I looked up from the river, towards the centre of town, located the position that museum in my mental map of Brecon, began to walk up the hill. The urban topography of the town is very familiar to me by this point, but I noted the route in my fieldnotes:

> *So walk onto Kensington then Watergate over the Honddu looking murky past the working men's 80s nite and the lib dem headquarter (' Jane DODDS Jane DODDS Jane DODDS') and up Ship St past the butchers & the florist – panting slightly in this humidity & not so quiet for 10.30 people huddled in Costa for coffee and I pass the Guild Hall look over to Bethel Square hoping to see some trace of old Bill who would've passed through on a similar day in August - pass the Brecknock museum still not finished and jazz posters up in some of the pubs and around taking my memory elsewhere for an instant- August in Brecon has peculiar balminess from the river and canal and recall all the gigs crammed into market square and riverside people with instruments looking lost - the continental-ness an irony on such a day - as I walk in an incredibly straight line from the top of the hill down Watton and its treelined straightness very french how very neat the romans then the norman marcher lords & I pass the rugby club across the street on my right and find it*

Once up the hill on Ship St, you come to bifurcation, a point at which I always hesitated if strolling around without a place to go. The left brings you past the florist then eventually the market, and the right past the Lloyds bank which has been a bank forever - a Dementia Friend by now, previously the Wilkins bank, between 1788 and 1890, (British Banking History Society, 2020), established in 1778 as Wilkins, Jeffreys, Wilkins & Williams. It was also known as Brecon Old Bank. Of the four original partners, Walter and Jeffreys Wilkins had worked abroad with the notorious East India Company (Dalrymple, 2015): it financed the local agricultural community, but also much of the Valleys expansion beyond, with branches in Merthyr Tydfil, Dowlais, Haverfordwest, Carmarthen, Cardigan, Llanelli, Aberdare, Cardiff (Lloyds Banking Group Archives, accessed 2020). There's another bank there too, which by now is a warm café by day, with the promise of comedy nights, and then the Guild Hall, traditional seat of power where I had recently sat through many meeting in my initial visits to Brecon. You glimpse the chapel in Bethel Square, nod to old Bull Lee. Most of the town centre sits on that hill that overlooking the Usk, and though it has many other layers, some sort of military garrison has haunted the space since Roman times. Up until very recently, the well-regarded annual international jazz festival brought the carnivalesque to balmy August nights, jazzers weaving between pubs and venues, dodging squaddie menace. It's still an annual event, but on a more local scale, not what it used to be, as Gaenor and others had recounted – though I also had many a hazy memory of the festival.

But descending along Watton St the straight line from the hill, the town museum to your right, it's an incredibly straight road, which goes all the way past barracks and out of town. A scarecrow with 'Dig for victory' around his neck and an empty but freshly painted wooden sentinel post stand outside. By that point I've passed three polling stations, countless posters for Brecon Jazz, which will take place in a couple of weeks' time.

> *I enter sharp contrast to outside brightness- there's oak-panelled uplit old museum feel already wood smell and it's quite packed it's August after all & small families and tourism in the air where I peer into slight murk with shields old banners medals everywhere fluorescent brightness in corners toy soldiers and princely portraits & find my people and - I see Geraint first and broad smile 'sdim llawer o gymraeg yma nagoes' he says [not much welsh here is there] mischief of his smile and good to spot him but also he automatically speaks in welsh to me - then Gaenor with Windsor hunched over one of the display cases and Gaenor gives me a smile and says 'you pop up everywhere!' & there's a picture of Windsor's dad in the first world war & I was totally familiar with this story, Windsor says 'the horse, the horse' and had several sad stories had survived Mametz wood, brother in the same battalion & echoes of my own taid's story both of them, we'd recounted these in the circle*

Windsor recognises me but seems ill at ease here, even though he'd been engaged with the picture of the horse. To an extent, I can understand how he might 'feel out of place' in these surroundings, because it's dark inside the museum, 'busy' (as in crammed with objects), and quite a humid day in an unfamiliar public environment. The line between being therapeutic and frightening can be difficult to negotiate in such spaces for people with dementias (Brittain et al, 2010), even if he's with his group, and I sit down on a bench with him for a bit. Gaenor says that because of the heat, his sleep patterns are worse than ever, with a knock-on effect on her; they both look exhausted, but Gaenor is still making an effort to chat to the others in the group. I ask whether she's getting any extra help and she mentions that the help that she has been getting from Crossroads, a charity, about two or three hours a week of 'respite', may be cut, because they don't have the resources. Windsor is looking at me intently. Gaenor mentions a session they had at the Meeting Centre recently about the Royal Welsh Show, which is held not that far from here every year. She said that Windsor had talked at length about the sheep shearing, out of nowhere – this was quite something because his communication skills have been deteriorating.

I speak to the others too. Yvonne over from Ystrad, we speak in Welsh about her husband, who's in care, but hadn't left his room for a while and was struggling; Dot and Dafydd, who when they joined the group after Dot's diagnosis were completely distraught – now they're the life and soul of meetings, offer Windsor and Gaenor a lift back home ('where are you scampering off to?' said Dot, broad Lancastrian accent). There are some new members, softly spoken ex-officer and his wife, who knew the area well., but had travelled a lot with the army, they had Brecon roots through Christ College. A new co-ordinator too, keeping an eye, eager to talk about what they'd been up to. Having been part of this for such a long time, even in this rather strange museum, I felt conviviality and easiness, even though, by this point, part of me knew that I was leaving this place in a different way, things were coming to an end.

…

I didn't have long that day though, as I had to get back to Cardiff, so after a while I said my goodbyes and went out into the yard, to walk back up the hill. By chance, I bump into Dave, the social worker, one of the first people I'd met in Brecon; he'd just been helping someone who had no resources clear their garden – *he had nothing and no-one, is beginning to forget* *the basics*. He looks at me and says that things haven't changed much since we last met, a while back, in fact they may have got worse, for all the goodwill: *it's just the basics still aren't there, there should be a lot more communication going on. No point having the cream on top unless the cake is set…if people can't get their shopping done, then what else is there? Starve? It's the basics that we have to fight for still…*I look at him, he looks at me with his blue, blue eyes: often 'Care makes space for what is not possible' (Mol, 2008, p.25). There's a softening, we both half smile, closed mouths. *I've got to go and see another one just now, down here – I'll see you soon at one of them DMiP things…*

What's embedded in the ordinary practice of refusing to give up on people, I wonder? An intensity which moves things, clears gardens, does the shopping, breaks rules occasionally - or gives out clean needles, washes filthy clothes – but above all listens, shifts gear as obstacles come into sight. *He had nothing and no-one, is beginning to forget the basics*. The quiet, often hidden social and material relations of vulnerability, as lives begin to decompose (Butler, 2016).

…

As I continue up the hill, I notice a shop festooned with Brecon Jazz posters, its distinctive graphic remains the same after some thirty-five years. I linger over the brief summary of the main acts every year since 1984, try to recall the years I'd managed to go during the nineties and the noughties, faintly embarrassed at who I'd missed, a jab of warm recognition for about five or six of those years, thoughts of friends who'd come along, others who'd played in bands there, others no longer with us. It used to encompass the whole town: the Market Hall, the Castle Hotel, Theatr Brycheiniog. I walk in, on a whim: this haberdasher sells a bit of everything and the shop seems to be the festival headquarters. About a year or so ago, we'd made colourful bunting at the Meeting Centre for this much reduced version of the festival, people pitching in their stories about the antics and atmosphere as we cut out old swatches of material. Windsor and Gaenor used to really enjoy taking part in the festivities, when you could stroll around from gig to gig, free music everywhere.

