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# **Becoming Disabled**

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**(nee Sellick)**

This thesis is submitted for the degree of Doctor of Philosophy

Department of Geography

University of Durham

January 2014

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## **Declaration**

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This thesis is the result of my own work. Data from other authors contained herein are acknowledged at the appropriate point in the text.

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Jayne Margaret Jeffries (nee Sellick)

The copyright of this thesis rests with the author. No quotation from it may be published without prior consent and any information from it should be acknowledged.

## **Dedication**

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This work is dedicated to all of the participants that gave their time, commitment and generosity, sharing their personal and emotional stories with me, often through invitation to their own home. However, it would not have been possible without the support of my husband, Saul, who has put up with me during the four years of the PhD, but also during the last ten years while we have been together!



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## Chapter 1: Temporalities

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Time matters in the context of our daily lives, in the past and in the future. Time shapes and structures work and routines, paid and unpaid, formal and informal, yet time is more than just a ticking clock. At times, time feels like it has flown or dragged, will never come or has come too soon. But time is as much about dying as it is about living, as each life course takes a different trajectory, lasting for varying amounts of time. However, the intricacies of time: the temporalities, the moments, the transitions, the trajectories of living and dying are complex and nuanced, yet analyses of time are slim or seldom discussed in geographies of disability, health and illness. While disability and disabled people's lives are shaped by histories of oppression and exclusion, by day-to-day circumstances and by uncertain medical, financial and social situations, it is the socio-spatialities of disability, health and (mental) illness that are emphasised in geographical accounts, rather than the temporalities. These socio-spatial geographies provide much needed and critical accounts of disabled people's lives. However, in this thesis I contend that the temporalities of these histories, circumstances and situations also have much to contribute to new understandings of disabled people's lives and subsequently their identities.

Within this account, I explore four further themes that, while they are fundamental to what I term the 'becoming' of disabilities, have received scant attention within geographers' understandings of disability, health and illness. First, I examine the emotional temporalities of disabled people's identities, addressing the ever-present role of participants' feelings in relation to experiences of diagnosis, accidents resulting in injury and bodily changes. By doing so, I discuss the importance of time, emphasising the histories, moments and futures that shape participants' emotional temporalities. Second, I address the temporality of recovery, as participants carry out different activities and practices as part of their daily and lifelong routines in order to temporarily 'recover'. I demonstrate that recovery is an ongoing and unfolding process of 'becoming well', which shifts and stretches in order to accommodate participants

changing needs, as they strive to feel better. Third, I explore disabled people's daily mobilities, showing that 'differently mobile bodies' provide new understandings of disabled people's movements, patterns and rhythms of moving. In the fourth and final theme I demonstrate that memories are more than just a revival of past experiences, as I draw together emotion, recovery and mobilities, highlighting the cumulative effect that memories have on participants' experiences of disability, health and illness.

In this thesis I focus on the temporal world in order to understand the complex temporalities that shape disabled people's identities as I explore eight participants and their partners everyday and lifelong experiences of disability, health, illness, impairment and chronic pain. Using a participatory approach and participatory methods, I show that everyday and lifelong temporalities are (re)presented through disabled people's personal, first-hand accounts of the past, the present and the future in their lives. Over the course of 14 months I met with participants through contacts at organisations and by advertising the research in a local newspaper, this produced various face-to-face encounters with individuals and groups as the methodology unfolded. As conversations were exchanged, participant interest developed (and waned) and ideas about how to 'talk', 'write', 'draw', 'take' and share experiences of disabled people's lives developed, the temporalities of disabilities, health conditions and illnesses became a central and overarching theme.

**Box 1.1:** *'Time and temporalities'*, provides a summary of the two key terms, which frame and are framed by the accounts given by participants and are used throughout this thesis.

**Box 1.1: Time and temporalities**

'Time' refers to the past, the present and the future in disabled people's lives, signifying a specific point in time, such as a birth, one off event or an accident; or a period of time, such as a day, a week, a month or a series of events. These examples indicate the passing of (clock)time, identifying the linear and sequential basis of time as it passes from moment to moment and day to day.

On the other hand, the lived experience of time illustrates the (dis)continuous and inconsistent feeling of time, as it is (re)lived, unfolding differently in everyday<sup>1</sup> life and throughout the life course. In this thesis 'felt'/'feeling' time is relational, challenging notions that reinforce the linearity of (life)time(s), such as the every 'day' and every 'night' time. Therefore, in the process of becoming, time is conceived differently, showing that there are different pasts, presents and futures, rather than unifying and singular accounts of time.

Relational (felt) time is (re)made by different 'temporalities', which in this thesis refers to momentary, fluctuating, fleeting and fluid experiences of disabilities, health conditions and illnesses. These temporalities reflect the intricacies of time, the moments, transitions and trajectories, as well as the cycles, rhythms, speeds, routines, histories and memories in disabled people's lives. However, while temporalities may take place at specific points in the past, memories of these specific events may change over time, as one temporality is interrupted by a 'new' temporality. This idea suggests that whilst each experience may be different, it may also be 'new(ly)' experienced at a different time. I explore the temporalities of feelings, well-being, mobilities and memories in the subsequent chapters of the thesis, as participants' accounts highlight different becomings in relation to the present 'now'<sup>2</sup>.

This research takes a feminist and post-structuralist approach in order to understand the concept of disability, exploring the potential breadth and complexity of disability by using a participatory framework. By co-producing research with disabled people, this thesis aims to examine the day-to-day lives of a range of people that have different experiences of disability, health conditions and illnesses. By doing so, the empirical and methodological material contained within this thesis emerged in the process of 'doing' the research, rather than

---

<sup>1</sup> A term, which is frequently used in geography and later discussed and critiqued for its taken-for-granted nature of time in every 'day' life and the limited exploration of the temporalities of the day in geographical accounts, other than as a backdrop to activities that take place.

<sup>2</sup> The present 'now' refers to participant's accounts as they were (re)lived and (re)told at the time of conducting this piece of research. For example, when drawing and completing a timeline, taking and discussing photographs, talking in conversations and writing in a diary. The contested notion of the 'present' is discussed further in Chapter 5: *'Becoming emotional'*.

through a pre-defined set of research questions. For this reason, the research does not focus on any particular physical, mental or sensory disability, therefore the specific research questions which developed through the course of the research are detailed in Chapter 3: *'The temporalities of participatory engagement: An unfolding methodology'*.

This research is based in the north east of England, a region that is often associated with quantitative statistical analyses, which highlight higher rates of disability and ill health especially in areas that have suffered most from increased economic and social deprivation in the 20<sup>th</sup> Century. However, whilst areas that were once thriving with extractive industries such as coal mining provide the focus for research that addresses health as a categorical marker, or health and well-being as a general marker of lifestyle, my research is designed to highlight the diversity of disabled peoples experiences over life course. By doing so I provide an in-depth qualitative analysis of the disabilities, health conditions and illnesses, focusing into the lives of disabled and ill people in order to (re)present their specific accounts, rather than as a means to represent disability as a statistical representative sample.

The theoretical claims and empirical accounts contained within the thesis have emerged from an iterative participatory methodological approach; therefore, this thesis does not adopt a traditional structure but emphasises the methodological, theoretical and empirical temporalities of the research process. Each chapter is presented in sequence, reflecting a different set of temporalities and demonstrating the cyclical nature of the participatory research. All of the chapters in this thesis are framed by the key argument, which is the temporal and transient nature of what we understand as 'becoming disabled'. This framework for 'becoming disabled' is itself shaped by the theoretical, methodological and empirical temporalities of the research, which are not represented separately in different chapters through the thesis, but flow into and through one another at different points in the research.