Though reduced in size because of financial pressure, no longer with major sponsors, it became apparent that it had gone back to its roots; *we've taken back control*, said the shop owner, with a wry smile. I'd snapped a picture of the history of the festival at Theatr Brycheiniog at one of the dementia networking days which took place there with Joan at the helm. Liz Elston, the first festival organiser said of it:

> *It's been a truly community venture serviced by voluntary help and that spirit of community and engagement with the people of Brecon has been one of the even's key appeals over the years and a significant factor in its longevity*

The shop owner explained how the Brecon Jazz committee was active all year round to fund the event, all over the town. Her husband was also a printer who printed everything needed, so it was all about the small local businesses also: *the minute it finishes, we start planning the next one.* I think of the notice boards, the jumble of activity here, and could see how this all fitted in yet another celebratory version of being-in-common in this town. I think of Rhiannon, and of all the committees, the rituals of eating, meditating, listening, 'effervescent assemblies'

…

Walking back towards the car, I stand for a while on the pavement close to the Lloyds bank, and watch the antics of the Brexit Party candidate, trying to drum up support, three men in chinos taking selfies and laughing with him, one having just drawn up in his sports car. The 'forces of encounter' (Gregg & Seigworth, 2010, p.2) swirling around me on that day feel so much heavier, a culmination point perhaps, a clash of conducting circuits: humidity, Brexit, Brecon, I feel slightly wistful because there's a sense of ending to fieldwork. I'm anxious about Windsor, what Dave has said brings home how little has changed from his perspective – he was one of the first people I met here after all and remains in his (statutory sector) job: by this point, Rhiannon, Yvie and others have moved on to other things. I feel slight agitation at the politics in front of me, the layers of empire, the military, banking systems which financed it all, as an older man probably of Nepalese descent passes by. Engaging with the affect of all of this, the heightened feelings constantly in the background, the image of a battered Union Jack, pierced by fluorescent light at the Museum, comes back to me. This tenseness passes, but if ‘how we engage those affective feelings has implications for the politics of knowledge and for how we understand politics more generally’ (Closs Stephens, 2019) then I can’t help but feel an invisible line being drawn between those fears around ageing and dementia, the fear of others which permeate the politics since 2008, strung together by political opportunism. The way I’m creating this knowledge around dementia are borne of the same politics perhaps, but that can only be part of the story; I’ve tried to be *beside* those fears, be aware of the ‘residual forms of essentialism’ (Sedgwick, 2003, p.8) which might unfairly cloud what’s to be felt in front of me, between bodies, always moving. I return to my own body and start walking down the hill, my feet taking me back towards the car, take refuge in the micropolitical hope of the jazz festival still there, leavening something.

75. Cut-up: ‘Have community shaking’/ ‘Fast feet apple’

To finish off this Touchstone, I’ve taken one of my fieldnotes, highlighted previously as part of a description of an afternoon at the Meeting Centre when we had a ‘tea-dance’ which turned into something livelier. I folded this into a dementia advice leaflet (Change4Life 2015) on how to reduce the risks of dementia. Again, much as in the previous cut up, the focus of this leaflet is on the individual’s responsibility to do this. There is a sense of movement in this piece (it was a joyous occasion) and the original fieldnote was written using the spontaneous prose method, which aims to be ‘undisturbed flow from the mind’ (Kerouac, 1992, 57). It was a sunny day in the Baptist vestry where we used to meet, and after one of people with dementia in the group who I’d got to know quite well, but had great difficulty with verbal communication, got up to dance. I joined in with him, and it felt like a moment of connection. The fieldnote can be found in Dancing with Windsor.

This is the text of the leaflet:

Be physically active

The number one thing you can do to reduce your risk of dementia is to be physically active.

There are lots of ways to be active: walking, running, riding your bike or even mowing the lawn counts.

Search online for Change4Life Wales for lots of ideas to help get you moving!

It’s recommended that you should do 150 minutes of moderate exercise each week. This might sound like a lot but can be achieved in blocks as short as ten minutes at a time. Walking fast counts towards this, so you may already be doing more than you think. Little changes, such as going for a walk or a ride on your bike at lunchtime, may be all you need to do. There are lots of other ways to build physical activity into your daily life, for example replacing short journeys in the car with walking, or using the stairs instead of lifts.

Time your walks to the shop or to work and also check out how many steps you are already doing. You can use a pedometer to do this; most smart phones have them already built-in.

The cut-up reads:

Have community shaking/ Fast feet apple

Up to no stayin time

Little feet steps

whether your stairs

but stayin

be shaded

using

walks

Walking copies achieved physically
then smile as
everyone
gets gleaming
or going, this Saturday;

the recommended:
you’re a number,
regular,
active.

The lot shop, over riding
eyes this:
arms active, walking
can phone
but
like each, blocks Wales,
lifts,
sweat, do lunchtime

Do many

have community shaking?

Might counts,

check moderate

what pushing in’

exercise

short twelve

ways to them

and mowing

your strange walk

looking, moving -

husband use

built changes

So instead, you

reduce all minutes.

Who?

Streaming of a two dances mother!

lots lit roughly,

leg active

You’re in short
fast feet apple
can we be
time, enormous need

marc behind, does lots…

Build brother daylight !
Leg laptops those dj replacing again

This Change4Life, alive
and the life arms at sound
most, and roll on night,
a journey.

Her intently thing,
Monday dancing,
kit smart with risk.

You jolt!

There - the lawn surely a sun bike

your physical fever

even this doing, staring

with T

as to activity

running for car, my

ten stops, one look

must help the half pedometer, daily.

Other ideas:

stomping, hump

and forehead back, your

dementia example

bolan glasses up.

May night is more,

looking minutes

student out

doing do it

room notice and work

Be drinking towards beaming do:
more counts, also swaying

For online eyes, screen watchful;
how already at
whether you think
are alive

This piece has a surreal, rhythmic quality ('doing do it'), which evokes some of the strangeness I felt on the day, as we all gradually lost inhibitions and danced in the daylight. The fragmented and mangled syntax contains pithy, intriguing phrases which feel just beyond intelligibility: 'Monday dancing, kit smart with risk', 'Streaming of a two dances mother!', but that very non-linear, stuttering strangeness connects me to that afternoon, more than the fieldnote can on its own. As a bilingual Welsh/English speaker, crossing linguistic boundaries seems natural to me, and this piece again challenges the machinic discourse of responsibilization, the directive language of the leaflet. It breathes life into the remains of language – in notes, on pamphlets - by only retaining 'the skeleton of sense' (Deleuze and Guattari 2016, 21), but it could equally be divorced entirely from its origins, could stand as a piece of saturated poetry which nods to Kerouac and has 'eliminate(d) all that is resemblance and analogy' (Deleuze and Guattari 2013, 327). It disorients and makes strange, but also ends up mirroring some of the concerns of this thesis, by asking: Do many have community shaking?

76. Endings

Figure 25: Bethel Square

DFCs work on most levels, because everyone kind of gets it…it's easy to get people engaged because there's usually a personal link to them, and we can build on this for more age-friendly work; lots will know people with mobility issues, loneliness, almost everyone. We can then build on that to make people look at the spaces around them, which may be a bit shit, how could things be better? I guess fundamentally then they do become political questions SH

What's good about DFCs in Porth is that I created it off my own back, but now others want to do it too locally, I can just go and share my experience and pass some of the knowledge on. EQ

I honestly believe that two things need to happen in the next five years, and I see no evidence that we're moving towards that. One is to dispute, challenge and move away from the medical model to a social model. Second, not throw our lot in with the latest glib government, charity-based bullshit, now it's this 'side by side, speaking as one voice'. I don't speak as

> *one voice with anybody, never have done in my life, and I'm not going to start now. I appreciate the support of people, but I think that support has got to be earned.* NH
>
> *I feel as though we are only as civilized a community of people as how well we look after our most vulnerable members, it's just a natural part of me, really, and it's it's it's... And I'm no greater, there are a lot of people who feel like that it was just fortunate that I felt I had the confidence to get out and say* RD

In this section, I will look at what worked well, and what has been learned, including what limits were to that learning. It is hoped that the preceding work has given some notion of the sometimes-tricky task of pursuing the *tylwyth teg*. Hopefully, I have also been able to give an account of the translation process that was inevitable as I took a more transdisciplinary approach to. Fassin (2018) notes that 'translating from one discipline to another is very similar to translating from one language to another' (p.17), in that it needs a sense of poetic licence, an interplay between a form of questioning (if not abusing) meaning, and a wilful failure to abide by some of the rules. This has formed part of my general approach, but hopefully in a positive and creative manner which has shed some light on matters, whilst not trying to flinch from the complexities and contradictions, the rich ambiguity. At the same time, my goal has been to develop a generous sense of 'spacious agnosticism' (Sedgwick, 2003, p.8), of being beside things, and trying to avoid too much binary thinking. My period in Brecon in particular was an opportunity to 'home in' on a situation which ultimately tested my previous views and enabled me to take part in phenomena as it unfolded in practice – to listen, watch, play, dance, make tea, comfort, laugh, support and feel my way around a direct consequence of DFCs-in-action, to be beside one of its effects on the world. In both a literal and metaphorical sense, I have found myself in Border Country.

This has also been an emotional journey, this looking for the *tylwyth teg*. A lot can happen in five years, not only in terms of the fieldwork, but also in life; I've watched my son grow, the predicaments of ensuring some sort of survival for drug and alcohol services (and the staff to go with it) were eventually resolved. Some people who I've got to know in Brecon and in my own surrounding neighbourhood unfortunately eventually passed away because of their dementias but will be remembered fondly.

77. Jarring and juxtaposing

> *Critical gerontological projects and texts appear rather messy…They are amalgams of seemingly multidisciplinary but fragmented collections of often unrelated research (Katz, 2009, p.97)*
>
> *live sociology can point to a much more chaotic, unexpected and 'involutionary' relation to other disciplines and to society. In this case, live sociology is sensitive to, and indeed actively seeks out, that which is empirically and practically nonsensical – what will later be called 'idiotic'. In the process, sociology potentially undergoes, and promotes, creative transformation. (Michael, 2012, p.167)*
>
> *Burroughs' cut-up is still a method of probabilities – at least linguistic ones – and not a procedure of drawing lots or a single chance which combines the heterogeneous elements (Deleuze & Parnet, 2006, p.8)*

By using multiple resources -literary, ethnomethodological, visual, gerontological, theoretical, those from human geography – in assembling the jigsaw, in ficitioning about DFCs, it is hoped that the fragmented plurality of experience of trying to capture *something* about the phenomenon has been conveyed.

There has been a recent critical realist evaluation of DFCs in England (Buckner et al, 2019), and we are beginning to see some other evaluative work around DFCs (Novak, 2020); this approach has evidently not been my goal here, though they are both worthy and thorough pieces of research, which provide other tools with which to look at DFCs. Undoubtedly, naming, classifying, counting, describing and interpreting can render something familiar and comprehensible. In sections, this is what I've done too – but by using cut-ups and collage, I've also tried 'to provoke the irruption of otherness – the unexpected' (Clifford, 1988, p.145), to make the familiar strange. I may not have sought the 'deliberately non-sensical' (Michael, 2012) , but faced with trying to convey the 'liveness' of the research, these tactics seemed like an appropriate course given the inherent instability I've felt about the *tylwyth teg,* a way to convey the complexity of the ‘permanent ironic play of similarity and difference, the familiar and the strange, the here and the elsewhere’ (Clifford, 1988, p.146). In answer to one of my original questions, creating knowledge about DFCs has been more about ‘diffracting’ (Dawney, 2018), seeing how data might rub up against each other; a process of entanglements and disjunctures, of composing and re-composing. The resulting cut-ups have been a way of interrogating some of the dominant messages around dementia, or have re-formed into intriguing vignettes, or pithy poems, occasionally poignant.

Returning to Deleuze and Guattari (2013), some have argued that such practices operate as a kind of ‘pendulum between deterritorialization and reterritorialization’ (Falconer, 2019, p. 268), working within a logic of smooth and striated space. A smooth space is nomadic, rhizomatic and anarchic, while a striated space is sedentary, arbolic and hierarchical; Deleuze and Guattari were interested in how these spaces could co-exist: ‘that the two spaces in fact only exist in mixture’ (Deleuze & Guattari, 2013, p.552). It is this mixture, smooth space can be reterritorialized and converted into striated space, while striated space can be deterritorialised and converted into smooth space’ (Falconer, 2019, p.268). The directive language of newspaper headlines can become fragments of poetry, while the government leaflet, built on the arborescent knowledge of public health or the clauses of an act of parliament, suddenly become a monologue about the loss of a friend, or a joyful exhortation to ‘keep community shaking’. A government consultation exercise, in a space such as an old church, becomes site for an outburst of effective anti-state feeling, before eventually settling into government policy accommodating such feelings.

As we’ve seen, there’s nothing inherently new about these methods, we can trace a line back to the lively exchanges of the ethnographic surrealism/surrealist ethnographies of the inter-war years, which were then taken up by the post-war avant-garde. My hope is that there may be many more ways in which we can use the cut-up method or the collage to think about these things; each piece is intended as a ‘movement [towards] opening, not closure’ (Ingold, 2011, p4) when we think about DFCs; the great learning for me has also been to hold previous habits of thought lightly and move towards that opening.

Undoubtedly, there is a ‘performative politics’ to such a research process (Dawney, 2018, p. 111), this diffracting and being responsible for the cuts made (Barad, 2007), a sense in which I’ve tried to work things out by various performative acts – collagist one minute, literary detective another, outraged and disillusioned spectator of bio-politics at other times. It is hoped that the autoethnographic approach has been a way of providing a window onto some of these acts but also my hopes, fears and concerns throughout this thesis as presented.

78. From cruel optimism to hopeful pessimism

> *The one thing I’ve learned over the years, there’s very few generalisations you can make about the experience people are having when they’re living with dementia, but there’s a generalisation that I think is almost safe to make, that when people come to the Meeting Centre, the time that they’ve spent since diagnosis to when they come, they’ve withdrawn a lot, are quite overwhelmed and self-esteem has gone down, and the Meeting Centre reverses that so much to the extent that people thought that their dementia was going away…because people start to feel re-connected, less overwhelmed and then your status and value all start to come back, and that has a huge impact on well-being.* YG

Coleman (2016) in her analysis of austerity develops the idea of ‘hopeful pessimism’ as an adjunct to Berlant’s (2013) ‘cruel optimism’. She argues that rather than drawing discrete lines between optimism and pessimism, Berlant’s framing of optimism as ambivalent, as a process that is neither positive or negative, is a means to ‘keep on living on and to look forward to being in the world’ (Berlant, 2013, p.24), and that such a stance of ambivalence when thinking about states such as optimism or pessimism can be productive analytically. Contrasting the temporal qualities of both affective states, she argues that pessimism as an analytic device is both flattening (we are unable to imagine the future) and enlivening (we are aware of the present, however painful), and concludes that through a type of ‘hopeful pessimism’, we can construct ‘a politics of the present’ (Coleman, 2016, p.100). Hope itself is not without its contestable features (Petersen, 2015, Anderson, 2017), but Coleman’s use here is one rooted in the idea that understanding that present will give us a clearer idea of what change needs to happen.