I use these three temporalities to thread 'becoming disabled' through the remainder of the thesis, as I show that theoretical-, methodological- and empirical- becoming is an open-ended process. Firstly, I show that the concept of 'becoming disabled' refers to the everyday and lifelong temporalities that shape disabled people's lives and their identities, as I explore becoming theoretically. In Chapter 2: '*Accepting differences*', which reviews existing historical and contemporary literatures on disabilities, I argue that becoming embraces the changing nature of disability in people's lives rather than the fixed nature of medical categories and labels of 'being' disabled, which imply a finality, a certainty, an ending. Secondly, I show that methodological becoming shapes the whole research process, as I emphasise the representation of disability, health and illness by, rather than for, disabled people in Chapter 3: '*The temporalities of participatory engagement: An unfolding methodology*'. I explore the multiple encounters that took place, the varying levels of participation, the ups and downs and the final eight who took part in 'deep' participation. Thirdly, I demonstrate that as participants' identities change throughout the course of time, as well as throughout the course of the research, becoming is never finished or complete. As I reiterate the importance of becoming using empirical material, I explore the theoretical, methodological and empirical temporalities of becoming disabled by dividing the subsequent chapters into four interlocking sections.

Four mini-methodological chapters (4, 6, 8, 10) are interspersed by four empirical chapters (5, 7, 9, 11), as I demonstrate both the unfolding nature and the close connection of methods and empirical themes. The four methodological chapters detail the development of participatory methods including drawing timelines, taking photographs in photovoice, talking in conversations and writing diary entries, respectively. The four empirical chapters take up the key themes of emotion, recovery (becoming well), mobilities and memories, respectively. During these discussions, I (re)present the in-depth qualitative accounts of eight participants and their partners, exploring the temporal worlds of participants' accounts of spinal cord injury, congenital dislocation of both hips (CDH), multiple sclerosis, sclerotic arthritis, spondylitis, spinal operations and adhesive

arachnoiditis, terms that are explained later in the thesis. Finally, the conclusion draws together the key messages of the research, and presents an agenda for further work with disabled people.

## Chapter 2: Accepting Differences

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### 2.1 Introduction

In this chapter my aim is to take a journey through the complex terrain of terms, models, definitions and philosophical and theoretical conceptualisations of 'disability', 'health', 'illness' and 'impairment', in order to situate my own conceptualisation of disability as a starting point for the investigation. The chapter also serves to establish the key concepts around disability, which it will go on to develop. Through providing an overview of the various ways that disability has been conceptualised, I suggest that historical and contemporary accounts prescribe fixed and static notions of 'being' disabled, both labelling and accepting disabilities, health conditions and illnesses. By referring to the acceptance- and accepting- of disability/ies, I argue that the bio-medical and social categorisations, which inform the bio-medical and social models of disability (re)create homogenising discourses that often reinforce the individuality and universality of 'being disabled'. Despite the widespread acceptance of these categories in day-to-day life and in academia, critical analyses of disabled and ill people's lives are expanding. However, by remaining focused on one particular mental, physical or sensory category, disability becomes accepted as a particular category in these analyses. In my research, the intention *not* to define disability is a significant part of my feminist conceptual framework and approach to research; I explore the former in section 2.3: '*Accepting differences*', while the methodological implications are discussed in Chapter 3.

In section 2.2 "*Historiographies of 'disability', 'health', 'illness' and 'impairment'*", I show that there is a well-established history of research that at times binds these terms together, whilst at others distinguishes between them, often in different arenas. However, by reference to political and civil rights movements, interventions of social policy and legislation, as well as the sites where these differences are played out, I unpack these terms in relation to my



own research to show that these competing discourses (re)produce fixed ideas about 'being disabled'. By challenging existing categories of disability and 'being disabled, I show that my approach to conceptualising disability allows me to explore the relations between accounts of 'disability', 'health', 'illness' and 'impairment'. The concept and terms used in this thesis are not fixed, but are fluid in their relationship to one another, as I demonstrate the importance of disabled people's multiple differences whilst also remaining aware of the potential to reiterate a homogenous approach to disability.

In section 2.3 *'Accepting differences'*, I show how a framework, which is accepting of disabled people's differences, can bridge geographies of disability and geographies of health and illness. By removing the rigid labels that are frequently applied to 'disability' and 'disabled people', I use these two terms throughout the remainder of this thesis, highlighting both a commitment to their political importance, whilst also recognising the tension between this usage of them and the concept of accepting differences used in this thesis. I use four axes to frame this concept: embodiment/materiality; emotion; relationality; and fluidity. The notion of accepting differences provides the framework for 'becoming disabled', which I suggest is a more appropriate theorisation that explores the constantly changing nature of disability and disabled people's lives. The idea of 'becoming' addresses the fluidity, relationality and temporality of disabled people's lived and embodied accounts.

In section 2.4 *'Becoming disabled'*, I show that time is explicitly connected to historiographies of disability, health, illness and impairment, firstly as understandings of disability change and develop over time creating (new) histories. Secondly, I show that lived experiences of disability ebb and flow in relation to different times, spaces, places, people and identities. Yet despite this, time and temporalities remain largely under-analysed in geographies of disability, health and illness (Worth, 2009b, Meadows, 2010), often being used more implicitly as a backdrop to spatial analyses of chronic illnesses. Using the concept of 'becoming' I argue that time forms a pivotal role in disabled people's

lives and in this thesis, as disabled people's differences are (re)produced through various temporalities.

In the following section I begin by outlining the histories that shape accounts of 'being disabled' in order to contextualise the concept of 'becoming disabled' used in this thesis. Drawing on interdisciplinary literatures, I then identify the significance of the temporalities of disabled people's differences to geographies of disability, health and illness.

## **2.2 Historiographies of 'disability', 'health', 'illness' and 'impairment'**

The terms 'disability', 'health', 'illness' and 'impairment' have a long history which continues to develop; they are applied in multiple arenas on a daily basis, from medicine and health care, policy and legislation (DDA, 1995, Imrie, 2004, 2012); to human rights and social justice issues (Oliver, 1990). These terms are often distinguished or defined in relation to various political, activist, academic and/or social positions and standpoints, and the distinctions between them may be multiple and often become blurred. I do not see this blurring as problematic; indeed I discuss the fluidity of disability and disabled people's lives in the interpretation of disability in section 2.3 '*Accepting differences*'. However, in this section I discuss the role of the bio-medical model of disability and the social model of disability as two of the most fundamental and frequently debated theoretical approaches that are used to understand disability. I argue that disability is (re)presented as a fixed category that is literally mapped *onto* disabled people and *into* their lives, reproducing static and homogenising ideals. I use the idea of the acceptance- and accepting- of disability to describe the failure of these models to represent the complexity of disabled people's lives, subsequently showing that stable medical and social categories have remained both fixed to and within historical and contemporary accounts of disability.

### 2.2.1 Social policy and social justice

The acceptance of disability as a fixed category of 'being' is reinforced by historical and contemporary representations of disability in social policy. A brief analysis of the Disability Discrimination Act (DDA, 1995) illustrates the role of capitalist structures in constraining disabled people's agency and in reinforcing medicalised terminology, both of which have been described as key features of the bio-medical model of disability. The bio-medical model of disability has been the basis for the treatment of disabled and ill people within the medical profession, highlighting individualising discourses that conceptualise disability in terms of personal tragedy and as something to be treated, cured or fixed by medicine or medical interventions. These references to 'fixing' disability demonstrate the degree to which the medical profession and medical practices are charged with (re)creating disabled people as not 'normal'<sup>3</sup> (Abberley, 1987, Butler and Bowlby, 1997).