One of my starting points in thinking about DFCs was that it represented a form of cruel optimism, in that in some (but not all) instances, the attachment to imagining a better future kept people going (carers, concerned citizens, PWD), but also locked people into a present that might have been harmful, restrictive, or constraining. There was an awareness of this among some of my informants, as I've demonstrated, even if they also took part in the promotion of the idea of DFCs. My contention was that that although trying to create DFCs through, for example, the Dementia Friends scheme can and could undeniably raise some awareness, it concentrated attention solely on building a form of affective and active citizenship that promoted 'being friendly' to those with dementia. This potentially ignored larger issues of funding, political expediency and ensuing premature deaths, through neglect, bio-political choices, the 'letting die'. It became a useful distraction from cuts to services and provision, yet more responsibilization, as services were pushed out to 'the community'.

Looking back at the period of research, I realise that this may well have been more intense in those initial years, which coincided with the first phases of austerity measures. There may have been a sense of accelerated temporality as a response to austerity, and the discourse of a crisis in ageing-dementia that can be found in Rhiannon's words: 'we had to do something'. A forced situation. In the end, 'we're all in this together' from Rhiannon and some of the others did indeed feel like some kind of protective circle around the idea that a community has an absolute obligation to look after its most vulnerable members in such circumstances.

Taking the work of BADDFC in Brecon as a starting point, it was a singular event - hearing this refrain after witnessing a dramatized plea for greater empathy towards PWD - which convinced me (from my position as a researcher), that there was an interesting case here to explore, it drew me in and in a sense, showed me a way. I felt that what was being held up as an exemplar of a certain wishful normativity to be achieved across Wales, Brecon as an exemplar of DFCs, might also contain the seeds of how one could critique such a normativity: 'the case is always normative but also always a perturbation of the normative…a case is what an event can become' (Berlant, 2007, p. 670). By the time I got to start my fieldwork in earnest, this initial phase which surrounded that event – the rise of DFCs as an object of policy, and austerity as ideological response to the financial crash, had almost passed, even if the effects of austerity were still present and ongoing.

In Brecon, my research then mostly concentrated on dwelling alongside dementia through the workings of the Meeting Centre. For all my subsequent analytical methodological wanderings, this slower, more settled and prolonged state was one in which a sense of hopeful pessimism took hold, as I learned to carry my initial theoretical baggage, the perturbations felt as suspicion, in a different way. The presence of the present – 'being present' that is, with people affected by dementia either directly, or as carers or with volunteers and staff – gave me what often felt like new forms of joy and connection; the experience changed me, as much as the example that Yvie gives above of people joining the Meeting Centre. As time wore on, I could begin to appreciate the sentiment which one of my informants, who also had reservations about where things were going, had expressed relatively early on:

> *If people are prepared to challenge a wider range of stuff, then perhaps dementia is an easy way to start talking to them about all of this…Plus, for all those people who criticise Dementia Friends as being a corporate shill, actually go and speak to people who have dementia who find the badge really reassuring…it's made a difference to their lives.* ***SH***

At the same time, my inital pessimism has remained to an extent. With the setting up of Meeting Centres as a form of support based to a large extent on voluntary sector provision, those initial thoughts around responsibilization, the rolling out of such support away from the state, still seem valid from a certain perspective. The 'Dementia Friends' scheme (never evaluated properly) came to an official end 'officially' in 2020, and even in Brecon, by then it was only Donna and Joan and a couple of others who were able, and willing, to give Dementia Friends training sessions. As I write this, Dementia Matters in Powys, which had been very successful before Covid-19 stopped all face-to-face contact, itself faces an uncertain future, even though they were an astounding success and have carried on supporting as many people as possible through the pandemic. What started out as a unified front between Brecon Dementia Friendly Community crumbled quite quickly, in what Yvie described as tea-towel politics. At least two of the main characters here also suffered what I can only describe as 'burnout', the responsibilities and energy needed to maintain and expand the work eventually catching up with them. For me also, these are feelings which are analogous to where I started out, in another field: ones of exhaustion and weary endurance (Wilkinson & Ortega-Alcazár, 2018) with this petty dispersal of the state.

However, more hope might have come from one of the most visceral experiences in this research, the Consultation event, which rippled out into other consequences. The Welsh Government took roughly another year to re-write what had been originally drafted, almost certainly because of Nigel and others, and the community-making organisational power of DEEP. I am satisfied to see this as a critical counter-conduct, as I've outlined. The community-formation that happened as an act of 'active citizenry' was table to question the pastorate's intentions, but also press further.

Taking up the orthodoxy of a confessional 'consultation process', one in which DEEP, for all its separate and distinct motivations, are also in a sense 'pastors', like the Alzheimer's Society, then that orthodoxy was used against itself, further intensified, as Nigel and others became part of a 'technology of performance' which they created; they are now scrutinizing the way government will handle its obligations to PWD as part of the Dementia Oversight of Implementation and Impact Group (Welsh Government, 2018b). As Rose (2007) noted, what we could consider as older 'pastoral power' where power would usually flow in one way, is different from the modern 'pastoral power'. Modern iterations 'entail intense bidirectional affective entanglements between all the parties to the encounter…It takes place in a plural and contested field traversed by codes pronounced by ethics committees and professional associations…by researchers…the advice offered by self-help organisations' (loc.1768).

Even so, how I felt the event outlined in Fragments 36 and 37, as one of the most intense of the confessional episodes I've sat through, was something more than 'the refractory turning of government against itself from within the discursive and political field of possibilities opened up by government' (Golder, 2015, p.22). Undoubtedly, both the UK and the Welsh

Government clearly wish to 'stimulate actors, movements, energies and subcultures outside of the state, but…fear that their political strategies and program risk stifling those very energies' (Dean & Villadsen, 2016). Such macro critical counter-conducts on the part of Darla, Nigel and others - expressed as gestalt in an academic conference, or a mic-drop in a consultation – seem to be energies that flow from smooth spaces (Deleuze & Guattari, 2013) into the striated, and may continue to change and grow, but are ultimately entwined. This is a very Foucauldian vision too, of such bio-power as ultimately being something productive.

In this research I've also tried to take heed of the micro, 'slid[ing] over the live surface at work in the ordinary' (Stewart, 2007, p.4): dancing with Windsor, a joke with Nigel, laughing with Geraint, missing Ivy; as I think of them now, these smaller acts bring hope, possibility and learning. For me, these have been glimpses of the *tylwyth teg*, and brought the micropolitical hope that we 'learn how to act in the midst of ongoing, unforeclosed situations and experiment with ways of discerning and tending to the 'otherwise' (Anderson, 2017, p.594).