The development of social policy in the UK in the early 20<sup>th</sup> Century was in one sense in opposition to the social harm caused by capitalism, but also reiterated the norms created within capitalist societies. In a system that classified workers based on their physical abilities and efficiency to work in relation to other 'normal' people, capitalist modes of production reinforce disabled people's "inability to 'fit in'" (Parr, 2008: 5). However, while policy measures in pre-1940s Britain were focused on segregation and institutionalisation (Borsay, 2005), more recently and beginning in the 1980s and 1990s there has been a shift to integrate and accept disabled people into society through social policy (Morris, 2011). Yet, despite the introduction of the Independent Living Movement (ILM) and the Disability Living Allowance (DLA)<sup>4</sup> to name a few, the following definition from the Disability Discrimination Act

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<sup>3</sup> I provide a more detailed discussion of the binaries that are constructed in order to (re)produce disability, health, illness and impairment as 'not normal' and therefore different to the 'rest' of society, in section 2.3 '*Accepting Differences*'.

<sup>4</sup> Although see SHILDRICK, M. & PRICE, J. 1999. Breaking the boundaries of the broken body. *Feminist theory and the body: A reader*, 432-444. The authors provide a critique of the DLA as reproducing disciplinary practices, as disabled people are forced to perform technologies of the self through self-surveillance.

(1995) still binds disability and disabled people in opposition to the 'rest of society and not normal as a result:

“[A] person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities”

(DDA, 1995, c.50, Part 1, Section 1)

The terms presented in the DDA (1995) are static and isolate disability, fixing it to physical or mental impairment, and reinforcing disability and disabled people as different in relation to other 'normal' people. Further, as Morris notes, “[it] has the disadvantage of requiring a person to first establish that the nature and severity of their impairment” (2011: 4) and therefore fails to respond to the original critiques of the social model of disability (Hughes and Paterson, 1997, Shakespeare and Watson, 2001, Gabel and Peters, 2004). Indeed, arguably the exclusion of disabled people from society and by society enveloped the subsequent social model of disability, which is outlined in the following quote and distinguishing between:

**“Impairment:** Lacking part or all of a limb, or having a defective limb or mechanism of the body”; and:

**“Disability:** The disadvantage of restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities”

(UPIAS, 1976: 3-4)

In the social model of disability, which arose from the disability rights movement around the '80s and '90s in response to the wide deployment of the

biomedical model, 'impairment' and 'disability' are given separate labels, the former referring to the functioning of the impaired body; and the latter to the physical, mental, social and attitudinal barriers (Swain et al., 1992) that prevent 'people who have physical impairments' from taking part in social activities. Since its introduction, the social model of disability has been used to bring attention to social justice issues. However, while the Disability Rights Movement (DRM) and Independent Living Movement (ILM) were pushing for equal access and opportunities of disabled people in daily life, Goodley (2012: 633) critiques disability scholars such as Oliver (1990) and Finkelstein (1993) for focusing simply on increasing socio-political participation rather than "changing attitudes or ... mainstreaming ... disability issues"<sup>5</sup>.

Outside of the academy, the political organisation of disabled people has grown, from political protests related to social policy in the US (Americans with Disabilities Act, 1990) and the UK, including the Disability Discrimination Act (1995), recent Bedroom Tax protests (Hardest Hit March, Newcastle upon Tyne, 2011; Darlington Against the Bedroom Tax, Darlington, 2013); including mental health- (Mental Health Foundation), diabetes- (Diabetes UK) and disability-awareness weeks which aim to change attitudes, create awareness and reduce stigma on disability and mental health related issues. These examples show that disabled people become engaged in their own politics of representation, utilising their own actions in order to challenge the assumed passive roles that they are labelled with in the bio-medical model of disability. However, as activism has grown, so different political positions amongst both disabled people and the charities that represent them can be found.

To summarise, the introduction of social policies has tended to reproduce particular political historiographies of disability, health, illness and impairment that reinforce the bio-medical model of disability. On the other hand, the social model of disability has tended to be folded into an everyday politics,

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<sup>5</sup> Changing attitudes and creating awareness on disability issues continue to be the goal of charities and non-governmental organisations throughout the world, from awareness weeks i.e. mental health reduce stigma.

pragmatically pushing for social justice and disabled people's human rights. In the next section, I move on to geographical literature to show that the representation and acceptance of disability takes place in different contexts.

### **2.2.2 The sites of disability, health, illness and impairment**

Firstly, I distinguish between three concepts of disability, health, illness and impairment, to show that in early medical geography 'being' disabled was constructed by research practices that labelled disability, disease and mental health in ways that reproduced bio-medical accounts of disability.

Epidemiological-, behavioural- and mental health- based geographies reflect these three concepts, where disabilities and health conditions are quantified into fixed categories of being. Secondly, as political activism moved from the streets and into academia, I map three further socio-spatial sites of oppression and resistance (Dorn and Laws, 1994, Kitchin, 1998), the home, institutional spaces and sites of care and caring. By referring to literature that is based more on the social model of disability, I suggest that the collective role of society disables people, through reproducing social norms that become accepted *over time*.

The positivist methodologies which were common in early medical geography placed the individuals, who were the focus of research, and researchers, who were producing statistical analyses, at a physical distance from one another. As researchers used quantitative data to produce large-scale correlations between health and place<sup>6</sup>, disability was accepted and understood through its relationship to epidemiological based geographies. Studies of disease ecology (Park et al., 1998), such as mapping rates of multiple sclerosis (MS) (Mayer, 1981) and spina bifida (Lovett and Gatrell, 1988), sought to locate environmental causes of disability. Such approaches might be seen as deterministic in their identification of environments where people lived as contaminating. However, while these approaches were critiqued for this, the mapping of individuals' access to health care (Park et al., 1998) and the physical

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<sup>6</sup> Health geography continues to focus on the relationship between '*Health and Place*', as one peer-reviewed journal reflecting the title indicates and as more critical analyses of health and place develop alongside the 'new' health geography.

movement of disabled people through urban environments continued to develop in behavioural- and mental health- based geographies in the 1980s and 1990s.

These studies addressed issues such as the mobility and access issues of elderly people and transport (Perle, 1969, Kirby et al., 1983, Gant and Smith, 1984, 1988, 1991, Gant, 1992); the location and admission of schizophrenics in the city of Nottingham (Giggs, 1973, Giggs, 1983); the mobility patterns of mental health service users (Dear, 1978, Dear et al., 1980); and visually impaired people's behaviour in and through urban spaces (Golledge et al., 1991, Golledge, 1993). Golledge's work is emblematic of behavioural geography, which on the one hand examined people's movements or behaviours in space, but on the other, ignored the "structural and institutions ... barriers people encounter" (Chouinard et al., 2010: 1).

By associating disability and disabled people with specific diseases, physical movements and patterns, and locations of health and health care, such analyses run the risk of (re)creating individualising pathologies (Parr, 2008) that do not capture the lives/agency of disabled people. Instead disabled people are (re)made through their own failure "to meet normal standards of form, ability and mobility" (Butler and Parr, 1999: 3), as disability becomes fixed to discursive understandings that label disability. Yet, despite these different understandings of disability from psychiatric and mental (ill) health to physical and sensory disabilities, by failing to see beyond these labels, the personal and political importance of disabled people's lives were absent in early medical geography. However, these epidemiological-, behavioural- and mental health- based geographies did distinguish the spatial location and spatial exclusion of disabled people from everyday spaces, advancing spatial analyses of disability, health and illness (Chouinard et al., 2010).

These spatial analyses provided an important inroad into critical analyses of disability, health and illness, as geographers began to write about different sites of exclusion, producing more qualitative studies that addressed directly affected groups. During the 1970s, 1980s and 1990s political activism around

the marginalisation and exclusion of certain social groups spilled over into the philosophical and social science debates of the time. Since this time social groups that were seen on the edge or margins of society began to be discussed by geographers working on gender (McDowell, 1993), sexuality (Bell et al., 1994, Binnie and Valentine, 1999), inequalities associated with ethnicity and race (Kobayashi and Peake, 1994) to obesity and early studies of disability, which emphasised structural disadvantage (Imrie and Wells, 1993, Kitchin, 1998, Chouinard, 1999). The spaces and places of health, health care and daily life, which are central to disabled and ill people's lives, were analysed as sites of oppression and resistance, from the home and the built environment to institutional spaces and sites of care and caring.

In response to these wider shifts, health geographers began to access 'hidden worlds' (Dyck, 1995), representing disabled people's lives through analyses of socio-spatial relations. This recognition of disabled people's individual experiences of place often addressed the micro-geographies of the home within the context of wider macro-geographies of structural relations (Moss, 1997); addressing the failures of earlier behavioural geography (Chouinard, from above, previous page). In accounts of chronic illness such as rheumatoid arthritis (Moss, 1997) and multiple sclerosis (M.S) (Dyck, 1995, Valentine, 1999), as well as mental (ill) health such as agoraphobia (Davidson, 2001a), the home<sup>7</sup> represents a space and place where disabled people negotiate their lives. These representations of disabled people's lives in critical health geography illustrate the complexity of living with disabilities, illnesses and health conditions, challenging the individualism of the medical model.

Issues related to disability and social justice triggered and enabled some disabled people to adopt active roles in society, as the social model of disability was and continues to be the catalyst for resisting ableism and fighting for accessible transport and housing. However, I argue that in the social model of disability, difference can be seen as a categorical marker that (re)produces

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<sup>7</sup> I provide a more detailed account of the meaning of the 'home' throughout the remainder of this thesis and particularly in Chapter 5: *'Becoming emotional'*.



exclusionary built environments (Imrie and Wells, 1993, Imrie, 1996a, Kitchin, 1998). As disabled people try to ‘fit’ into the ableist nature of “ideas, practices, institutions, and social relations that presume able-bodiedness” (Chouinard, 1997: 380), while built environments are designed to keep disabled people ‘in their place’ and to let disabled people know that they are ‘out of place’<sup>8</sup>. Kitchin’s (1998) work suggests that:

“[S]ocial relations...exclude disabled people in two main ways: spaces are currently organised to keep disabled people ‘in their place’; spaces are social texts that convey to disabled people that they are ‘out of place’”.

(Kitchin, 1998: 345)

The relationship between the spatiality and sociality of new geographies of mental (ill) health has been researched in different ways over time, from the location and admission of schizophrenics (and subsequently others labelled with mental health problems) into institutional spaces or ‘space of the hospital’ and towards deinstitutionalisation and the re-introduction of disabled and ill people back into social spaces (Parr, 2008). However, Foucault’s (2007: 148) retrospective study of maritime and military hospitals from the 17<sup>th</sup> Century onwards, illustrates that prior to the introduction of the doctor, soldiers in the military hospital were observed by pastors from a religious background rather than a medical one, as hospitalisations at this time were linked to illness, disease and dying. The shift from the (military) hospital as a space conceived as a space of death and dying to one where people were treated as ‘patients’ to be fixed (re)produces certain historiographies that continue to shape perceptions of disability, (mental) health, illness and impairment.

Medical professionals and practitioners have established a history of providing treatments and temporary relief from short- and long- term symptoms

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<sup>8</sup> Feeling ‘out of place’ is addressed at numerous points in the thesis, in methodological and empirical chapters.

and (health) conditions within medical spaces such as the hospital. However, disability, health, illness and impairment are also frequently treated beyond the space of the hospital. Work by geographers on formal and informal sites of care and caring highlight that such treatment, including rehabilitation, often takes place in the home (Dyck and O'Brien, 2003, Dyck et al., 2005).

In this section I have introduced the range of concepts and sites of disability that have featured in geographical research over past decades. I have shown that, despite the political strength of the social model, disabled people continue to be categorised according to a universal understanding of disability, which in early geographical research was reflected in the assumption that adjustments to the built environment will 'fix' the way disabled people feel in society. This demonstrates that 'being' disabled is accepted through its association to a specific disability in the built environment, in hidden geographies of the home and in social space. However, Wendell's (2001) work acknowledges, "it is a mistake to suppose that affirming our bodies by getting our political positions right will make us feel right about our bodies or make our bodies feel right" (Kittay et al., 2001: viii). This illustrates one of the many critiques of the social model of disability that I go on to draw out in the following section.

### **2.3 Accepting differences**

There are a number of key points that underlie my framework for accepting differences. Firstly, as disability is a fluid and shifting set of conditions, it is always in flux and always changing. This emphasises the potential physiological, psychological, social and cultural changes that may unfold as disabled people's disabilities, health conditions and illnesses are subject to change, at any time. Secondly, my framework supports a move away from binary thinking, as I reinforce the idea of disability as a complex and nuanced idea that is shaped by different circumstances in different contexts, rather than as a social category that may be demarcated by its opposition to 'ability'. Thirdly, I use feminist theories in order to analyse the role and importance of the body and

embodiment in disabled people's accounts, exploring the sustained and repetitive use of analyses of the normative body, reinforcing the concept of disability through the medical-social model.

Fourthly, I draw on feminist geographies of gender, health and illness, in order to open up my analysis of disabled peoples' lives to the complex social web of multiple and criss-crossing identities that constitute disability. However, while some feminist geographies of gender highlight the importance of representing autistic women as a minority (Davidson, 2007), as well as men's emotional experiences of HIV/AIDS (Thien and Del Casino Jr, 2012), in my research I provide a framework that explores both men's and women's differences in relation to disabilities, health conditions and illnesses. Fifthly, while the principles of the civil rights movement were similarly embraced in the disability rights movement; in my framework I show that the western centric critique of feminism, as a political movement, is also an ableist critique (Chouinard and Grant, 1995). Ableism reinforces the values<sup>9</sup> of a non-disabled population, both in and through social practices, ignoring the needs of disabled people and re-creating environments that accommodate people with 'normal' bodies. This links to the sixth point, as I challenge the concept of a 'normal' body, using a feminist framework in order to critique the inherently dichotomous nature of disability-ability, categories that are fixed by the social model of disability (Price, 2007). In doing so in this thesis I explore the concept of disability as a 'system, a set of practices, a relationship, kinds of embodiment, interactions with the built environment, frames of mind' (Garland-Thomson, 2004), thereby challenging and exploring disabled people's identity, experience and representation (Dias and Blecha, 2007).

The philosophical concepts that support this framework have been discussed throughout this chapter and are summarised in Box 2.1: *'Being' and 'becoming' disabled*.

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<sup>9</sup> Discussed in more detail in section 3.2.1: *'Developing an ontology'*.

### **Box 2.1: 'Being' and 'becoming' disabled**

In this thesis, I refer to 'being' disabled in relation to previous academic accounts of disability that (re)present *one* specific disability, health condition or illness; as a 'way of being' through cultural expression, for example as associated with autistic (Davidson, 2010) or D/deaf identities (Valentine and Skelton, 2007); or as being doubly disabled (Chouinard and Grant, 1995, Butler, 1999) through the simultaneous experience of multiple identities. I refer to 'becoming' disabled to forefront the significance of time as a lived experience, for example as visually impaired adolescents *transition* to adulthood (Worth, 2009b); and to becoming as an affective *process*, which takes place through body-landscape relations, walking and VI (Macpherson, 2010) and the uncertainties of chronic pain and its varying intensities (Bissell, 2009).

However, there has been a tendency in the social sciences to (re)produce binaries in order to distinguish between self-other, mind-body, disability-ability, being-becoming and so on (Butler and Bowlby, 1997). Such dualisms have been challenged for reinforcing western-centric knowledge and undermining the complexities and nuances of social relations and social identities (Moss and Dyck, 2002, Valentine, 2007). In particular, these binaries are problematic in relation to disabled people's lives, both objectifying disability and (re)creating discourses that homogenise disabled people's experiences.