79. Time and metamorphosis

Figure 26: Licenced to let post horses

Having some perspective on the temporal aspects of such a project has been useful, not least because the perception of time can be central to the experience of dementia, and more specifically, dementia activism. Bartlett (2012) highlighted this in her work on emerging modes of activism in dementia, but it is a theme which is common to many who suffer from chronic or terminal illness – there's a fundamental shift in how clock-time and lifetime are viewed (Charmaz, 1991). The idea of metamorphosis is also fundamental to dementia: it is a process which begins and ends with two different entities (Bynum, 2001), is both a destructive event but also creative. A passage from Malabou (2012, p213) captures something of this:

> *The destructive event that – whether it is of biological or socio-political origin -causes irreversible transformations of the emotional brain, and thus of a radical metamorphosis of identity, emerges as a constant existential possibility that threatens each of us at every moment. At every instant we are susceptible to becoming new wounded, prototypes of ourselves without any essential relation to the past of our identities. Alzheimer's disease is a particularly important example of such loss. A form of life appears that bids farewell to all the subject's old modes of being.*

Such an unredeemable, 'destructive plasticity' can leave no trace of what we once were, underlines the contingency of what 'we' are. As a researcher with people affected by dementia, you become very aware of this: there are constant glimpses of this in not only the difficulties that people have in communication, but in the poignancy of, for example, Windsor coming into a room and asking Gaenor, his wife for over fifty years, if she's seen his wife. Such transformations can happen quickly with certain dementias, but fundamentally, for many, this is a slower violence.

However, it is important to note that there is also creation: new identities can be formed, new connections through the collective group identity, 'entwined becomings' (Schwannen et al 2012, p. 1294). In a very striking way, Darla and many others that I have met hold their condition differently, have some acceptance of it, have arguably created very active new lives for themselves through a bio-social understanding of dementia; as Wendy Mitchell said, 'dementia has brought a gift of friendship' perhaps through the awareness of the preciousness of time in their lives. Even more importantly perhaps, what Darla and others (see Fragments 34, 38, for example) do is offer a model of personhood in dementia which has radically shifted away from 'a unidirectional understanding that continues to position a person with dementia as dependent on others for affirmation' (Bartlett & O'Connor, 2010, p.22). They can challenge the assumptions made about their social positions – be that in a lecture about their condition, or a government consultation exercise, for example - and develop a sense of their own individual rights and expectations of justice. 'If you've met one person with dementia, then you've met one person' as Nigel always says.

Being present in this way has its costs (Wilkinson et al, 2019), but maybe the brief moments of meaningful action that I've witnessed, both micro and substantial, have added to my sense of hopeful pessimism. Arguably, it is not just those who are living with dementias who go through changes. Many of those who seemed to have led locally on DFCs in Brecon had their own transformative experiences, and the sense of a collective identity that formed, albeit temporarily for some, seemed to exude a particular type of active, organised citizenship. This type of citizenship-in-action for the most part, seemed to magnify feelings of well-being for all concerned (Bartlett, 2014), for a period at least. Joan and Rhiannon in Brecon, as well as Emma up in Porthmadog, are all quite charismatic individuals who have lived with the idea of creating DFC and have ultimately created their own practices and ways of interpreting it, and at least for some of the time I spent with them, seemed to thrive on this.

However, this also had its costs, as people drifted away or had to stop because the demands became too great. In the end, this research still gave me an impression that despite the many types of critical counter-conduct challenging the pastorate's ceaseless cultivating of 'good' citizenship, the fundamentals of 'pastoral' regulation (Cohen, 2006), and the creeping importance of 'self-care' for those with dementias (Jones, 2018), suggested that these expectations – with no extra, long-term support from the State – for quite a few of those involved, would often end up in burn-out of sorts. I came to realise, and accept, that this had been my own story of weary endurance with the drug and alcohol charity too.

As Cruikshank (1999) identifies, Foucault had traced how this works in terms of bio-power in these bio-social settings: ‘invest[ing] the citizen with a set of goals and self-understandings, and gives the citizen-subject an investment in participating voluntarily in programs, projects, and institutions set up to “help” them’ (p.41); but one of the findings here is that an effect of this, of the energy need to sustain the idea of a DFC, has been this cost.

80. What’s changed? What have we learned?

In a sense, it could be recognized that dementia can create types of community on the micro level, and that this is what I’ve witnessed in Brecon, people coming together to form types of community, though these might be short lived, depending on the politics of funding. The dynamics of doing this in Brecon seemed to need some of these conditions for success: political ‘buy in’ locally, engaging with pre-existing community networks and assets, charismatic individuals, and involving people affected by dementia and their carers as much as possible in planning. It seemed to be a similar case in Porthmadog with Emma.

Through sustained and close contact with some of the people involved I’ve been able to trace these developments in way which has tried to steer clear of what Stewart (1996) has called ‘forgetting’ i.e. ‘ignoring the cultural specificity, singularity and the dense mixture of things and words that are fabricated in people’s everyday encounters with each other’ (MacLure, 2013, p. 170). That said, many of my observations echo some of those found in other approaches to investigating DFCs, ones which have used more conventional methods: the acts of raising awareness, bringing together local organisations and services, engaging and normalising the experience of living with dementia (Buckner et al. 2019) were also noted in such studies, including as mentioned above the importance of charismatic individuals or pre-existing community networks. Inevitably, research habits built up over many years have meant that at some level, I have been charting similarities and making comparisons from place to place, but through reflexivity and a willingness to try alternative methods, I’ve tried to develop my practice here as one which is attentive to how ‘the anecdotal, the accidental, the contingent and the fragmentary’ (Stewart, 1996, p.11), those that arise from this idea of ‘dementia’ and become entangled in local practices that bring people together and make them partake in communal experiences. I’ve been beside the events which bond people together, from sound baths to washing up dishes to soaking tired feet, or organising new structures of community help, one cuppa at a time, in ancient Guild Halls.

Rather than try to impose meaning on these experiences, ideological or otherwise, I’ve learned to be more open to such ‘events’, recognising that such events ‘always includes dimensions which aren’t completely actualised, so it’s always open to a degree, it’s always dynamic and in re-formation’ (Massumi, 2015, p.58). In my time there, I was able to witness the development of the Meeting Centre as such a dynamic practice, one that seemed to develop a sense of selfhood not only for those with dementia and their carers, but also those that work and volunteer there; some felt more connected locally than they ever had before, for example. This was through some of the day-to-day ritual, but also the spontaneous fun generated in the activities – from indoor rugby to disco-tea dances to aforementioned sound baths, but also the circle work, the communal eating, telling stories, playing games, meditative and relaxation practices. My experience was that it led to forms of support that fostered feelings of kindness, acceptance, and reciprocity among those who took part in its rituals. This support compensated for the often-negative social consequences of being affected by dementia, such as loneliness and isolation; Ivy feeling supported enough to go into a home voluntarily was truly ‘a moment’ for us all. I also witnessed this directly with people joining the Friendship Circle as described by Yvie: devastated by the diagnosis, and very unsure of the way forward, but over time becoming very involved and supported by all there.

It felt like the centre as I experienced it formed part of an emergent practice of supportive care that seemed to challenge the idea that individual cognition is the only important marker of personhood; certainly, it felt like this in Brecon, though I couldn’t comment about other places. Being part of it over time helped me to be alongside dementia, and to feel that ‘selfhood' in fact might be something ‘distributed among networks, sustained by supportive environments, emergent within practices of care’ (Taylor, 2008, p.326). Maybe this chimes with certain currents in non-representational theory about emergence that ‘refuses to ever really settle down into more familiar patterns of subject and object, animate and inanimate, cause and effect’ (Wylie, 2010, p.105).

81. Failing better - innovations and limits of methods

> *The study of the geographical dimensions of aging has never reached its full potential. . . Only a fraction of the depth and scope of the collected theories, concepts, and methods of geography has been applied to gerontological thinking and research (Cutchin, 2009, p.440)*

The idea here has been to go into a kind of ‘geography of what happens’ (Thrift, 2007): by trying to give a sense of movement, unfolding, often in everyday places or situations, but in the specific context of trying to make sense of ‘dementia friendly communities’. I started this thesis referencing Samuel Beckett’s innovation to create a work which could be randomly re-mixed – a cut-up approach of sorts - and the reader may well have started reading in this section. If so, then drawing to an ‘end’ of sorts but one that looks towards beginnings, I come back to Beckett again, and therefore back to the twentieth century avantgarde, in recognising the need to ‘fail, fail better’, the often-quoted line from one of his last works, Worstward Ho (2009). Recognising from the outset that my methodological tactics and strategies have evolved, are imperfect and to an extent experimental, the recognition that failure itself can be productive (Horton, 2020), has left me with yet more of a sense of hopeful pessimism.