In this thesis I follow the work of the feminist geographers listed here, critiquing knowledge that (re)produces binaries and instead opening up the concept of disability to its various 'becomings'. In doing so I emphasise the blurring of boundaries (Dyck, 2003), offering individual accounts of 'being' disabled, but within an ontological framework (See section 3.1.1) that unfolds throughout the remainder of the thesis. Through this framework, I seek to demonstrate the theoretical, methodological and empirical significance of 'becoming' disabled as a fluid and changing process that is situated within the temporal world.

Next, I discuss four key axes that underpin my understanding of disability and which contribute to my framework of the acceptance and accepting of (disabled people's) differences. These are embodiment/materiality, emotion, relationality and fluidity. These key axes underpin the analysis in the remainder of the thesis.

### **2.3.1 Embodiment and materiality**

Embodiment and materiality are interconnected terms, each demonstrating the importance of the body as an avenue through which to explore disabled people's identities. A call for more embodied accounts of disabled people's lives developed from the absence and reduction of the impaired body (Imrie, 2004, Hansen and Philo, 2007) in analyses of disability, as well as the disembodied nature of the social model of disability (Hall, 2000) and the general orientation of the discipline of geography during the 1990s. Longhurst (1997) argues that the body was being taken for granted in geographical analyses, despite the repeated discursive and representational use of the word the 'body'. My research examines the way that disabled people experience physical changes to their bodies, and I argue that these materialities of each impaired body, its fleshiness and its "blood, brains and bones" (Hall, 2000: 22) cannot be ignored in accounts of disability.

### **2.3.2 Emotion**

With the second axis, emotion, I contend that the role of feeling[s] is significant in relation to lived experiences of disabilities, health conditions and illnesses. This position draws on the recent field of emotional geographies, where the role of emotion and affect in constituting social and spatial forms has been placed centre stage (Davidson et al., 2005). Disabled people face numerous instances where they negotiate their own place in the world, from the context of their own homes, to interactions beyond the home and in other environments. Whilst the negotiations that take place in these contexts may be faced alone or involve other people, the feelings associated with these experiences play a continuous role in disabled people's lives. Significantly, these feelings do not take

place in isolation from the embodied experiences described above (in section 2.3.1), distinguishing ‘the political materialities that resonate from and that are formed through emotions’ (Tolia-Kelly, 2006: 213) from affectual experiences.

On the other hand, affect is described as the ‘passage from one bodily state to another’ (Watts, 2009), a concept that is all the more difficult to grasp because of its intangibility. However, while research on affect has subsequently been described as apolitical (Tolia-Kelly, 2006), Macpherson’s (2010: 4) work on affect highlights how the (disabled) ‘body takes shape through its interactions with other objects, bodies and landscapes’. By drawing comparisons between the embodied and processual experience of disability in research that is informed by the social model of disability (Swain et al., 1992), Macpherson demonstrates the ‘cumulative affects’ that shape disability and the disabled body. Further, in this thesis, I respond to Colls’s (2012: 433) concern that: “[t]he sparse reference to feminist theoretical work on affect or the body across non-representational geographies is indeed highly problematic and indicative of how affect has not been utilised to explicitly engage with bodily difference(s)”.

### **2.3.3 Relationality**

The third axis, relationality, draws a delicate balance between the “specificities of individual impairments” (Hansen and Philo, 2007: 494) and the wider social, material, emotional, cultural, economic and political processes that shape disabled people’s identities. A relational approach to disability opens “up the idea of fixed identities and fixed relations” towards identities that are “fluid, dynamic and continually (re)situated” (Thien, 2011) and illustrates the difference that the individual circumstances of each impaired body make to each disability, health condition or illness. However, as these specificities are just one set of contributing factors that shape disabled people’s lives, wider processes, such as those outlined above, also come into play at different times and in different contexts. Therefore, a relational analysis also encompasses the transient and continuously changing nature of disability.

### 2.3.4 Fluidity

The fourth axis, fluidity, is used to emphasise the *multiplicity* of disabled people's lived experiences, which I demonstrate in the subsequent methodological and empirical chapters of this thesis, as my research seeks to express disabled people's *identities*, rather than a disabled *identity* (Dyck, 1999). Firstly, engaging with feminist theories of the body (Butler and Bowlby, 1997, Moss and Dyck, 1999, Shildrick and Price, 1999, Garland-Thomson, 2004, Inahara, 2009), I demonstrate the fluidity of disabled people's identities. Milligan's (2005a: 214) work has shown that "[i]t is by emphasising the embeddedness of identity in overlapping networks of relations that shift over time and space, that we can avoid categorical rigidities". However, in my research I emphasise the fluidities of *identities*, showing that it is not just the networks that shift in relation to space and time that matter, but the way that space and time are also fluid. Secondly, I explore the fluidity of disciplinary boundaries, bringing geographies of disability and geographies of health and illness together. I show that critical analyses of health and place (Dyck, 1995, MacKian, 2000), which sit on the 'edge' or 'outside' of the sub-discipline (Kearns and Moon 2002) share the same goals as perspectives on the socio-spatial exclusion of disability, which tackle the 'margins' of society (Chouinard and Grant, 1995, Chouinard, 1997, 1999).

### 2.4 Becoming disabled

In this final section I suggest that temporality is fundamental to my concept of 'becoming disabled'. The temporalities of becoming disabled glue together the four axes (above) as part of my feminist framework, as disabled people's identities twist and turn in relation to mundane, everyday experiences of disability. The unfolding of mundane and banal experiences in disabled people's day-to-day lives is the focus of my framework of accepting differences, which shifts away from the social model's ignorance of the body (Hall, 2000, Hansen and Philo, 2007) in order to stress the materiality of the body (Hall, 2000) and embodied accounts of disability (Longhurst, 1997). Yet, it is not a

'new' model that I am suggesting, but an approach that incorporates the fluidity of disabled people's social and cultural identities rather than the inherent fixity that is re-produced in the medical and social models of disability. Becoming disabled, as a concept, reinforces the importance of disabled people's social and cultural identities, as different social and cultural circumstances illustrate that multiple differences matter.

A state of becoming implies an unfinished or never ending process (Grosz, 1999), demonstrating an inherent connection to time. However, in this thesis the concept of 'becoming disabled' is used to demonstrate the ways in which disability can be thought about in terms of temporalities. As disability and disabled people's experiences of disabilities, health conditions and illnesses change and shift over time, four temporalities - the everyday, the life course, rhythms and futures - are used to explore disabled people's identities in this research.

#### **2.4.1 Everyday life**

'Everyday life' is a term used in geography to describe ordinary, banal experiences, such as 'cooking, eating, drinking, shopping, playing [and] walking' (Pinder, 2009), which is largely underscored by a focus on the spatialities of the everyday, including the home. Crooks and Chouinard (2006) who describe, "the multiple material, lived and imagined differences between disabled and able 'womanly' ways of being and becoming in place", focus on everyday places, such as home, workplace etc.

Box 2.2 draws on the (re)presentation of particular analogies of time in relation to everyday geographies of chronic illness<sup>10</sup>.

#### **Box 2.2: Everyday geographies of chronic illness**

The everyday geographies of chronic illness appear at various points throughout this thesis. My conceptualisation builds upon Moss and Dyck's

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<sup>10</sup> See section 2.2.2 '*The sites of disability, health, illness and impairment*' for a discussion of the critical geographies of disability, health and illness and socio-spatial approaches.



(2002) study, outlining the importance of time in the lives of women with chronic illness. This work is a leading example of feminist scholarship in geography, which explores the simultaneity of relations that constitute power, knowledge and space in everyday life within the context of the material and discursive body. Some of the temporalities in their work include: arranging daily living, spacing tasks over a whole day, addressing flexible weekly, monthly and yearly patterns, as well as challenging a typical day. However, while the (re)negotiation and (re)structuring of the physical environment often leads their analyses of the everyday, this particular work is exemplary of the chronic illness literature, which privileges the socio-spatialising of identity (Moss and Dyck, 2002, Crooks et al., 2008), rather than the specificities and intricacies of time.