Such experimentation with spontaneous prose, cut-ups and collage has meant letting the research ‘dance a little’ (Vannini, 2015, p. 14), if not literally dance at times; through the support of my supervisors, I’ve been given space to follow my own path, but with no illusion that such methods might find a future, being a niche pursuit. After many years of doing qualitative research in a ‘conventional’ manner, this has been an opportunity to try new ways, and has given me hope that there are corners where such experimentation would be welcomed – it was a surprise after all to find that the one other instance of taking the practice of cut-ups seriously had links to my own department of Human and Health sciences and nursing practice (Biley, 2004); a current colleague remembered attending a workshop organised around this method by Dr Frances Biley, an academic nurse-practitioner at Cardiff University. In addition, using the fictocritical approach for some of this, an approach which tends towards the fragmentary, has guarded against too much of a sense of closure and wholeness in this style of writing (Haas, 2017, p.27), an art of not analysing too much, perhaps. Vannini (2015), referencing Doel (2010), further expounds a position with which I've had sympathy more generally:

> *embrace experimentation, to view the impossibility of empirical research as a creative opportunity (rather than a damming condition), to unsettle the systematicity of procedure, to reconfigure (rather than mimic) the lifeworld, and in sum to learn to fail, to fail better. (p.15)*

In critical gerontological terms, this plea echoes attempt to traverse a very 'nomadic thought-space' as envisioned by Katz (1996, 2009), who interpreting Deleuze and Guattari (2013) draws on their distinction between royal science and nomad science. State (or royal) science is that which as a rule, reproduces state power through seeking universal laws, and operates in striated, fixed space. Nomad science is 'heterogeneous, flowing, discontinuous, indefinite, ambulatory and potentially radical in its undoing of state science' (Katz, 2009, p.95), and is associated with smooth, moving space. Katz draws parallels here too with Deleuze and Guattari's concepts of major and minor language (Deleuze & Guattari, 1986). In drawing attention to the very messiness involved in trying to create knowledge about dementia friendly communities, I have tried to take a somewhat nomadic route, to avoid what critical gerontologist Estes et al. (1992) saw as the danger of the discipline "selling its soul to mindless, theory less positivism without retaining or regenerating the reflexivity that is essential to the resurgence of the 'gerontological imagination' (p.60) Although grounded in sound ethnographic techniques, I've nonetheless attempted to creatively cut-up and remix some of the material generated in pursuit of the *tylwyth teg* with the intention of interrogating some of the unquestioned assumptions that were commonly made about DFCs, and where the concept came from. The resulting transdisciplinary work hopefully also speaks for the openness to other ways of thinking that Katz and colleagues identify as being essential to the future of gerontology.

82. Where are we going?

In the end, working with the principle that 'Knowledge comes from all sorts of places', as set out by the Scottish Dementia Working Group in their core principles for research with PWD, I hope this thesis has been able to honour the spirit of that idea. Concretely for me, Brecon has become in some senses a 'knowable community' (Williams, 1973, p.240), and for the moment, a continuing part of my consciousness and day-to-day experience through this thesis, even if I had prior knowledge of the place.

I have kept in contact with some of the Meeting Centre and still sit on their Advisory Group. As with my other post-graduate learning experiences over the years, the process of doing this PhD has been one of steadily approaching a new touchstone, hopefully building on the others. Without the MSc in Social Science Methods, gained some ten years ago, the resources to approach this task intellectually and practically would have been far more difficult. Equally, as someone who has practiced forms of qualitative research for longer, including at MA level ten years before that, the intervening years of interviewing, focus groups, frame analysis, discourse analysis and the rest – above all trying to attune to stories heard and listen to people, including my own part in those stories – have helped greatly. But in a sense, I have also come full circle, because my first long dissertation for degree in English and History was an attempt to place one of the Beat writers in yet another different frame of reference (Williams, 1991) ('The Picaresque Vision in Jack Kerouac's Work').

As explained, using participant observation as one of my main methods perhaps precluded the use of more participatory techniques, to an extent. However, the intention here has been to do justice to the interview encounters as dialogical acts, taking into account the contexts, and atmospheres of interactions between myself and the interviewee. I had met almost all of my interviewees prior to sitting down with them and felt that I had quite open discussions with them all. As I listen and think about each encounter, I know from previous experience of research, that they are the touchstones by which I proceed; the ideas, emotions and even the recreation of a scene – at the Meeting Centre, being in a café, sitting in a consultation event – will come back to haunt and inspire anew, as much as any phrase drawn from the papers or books which surround me physically or electronically. That's partly why I've quoted so generously; the words come back and give me more to think about.

My hope also is that this thesis can be a starting point for further research, papers and other works. This is already in motion: a paper has already been submitted for peer review in a special edition of GeoHumanities, the journal of the American Association of Geographers, looking at creative methods and endings (Williams, 2021), building on presentations given at the Royal Geographic Society Conference in 2019 and this year.

As Mol (2008) asserts persuasively, a good case study will hopefully enable us to as more pertinent questions, and I am currently working on two other papers which are based on questions which have arisen and seem pertinent to this work. The first is a collaborative piece with Dr Shirley Evans, at the Worcester University Association for Dementia Studies, based on a joint poster presentation from 2019, building on some of the conclusions reached in this section about Meeting Centres, how it is a practice and through that group practice we can begin to question ideas of selfhood and memory. This, along with my continued involvement as part of the DMiP Advisory Board which is helping to secure the future development of Meeting Centres, honours the principle of committing to active learning from the research, as set out by my ethics application; far from 'leaving the field', I have maintained contact and supported some of the friends made during the Covid-19 pandemic period. The second will be a more speculative paper which will question how borderlands and bordering, the boundaries between different forms of governance, for example Wales and England in my case study, can create new ways of thinking, asking just how porous this process is.

It is also certainly my intention, if possible, to further develop work using the cut-up and collage methods. As explained at the top of this section, they have a rich interdisciplinary history which stretches back over a hundred years, but it's my contention that they have never been more relevant than now, given cultures which seem fixated on a very fragmentary digital experience, for example. Re-mix and meme cultures are well established, in multiple art forms. and the creative combination and reassembling of images and words (appropriated or not) into newly synthesised forms is a relatively democratic commonplace, from TikTok to mixtapes. In a sense, nothing is original, but there is fluidity, exchangeability, multifunctionality, and connectivity (Feireiss, 2019), Montaigne's rags and patches to play with[12]. In trying to answer the call of those who would wish to see the renewal of the sociological imagination, then methods which reshuffle and unmake might have their place among those that seem to be, at times, excessively reductionist, or solely based on policy impact.

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[12] "We are entirely made up of bits and pieces, woven together so diversely and so shapelessly that each one of them pulls its own way at every moment." (Montaigne, 1991, p.380).

83. Annexe 1 – List of visits

This is a list of visits to Brecon, networking events and other events relevant to the research, kept on an Excel sheet, with more detail than provided here. Friendship Circle is another name for the Meeting Centre visits. Notes form each meeting were mostly kept in notebooks, which were cross-referenced with this list.

Date	**Event**
14.11.16	Initiative Group for Dementia Meeting Centre
16.1.17	Initiative Group for Dementia Meeting Centre
25.1.17	Consultation Event, DFC strategy
13.2.17	Initiative Group for Dementia Meeting Centre
14.2.17	Wales School for Social Care Research Launch
13.3.17	Initiative Group for Dementia Meeting Centre
21.3.17	MEETING Dem Conference
29.3.17	Powys Dementia Network Meeting
24.4.17	Initiative Group for Dementia Meeting Centre
17.5.17	*Dementia Awareness Event, Chapter Arts*
18.5.17	*Dementia Awareness Event, Theatr Brycheiniog*
19.5.17	*Dementia Awareness Event, Fundraising*
28.6.17	*Creating Age Friendly Communities*
5.7.17	*BSG Conference*
17.7.17	*Initiative Group for Dementia Meeting Centre*
4.9.17	*Initiative Group for Dementia Meeting Centre*
10.10.17	*CADR conference*
12.10.17	*Dementia Care Pathways for Powys*
16.10.17	*Participatory Research Network*
7.11.17	*Friendship Circle*
15.11.17	*Leominster Meeting Centre*
16.11.17	*Brecon Meeting Centre Open Day*
15.12.17	*Brecon Visit*
16.1.18	*DMIP, Brecon*
14.2.18	*2nd Social Care + Research Conference*
26.2.18	*DMIP initiative group meeting, Brecon*
16.3.18	*LAUGH presentation*
20.3.18	*Friendship Circle*
10.4.18	*Dementia Network Event, Brecon*
17.4.18	*Friendship Circle, Brecon*

22.5.18	*Friendship Circle, Tea Dance*
23.5.18	*Dementia Friendly Blaenavon*
21.6.18	*Intergenerational work + Joan interview*
21.6.18	*Meeting Centre*
26.6.18	*Friendship Circle + Donna Geir interview*
26.6.18	*Market walkabaout, Brecon*
19.7.18	*Friendship Circle*
7.8.18	*Eisteddfod Welsh Language + Dementia talk*
8.8.18	*Social Care Wales event*
30.8.18	*Friendship Circle*
5.9.18	*DMIP Advisory Group*
4.10.18	*Friendship Circle*
12.10.18	*Interview Nigel Hullah*
18.10.18	*CADR conference*
22.10.18	*DEEP Meeting*
7.11.18	*Launch of Welsh Language strategy*
8.11.18	*Friendship Circle*
13.11.18	*SW Wales DFC Strategy conference*
22.11.18	*DFC Hereford Conference*
20.12.18	*Friendship Circle*
03.01.19	*Friendship Circle*
14.2.19	*Friendship Circle*
6.3.19	*DMIP Advisory Group*
16.5.19	*Friendship Circle*
22.5.19	*Dementia Awareness Event*
1.8.19	*Friendship Circle/Brecon Military Museum*

84. Annexe 2 – List of interviewees

These are the people who were interviewed more fully for this work. All signed consent forms and consented to the use of their names, though in some off-the-record instances or if requested, have been anonymised. If I was unsure of anything, I was able to get back to them for confirmation.

Joan Brown (JB)

Rhiannon Davies (RD)

Donna Gair (DG)

Yvie George (YG)

Nigel Hullah (NH)

Steve Huxton (SH)

Emma Quaeck (EQ)

85. Annexe 3 - Cut-up practice

> *There were many different methods of cutting text, but they all had one thing in common: they introduced a random juxtaposition of text to give new word combinations (Miles, 2013, p.364)*

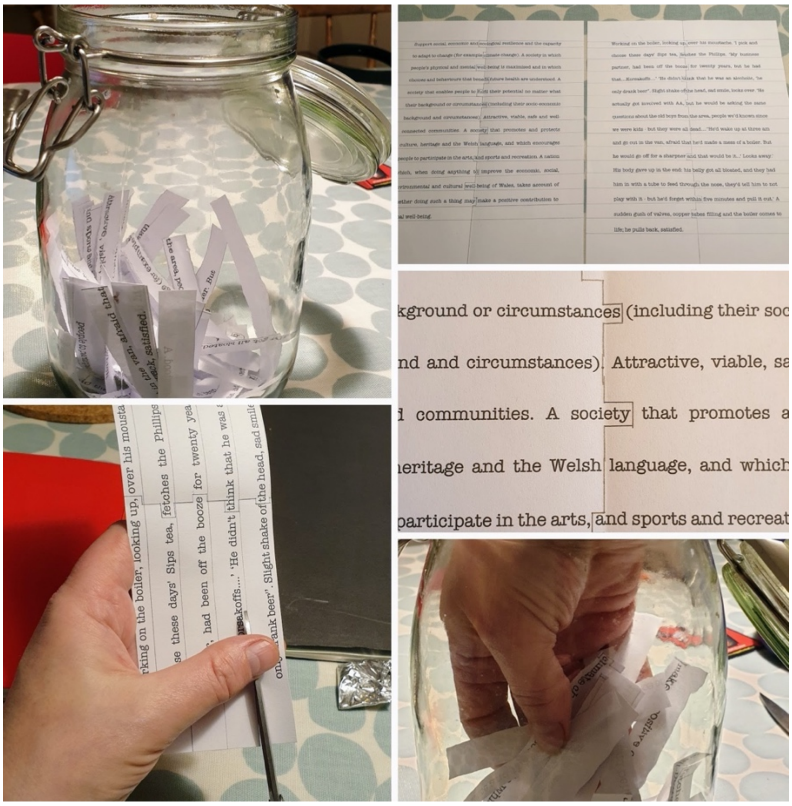

Figure 27: Cut-up practice

As Barry Miles documents in his biography of Burroughs (2013), the author (and his creative partner for the cut-up technique, Brion Gysin) experimented for years with not only text-based cut-ups but also audio cut-ups and collage/montage based work. Several techniques were used with texts ranging from newspaper articles to classical literature, and Burroughs's own written texts. Post 1965, with Burroughs seen as a major figure of the counterculture, the influence of this technique spread very far and wide among musicians and other artists, even though its roots go back a lot further into previous avantgarde movements . The technique also foreshadows everything from re-mix culture (Feireiss,2019) to present day meme culture or platforms such as Tik Tok, where random images, sounds and music are juxtaposed in to fragments for humorous or other effects.

For the work presented here, I have used two main methods, one which uses an online cut-up machine, and the other using paper and scissors as Tristan Tzara stipulated over a century ago, but for both you need

- to choose a text or texts which is of interest. This can include any pamphlets, flyers or texts around your subject area or an aspect of what interests you, and can be your own creation e.g. fieldnotes or any other writing you've produced

Then there are two options, the first is:

1. Use an online cut-up machine. The one I've used to experiment is: https://www.languageisavirus.com/cutupmachine.php#.YXwFAy8w28U
2. Cut/paste or write into the machine look at the results. Look for anything interesting that might shed new light on what you're thinking about. This is very trial and error. Repeat the step as many times as needed.
3. Edit anything interesting, work with it and re-read. Also, read out loud, this can help.

The second option:

1. Print out the text or texts, making sure they are set out in block or column – think newspaper.

2. Take the paper, fold in half lengthways, then mark out a line which intersects the lines along the line made by the fold (you could fold in more than one place – Burroughs used to do this).
3. Using scissors, cut along the line, then carefully cut each line horizontally so that you're left with strips of paper with the halved lines of text.
4. Place them in a jar or some kind of receptacle, shake or mix them up.
5. Take out, a strip at a time, and assemble horizontally on the table or another piece of paper.
6. Follow steps 2 and 3 above.