In seeking to establish a radical body politics, the authors use women's everyday accounts to help frame tensions between the material and discursive body. By highlighting the volatility of chronically ill bodies, as women 'transition from relative health to chronic illness' (p.127), Moss and Dyck (2002) reiterate and critique the inherent challenges of (re)producing the body/ies through existing binaries (See Box 2.1). In an effort to re-define borders and their fluidity, their argument contributes towards a 're-working of being' (p.147). However, in my work the fluid and fluctuating notion of disabled people's identities are harnessed by breaking down broader temporal frames of reference, exploring the intricacies of time (See Box 1.1), leading to a re-conceptualisation of disability through the lens of 'becoming'.

However, while time trickles through these accounts I argue that analyses of the everyday as a temporal frame of reference are missing, as I show that from minute-to-minute, moment-to-moment and day-to-day, disabled people's routines shift and move in flux, in line with their experiences of disability, health and illness. In doing so, this research demonstrates the way that so-called ordinary and taken for granted experiences, such as sitting (Bissell, 2008) and walking (Macpherson, 2009b, Edensor, 2010c) take shape through multiple and complex everyday temporalities. However, while an exploration of everyday life might focus on the 'present' in disabled people's routines, collective and social

histories of exclusion and oppression continue to shape the way that disabled people experience their everyday lives.

Therefore, the examination of the temporalities of everyday life in this thesis, demonstrates the minute and intricate ways that time is experienced as everyday practices make up participants' daily routines and are shaped by the 'past'.

#### **2.4.2 Life course**

This second temporality, the life course, reflects the significance of time and temporalities as they stretch and unfold at specific moments and as a process of longer-term change across the life course. Firstly, disability takes place at different times within each person's life, from congenital conditions as some people are born with sensory or physical impairments to other impairments and neurological differences that develop over time. Using theories of becoming, I show that disabled people may experience time as a chronological succession of different events that flow from one point in time in the past, to the next point in time in the present (Bergson, 1910a, 2001). Secondly, while Bergson's concept demonstrates the relationship of time as a linear sequence of events, I use Deleuze and Guattari's (2004) concept of becoming, to show that as "time is the hiccupping that expands itself, encompassing past and present into a kind of simultaneity" (Grosz, 1999: 25), events come together and coalesce at one emergent moment. The empirical findings in this research reinforce the uncertainty of the life course as a series of discrete life 'stages' (Hopkins and Pain, 2007, Worth, 2009b) showing that time and disability are unfolding relational concepts that emerge and alter throughout the life course, rather than remaining fixed in time.

#### **2.4.3 Rhythms**

The third temporality, rhythm, is significant to the concept of becoming disabled used in this thesis, as the following quote demonstrates.

“For Lefebvre, rhythm is relational, a site of interaction and instability rather than order. It is a process where *competing temporalities*, emanating from different *sources*, collide and redefine each other to stitch together the everyday”

(Nansen et al., 2009: 184, my emphasis).

This draws together a number of key ideas, which have already been outlined above, firstly, the idea of competing temporalities illustrates the multiple rhythms that constitute disabled people’s daily and lifelong experiences of disability, health and illness. It also addresses the second idea, the fluidity of rhythms as different rhythms, in different spaces, times and places (re)produce disability as a lived experience. The rhythms and temporalities of the ‘day’ and ‘night’, fluctuate in-between cycles of order and disorder, shaping disabled people’s lives. Thirdly, in the empirical material presented in the remainder of this thesis, I emphasise the role of disabilities, health conditions and illnesses in shaping ‘new’ rhythms, as well as the importance of ‘rhythms shap[ing] human experience’ (Edensor, 2010a: 1). Finally, human and material relations also matter in the production the bodily and mobile rhythms of disability, shaping the everyday rhythms of becoming disabled.

#### **2.4.4 Future(s)**

The fourth and final temporality, the future is often unknown, uncertain and may occur unexpectedly. While it is a term that everyone can, and does relate to, despite all the intention and planning, the future cannot be pinned down, but is necessarily framed by possibility, by reaching forward, by unfolding. I have labelled this section future(s) because the open ended-ness of becoming suggests that the future is defined by its multiplicity as opposed to its singularity. In this research, the future might explore the next moment, next day or next event in a disabled person’s life, or the future might reflect back on ‘events, processes, movements and things’ (Grosz, 1999: 2) that came to fruition or didn't

turn out as planned. However, in the face of the unknown and the unknowable, the future is also about planning for the yet to come, so I explore the way that disabled people's futures are open to contestation, (re)negotiation, change, transition, movement and flow, as I examine the complexities of the 'past', the 'present' and the 'future' in disabled people's lives. Grosz (1999) describes becoming as essentially open to futurity, and, while grounded in and through the embodied, emotional and affectual experiences of disability, this open-endedness makes the future very important as an overarching narrative in this research.

### **Chapter 3: The temporalities of participatory engagement: An unfolding methodology**

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This chapter is the first in a series of mini-methodological chapters where I introduce the participatory methodology that developed in my research with disabled people in the North East of England. The chapter focuses on the temporalities of participatory engagement, describing my attempt to use a Participatory Action Research (P.A.R) approach and ending up with different strains or degrees of participation. Despite setting out with the purpose of engaging participants in 'action', 'Action' as big change or 'action' through smaller change did not necessarily 'fit' or align with the interests of most of the eight participants and their partners who took part in the research. I describe how I carried out in-depth qualitative participatory research with these eight participants in order to understand the way that their identities are shaped by disability, health, illness and chronic pain in their daily lives and over the life course.

In the remainder of this chapter I use a temporal framework to explore the way that four important and interconnected practices fitted together as the 'research' developed over time. 'Thinking', 'doing', 'feeling' and 'writing' are not separated by distinct and fixed boundaries, nor do they occur as separate events in chronological succession. Instead, I show that these four practices merge and blur together, overlapping and churning through cycles of participation, action and reflection (Kindon et al., 2007). In this sense I address the unfolding and emerging methodological process that developed when conducting *this* piece of participatory research for the first time with disabled people. A participatory informed and led agenda provides an additional lens through which to explore disabled people's identities in this research and is significant in three ways.

Firstly, by using theoretical frameworks that focus on critical approaches to understanding complex socio-spatial injustices (mrs c kinpaisby-hill, 2011) and marginalisations (Chouinard, 1997), participatory approaches and enabling social geographies share a common goal. Enabling social geographies have the

potential to engage participants more fully in the research process, valuing the contributions of participants. Feminist and emancipatory methodologies are suitable, in-depth and appropriate for the topic and type of research. In section 3.1: '*Thinking*', I explore the appropriateness of using an ontological politics (Greenhough, 2011) within a feminist and empowering participatory framework (Chouinard, 1997). While this research was not wholly participant-led I illustrate how I incorporated an ontological politics, encouraging participation based on self-identification (3.1.1).

Secondly, there is a dual and tied endeavour between inclusive approaches to research 'with' disabled people and the collaborative and political underpinnings of a participatory ethics. In this research ethics in practice were shaped by theoretically informed feminist and participatory methodologies and ultimately in relation to the participants with whom I engaged (Cahill, 2007b). In section 3.1.2: '*A relational participatory ethics of care*', I explore the fluidity and processual nature of a participatory ethics, which is significantly different to more formal approaches to ethics. In doing so I argue that ethics come into being throughout the research process (Manzo and Brightbill, 2007) rather than as a bounded practice that takes place before engaging with participants. By highlighting the challenges of accessing participants and getting people together, this section explores the difference that a participatory ethics makes, as well as the way it stretches to suit the participants involved in the research.

Thirdly, by engaging with participants in participatory ways, the importance of time and temporalities unfolded, as a methodological and an empirical theme. Firstly, as I was finding my way around participatory research for the first time, this chapter highlights the importance of methodological temporalities, adding to existing geographical understandings of P.A.R's theoretical contribution to 'spatialities', 'relationalities' and 'materialities' (Pain et al., 2007: 29). In section 3.2: '*Doing*' I explore the way the research pivoted on this methodology, using inclusive practices *with* individuals and small groups and reflecting an open and innovative approach to researching the lives of disabled people. In this section I justify my use of feminist and participatory

methods, focusing on positionality and reflexivity, choosing and designing methods, and ownership and analysis.

Secondly, through the use of participatory methodologies, time also became apparent as an overarching empirical theme, binding participants' accounts of their own lived experiences of disability, health, illness, impairment and chronic pain. I briefly discuss the four main methods that developed with participants, providing a more detailed account of drawing timelines, using photovoice, having conversations and keeping a diary in a series of mini-methods chapters.

In section 3.3: *'Feeling'*, I show that throughout this unfolding agenda the role of emotions including both my own feelings and participants' feelings became more and more apparent. This reflects the intensities of doing fieldwork over a 14-month period, facing the ups and downs of the research process (Cahill, 2004, Askins and Pain, 2011), transcending emotional boundaries (Sultana, 2007) and feeling (un)comfortable as different friendships developed (Parr, 1998, Blake, 2007). While my methodological discussion throughout this thesis may appear coherent and smooth, my aim is to reflect the events as they were happening, therefore section 3.4: *'Writing'* explores the messiness of this process. I explore the temporalities of participatory engagement, outlined in section 3.2, showing how the research unfolded organically rather than taking place in a linear fashion, reflecting on this process as I experienced it.

Through this discussion, I argue that the participatory research methodology stitches together and shapes these four introductory sections, as thinking, doing, feeling and writing developed in response to one another throughout the research process (Bradbury and Reason, 2001). The messy and fuzzy nature of weaving emerging ideas together with participatory approaches and methods (Law, 2004, Tamas, 2009, Askins and Pain, 2011) is discussed in terms of grounded theory (Charmaz, 2006).

### 3.1 'Thinking'

In this section I explore how my ontological approach is shaped by diverse concepts and nuanced accounts of disability presented in the literature on geographies of health and disability<sup>11</sup>. Using Greenhough's (2011) theoretical work on the ontological politics of biological citizenship, spaces of care and spaces of cross-species companionship I show that this work coincides with Chouinard's (1997) conceptual arguments on disability, challenging and unsettling categories. These ideas provide the basis for my ontological politics and subsequently frame participation in the research. As I explore the significance and use of a politics of self-identification I show that participation was a two-stage process that involved 'going' to participants, as well as enabling participants to 'come' to the research.

By using participatory methodologies I show that one of the aims of the research was to both challenge and add to current understandings of disabled peoples lived experiences of disability. Using existing knowledges that shape conceptualisations of disability and ways of 'doing' research, I explore my participatory methodology in order to demonstrate the inherent problems of passing between pure and applied research settings (Pratt, 2000, mrs c kinpaisby-hill, 2011); and to highlight the inclusivity of such an approach, that remains underused within geographies of disability (Chouinard et al., 2010). In the following section I sketch out a developing ontology and introduce the eight participants that became involved in the research process, outlining the shared ethical commitment that exists in research 'with' disabled people and the politics attached to '*A relational participatory ethics of care*'.

#### 3.1.1 Developing an ontology

There has been a theoretical and methodological shift in the way that geographies of disability, (mental) health and illness are applied to understand the everyday negotiations that disabled people face. Firstly, a broader shift from

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<sup>11</sup> In chapter 2: '*Accepting differences*' I explored wider theoretical and empirical work that focuses on the bio-medical and social models that are used to describe disability, health and illness.



more traditional medical geography to health geography (Kearns and Moon, 2002, Dyck, 2003, Parr, 2004) developed a 'new' direction away from quantitative methodologies and towards more qualitative concerns (Kearns and Moon, 2002). However, while quantitative approaches still have their place within this new regime, Dyck notes that "alternative modes of 'knowing'" are about actively "talking to people, rather than about dots on a map" (2003: 363). This engagement with people emphasises their subjectivities and provides a critical lens to explore neglected or marginalised groups in relation to gender, race, sexuality and disability (Dyck, 2003, Parr, 2004, Cahill, 2007a).

Secondly, within the discipline "the broadening and growing complexity of the concept 'disability'" (Chouinard et al., 2010: 16) highlights the theoretical shift away from the social model of disability and towards more embodied accounts of 'disability' (Hall, 2000). Yet Chouinard's (1997) earlier work is still pertinent today, reminding us of the political agenda of the 'first wave' of disability studies:

"[I]t is important that critical geographies of disabling differences challenge and unsettle conceptual and discursive categories such as 'disabled persons', 'the disabled community', and 'disabled women'"  
(Chouinard, 1997: 384).

By introducing a politics of self-identification, I aimed to 'challenge' and 'unsettle' these categories in my research, drawing on Chouinard and Greenhough's work to produce more critically based knowledges. This includes opening up the research to participants' own interpretations of 'disability', assisting in the production of new ontologies.

Greenhough's (2011: 1) work demonstrates the importance of ontological politics by exploring the different sites and scales where the "relations between biomedicine and science" take place. Greenhough explores how biological citizenship, spaces of care and cross-species companionship are formed through

different encounters, and in doing so considers the way relationships between different actors, objects, environments and scales come together and are understood. By focusing on these new understandings, Greenhough puts forward an ontological politics to emphasise both the relational and situated nature of these ways of knowing, showing that:

“If existing knowledges and understanding are not universal facts, but negotiated and contingent achievements, then they are open to contestation, challenge and reinterpretation”

(Greenhough, 2011: 2).

There is increased concern surrounding methodological attentiveness to the everyday lives of disabled and ill people in geographies of disability and health; but in a different context, Greenhough’s work highlights the importance of developing an ontological stance as a new way to understand a situated and relational concept of disability. The explicit and political goal of working *with* disabled people and the politics of representation<sup>12</sup> adhered to in participatory approaches to research, shaped my ontology when approaching potential participants. By questioning the constitution of ‘disability’ I did not set limits on the type or number of participants that would become involved in the research, therefore, I did not label disability as physical or sensory impairment, as intellectual disability, as mental health or by any other category (See **Box 3.1: ‘Doing’ research: Approaching organisations**).

Using Greenhough’s work I developed a politics of self-identification as a way to question existing categories of disability and to empower participants in the research. Pragmatically, this involved addressing participants through a two-stage process and focused on one of the underlying questions of the research, ‘*What is disability?*’ This supports the notion that any reinterpretation of existing

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<sup>12</sup> The politics of representation are discussed in further detail in section 3.1.2 ‘*A relational participatory ethics of care*’.

knowledges should be understood through “practices and processes rather than pre-given truths” (Greenhough, 2011: 3). This draws on Philo’s (1997) work on ontological tricks and, in my research, involved thinking about the potential for multiple interpretations, from conceptual and empirical literature on disability and participants’ perceptions of their own lived experiences to my own role in the production of these ontologies. In order to put a politics of self-identification into practice, in the first stage of the research I approached clubs and societies that were already organised around a shared political identity (**Box 3.1**).

**Box 3.1: ‘Doing’ research: Approaching organisations**

During May-August 2010 I attended sessions on a weekly and monthly basis, focusing on clubs and societies in the north east of England that were associated with disability, health and illness and organised at local and national scales. I continued to liaise with groups that represented blind and visual impairment, multiple sclerosis and mental health, sharing conversations, facilitating (un)structured workshops and keeping regular contact with those people that I became familiar with and vice versa.

The degree to which these encounters were successful was inevitably unpredictable and occasionally a source of strain (See 3.3: ‘Feeling’ for a more detailed account); however, from these meetings the following participants became involved further in the research:

- Robert who had recently turned sixty had to leave paid work some years before as he was diagnosed with multiple sclerosis; and
- Steve who is in his late fifties and was also diagnosed with multiple sclerosis while he was still receiving paid work.