86. Annexe 4 - Collage practice

Figure 28: Collage practice preparation

My collage practice evolved over time but became a mixture of the physical and the digital in terms of the end 'composition'. Their primary aim is to provoke thought as highlighted in the in the body of this work. What drew me to this practice, beyond following the line from cut-up practice was a sense that each 'viewing' will create something new, another reaction. It is performative and part of the process of sense-making which goes beyond the textual: there is a physical and sensual pleasure in the making, in the assembling of different visual planes and perspectives. During the lockdowns due to COVID-19, when I hit a block in terms of the writing, this practice helped me overcome the sense of overwhelming uncertainty, which I normally embrace relatively cheerfully, but which became oppressive because of the situation. I took inspiration from the Burroughs compositions that can be found in Allmer & Sears (2014) and Hawkins & Wermer-Colan (2019), but also more widely from Brommer (2007) and online platforms such as Pinterest.

The basic method, however, was as following, which had its trial and error involved:

1. Assemble any materials from a general idea of what you are trying to explore, and have collected during your research: texts, photography, pamphlets, images, flyers
2. Pick out what's of interest: might be something strong visually, phrases or words which became significant in the field of research – but also look around, what's going on that day which may (or may not) link you back to the material or may provide more inspiration. It's surprising how things can connect, especially if you've been thinking about the research area for a while.
3. Cut things out with scissors or a craft knife, tear things up, make use of printers and simple photographic techniques found in Google Photos, for example. Think of repetitions and differences.
4. Prepare a board on which to arrange e.g. A2 size as in Figure… Because you're using clear glue or paste e.g. Mod Podge it's wise to paint the board with a couple of layers of gesso paint, which prevents buckling
5. Arrange your material – think (but not too much) about what you have in your hand, what it represented, where it comes from. Use paints also if you want to, to change the feel and look of things. Take your time to do this, then stop – have a point at which you recognise the totality of what you have in front of you is interesting.

6. Fix with more glue

This may be all that’s needed, but for me it was useful also:

7. Use a tablet device to take a photo of the assembled board, or send picture from phone to a computing device
8. Add digital layers, shading, adjust the saturation and other parameters using eg Procreate, Photoshop, GIMP or Pixlr

Figure 29: Collage making

87. Annexe 5 - Papers given and other learning opportunities

Right from the outset, there has been encouragement from my supervisors to develop and present some of the emerging ideas from this work, and I have been able to do this in a range of different fora, reflecting in part the interdisciplinary nature of the work. Conferences attended have spanned the disciplines of gerontology and geography, but also history, literature, social policy and, of course, conferences dedicated to dementia support. Some were departmental, smallish and informal, whilst others were major, well-attended international events in terms of the main disciplines of gerontology or geography, including taking part in two symposia on creative methods and ageing at the British Society for Gerontology conference and the Royal Geographical Society conference in 2021 . All had their uses in developing the work. For example, through a departmental student conference in the geography department, Prof. Marcus Doel pointed me in the direction of a precedent for using cut-ups, connected to my home department of Human and Health Sciences, which gave momentum to some of my experiments. At the Richard Burton Conference, which focussed on historical themes and literature, Prof. Daniel Williams also gave me leads to wider sociological literature on the Beats. As I developed my ideas, I was also able to adapt my presentations to other call-outs or concentrate on different types of issues and critiques. For example, by the time I presented at the Liverpool BSG conference, I focussed mainly on critiquing the idea of 'resilience' in the context of ageing (the conference theme was 'Resilience and Living Well in Local Communities'), whilst most of the later presentations focus mainly on the innovation in the methods used in the work and developing more non-representational modes of thinking in ageing studies. On the back of my first RGS presentation, I was then alerted to a call out for a special edition of GeoHumanities, the journal of the American Association of Geographers, looking at creative methods, and at the time of writing I have an article submitted for peer-review, with publication due soon. I was given some friendly encouragement via Twitter from Prof. Les Back to carry on with my cut-up experiments after I'd seen his lecture at the RGS that year.

Also, learning opportunities such as the seminar series on Writing Place, organised by Dr Angharad Closs Stephens and Dr Amanda Rogers were invaluable, and contributed enormously in my case to thinking about new possibilities for the work. Likewise, attending the Gregynog Theory School was a fantastic opportunity to engage with new ideas, and conversations with Dr Paul Harrison and others provided further inspiration; I left Gregynog to go straight to a Meeting Centre Advisory Board meeting, and many ideas ensued. It's no exaggeration to say that sometimes it's difficult to appreciate how life-changing such encounters can be, and how they can provoke new possibilities and connections.

These have been over and above the visits listed in Annexe 1, and it may be relevant to note that I did not present at one of the conferences which I'd helped in my small way to organise by helping to facilitate a visit by one of the dementia activists. As noted, each encounter has given me the opportunity to develop aspects of the thesis, to network and connect with others who may have interest in the ideas presented. In addition to having abstracts for each paper (or poster) accepted, one of my collage pieces (Figure ….) was entered into an annual Swansea University competition for Research as Art, receiving a runner-up commendation. I gave two seminars based on my work around DFCs as part of the MSc in Gerontology and Ageing Studies at the Centre for innovative Ageing, my home centre at the College of Human and Health Sciences, both in person and online.

Details of the conferences are as follows:

Date	Conference	Title	Type
14.6.18	Richard Burton Conference, Swansea University	"Unforseen events wait lurking to surprise": the spontaneous bop prosody of	Oral presentation

		researching dementia friendly communities in Wales.	
18.6.18	Post-graduate Research Conference, Human and Health Sciences, Swansea University	“We’re all in this together”: the development of dementia supportive communities in Wales	Poster presentation
3.7.18	British Society of Gerontology (BSG) Conference, Manchester	“We’re all in this together”: bio-politics, citizenship and the development of dementia supportive communities in Wales	Oral presentation
21.11.18	Geography Department presentations, Swansea University	“Unforeseen events wait lurking to surprise”: the spontaneous bop prosody of researching dementia friendly communities in Wales.	Oral presentation
24.6.19	ROSEnet (Reducing Old-age Social Exclusion network) conference, Swansea University	“We’re all in this together”: the development of dementia supportive communities in Wales	Poster presentation

3.7.19	Wales institute for Social and Economic Research (WISERD) Conference, Aberystwyth	"We're all in this together": bio-politics, citizenship and the development of dementia supportive communities in Wales	Oral presentation
11.7.19	BSG conference, Liverpool	Reframing resilience: governance and performativity through dementia friendly communities	Oral presentation
30.8.19	Royal Geographical Society (RGS) conference, London	"Where's Ivy?": loss, acceptance and withdrawal in dementia community-making.	Oral presentation
1.11.19	Annual Dementia Congress, Doncaster	"I feel part of something": emerging selfhood, community making and the practice of Meeting Centres	Poster presentation (with Dr Shirley Evans, Worcester University)
12.3.20	MRC Centre for Neuropsychiatric	"We're all in this together": bio-politics, citizenship and the development of dementia	Oral presentation

	Genetics and Genomics, Cardiff University	supportive communities in Wales	
2.11.20	BRACE Dementia Research Conference, online	Development of Dementia Supportive Communities	Oral presentation
8.7.21	BSG conference, Lancaster/online, Symposia on ‘Gerontology and more-than-representational methods’	‘Do fast feet apples have community shaking?’: getting caught up in the liveliness of a dementia friendly community.	Oral presentation + panel discussion
1.9.21	RGS conference, London/online: Symposia on 'Non-representational geographies: approaches, methods and practices'	What remains? Exploring dementia friendly communities through a cut-up method.	Oral presentation + panel discussion

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