During this first stage of approaching participants, I felt that I was reproducing a paradox that lay between my scope to include groups that were already politicised around shared ‘disabled’ identities and labeling disability as visual impairment, as mental health and as multiple sclerosis. As I was aiming to understand and value participants for their ‘deep’ (Torre and Fine, 2006: 458,

cited in ) (Cahill, 2007a: 268) and ‘situated’ (Manzo and Brightbill, 2007: 37) knowledge, by honouring a politics of self-identification I wanted to go beyond organisations that were already re-producing their own pre-given truths (Greenhough, 2011). Therefore it was important that I provided an opportunity that enabled participants to determine if the research would ‘fit’ them rather than solely trying to fit participants ‘into’ the research.

Inspired by previous research into the complex and embodied accounts of disabled people’s lives, I wanted the contribution of the research to disability as a concept (Chouinard et al., 2010) to be shaped by the participants, rather than by my choices. As participants were able to represent themselves rather than being represented<sup>13</sup> by others, as is the case in more traditional methodologies, in September 2010 I had an editorial published in a free local newspaper. By calling for other potential participants to participate, I received emails and telephone calls from individuals who wanted to share their accounts of disability, health, illness, impairment and chronic pain, including two people representing a locally based support group.

### **Box 3.2: Responses to the newspaper**

I spent a substantial amount of time building relationships with people at the organisations I approached in the first stage of going ‘to’ participants (Box 3.1), at times without producing further or continuing dialogue. However, six other participants became involved as a result of advertising in the local paper. Three participants responded within two weeks of the editorial being published, expressing their interest and taking part in the research:

- Mark, a man in his early fifties who became spinally injured in a cycling accident ten years ago;

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<sup>13</sup> See section 3.4: ‘*Writing*’ for a discussion of the challenges of letting go and selecting participants’ accounts in order to understand the temporalities of disabled people’s identities.

- Elizabeth, a woman who has experienced severe chronic pain for the last forty years as the result of a routine medical practice when she was in her twenties; and
- Sue who was born with congenital dislocation of both hips (CDH) and has experienced multiple hip replacements in the last 40 years.

Three additional participants also joined the research from the chronic pain support group that Elizabeth was a member of, including:

- Simon, who has spondylitis, is in his sixties and has had problems with his back and chronic pain since his 20s;
- Victoria, who lives with chronic pain on a day-to-day basis, is in her 60s and received surgery on her spine five years ago; and
- Hannah, who is in her sixties, has sclerotic arthritis and is an amputee.

By offering participants this choice to come to the research, the meaning ascribed to 'disability' and 'participation' have been 'open to contestation, challenge and reinterpretation' (Greenhough, 2011) throughout the research process. In doing so, I would suggest, the research developed with an awareness of Chouinard's call to unsettle categories, aiming to represent the breadth, fluidity and multiplicity of 'disability' and disabled people's identities using a participatory framework.

In the next section I show that a relational participatory ethics of care filters through a series of interactions with disabled people, as I show how multiple negotiations took place throughout the entire research process (Sultana, 2007, Hopkins, 2007b). I argue that through these specific negotiations, the fluidity and temporality of participatory engagement becomes clear, as ethics are folded into a Participatory Action Research approach.

### 3.1.2 A relational participatory ethics of care

P.A.R. can be and is frequently described by and through the keywords that produce its name: Participatory, Action, Research - suggesting 'doing' the research 'together', through a 'process', with the impetus for 'change'. There is a strong emphasis on doing research 'with' participants as opposed to 'on' participants, implying a sense of shared ownership and enabling "co-researchers opportunities for ontological reflection" (Goodley and Lawthom, 2005: 147). This growing need to incorporate disabled people as co-researchers (Pain, 2004) and to avoid the previous silencing of disabled people in traditional methods (Chouinard and Grant, 1995) that has led to the development of participatory approaches as a more appropriate way to conduct, interpret and use research on issues related to disability, health and illness (Kitchin, 1999, Kitchin, 2000, Valentine, 2003b).

A 'classic' ethical procedure may consider issues such as anonymity, doing no harm, giving voice, understanding potential risks and providing informed consent (Manzo and Brightbill, 2007). However, I demonstrate that these ethical issues and responsibilities are just as important to P.A.R as they are revisited throughout the process as both the research and relationships with participants and between participants develop. By placing emphasis on research design that allows participants "to *'live the research process'* in a very direct way" (Chouinard and Grant, 1995: 140, my emphasis), participatory methodologies aim to encompass "a plurality of knowledges in a variety of institutions and locations" (Kindon et al., 2007: 9). Kindon et al. note that this in itself distinguishes a P.A.R approach from other qualitative methodologies, and in my research this manifested as incorporating disabled people's knowledges, enabling participants as they become involved in making the decisions, and taking more of an active role in the process, if they wished<sup>14</sup>.

In the remainder of this section I use the concept of a 'relational participatory ethics of care' to understand the changing, situated and contextual

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<sup>14</sup> See Table 3.2: '*Levels of participation*'.

nature of ethics in my research. Ethical issues are understood in relation to the participants with whom we work (Cahill, 2007b), changing as the process develops (Sultana, 2007) and throwing up new challenges as they emerge (Manzo and Brightbill, 2007). Banks et al., (2013) refer to the multiple roles, tensions and challenges that arise from the blurred the boundaries between the roles of the 'researcher' and the 'researched' in participatory research. In this sense an 'everyday ethics' becomes stitched into participatory relationships, stretching the idea of static and defined roles for researchers and those who are researched (Crang, 2003), shifting towards research that encompasses the fluid and emerging capacity of participants as co-researchers. Therefore, in my research a 'relational participatory ethics of care' responds to ethical issues as and when they appear, highlighting the temporality and multiplicity of ethical conundrums, which occur unexpectedly and require negotiation throughout the process. My attempts to integrate participants face-to-face, as well as through online methodologies such as setting up a research blog<sup>15</sup> and using a twitter account<sup>16</sup> can be understood by considering the role of power relations.

Participatory methodologies build on earlier feminist work that "demand[s] attentiveness to the voices of *researched* people" (Kearns and Moon, 2002: 610, my emphasis), enabling a potentially less hierarchical process. However, at times by offering participants a voice in the research process, this challenged the expectations of the research(er), highlighting the importance of positionality and reflexivity [ref] when building trust and rapport. Feminist methodologies demand attention to power relations that play out in the form of positionalities, referring to the varying positions and roles of those involved in the research process. I draw on some of my own positionalities as a (new) researcher, as a young, white female, and as non-disabled here in this chapter and subsequently in other mini-methodology chapters, using Sultana's (2007) work to understand the temporary politics of positionality in my research with disabled people.

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<sup>15</sup> The research blog can be found at <http://www.disidentities.com>

<sup>16</sup> Using Twitter as a medium for communicating with potential participants was a new challenge. The twitter account can be found at J\_Sellick

The following examples illustrate the blurred boundaries between 'thinking' and 'doing', as ethical issues such as the language used in promotional material may (re)produce relationships of power<sup>17</sup>, whilst gaining access to participants involved building trust and rapport and can potentially lead to (not) doing the research. Firstly, Freire's (2000) philosophical approach to working 'with' marginalised and oppressed communities highlights the connection between language, ideology and power. The implicit role of language can act as a barrier to participation, especially in relation to disabled people lives. This language may be conveyed through spoken word or read symbolically through the design of the built environment (Imrie, 1996a), excluding disabled people from participating in day-to-day activities. Kitchin (1998) explains that disabled people often feel 'out of place' and are excluded from social spaces where they do not feel that they belong or they are not made welcome or invited to join in (Parr, 2008).

Therefore, choosing and using appropriate language to reach participants and to describe participants' identities was one of the first methodological challenges and was a continuing concern throughout the entire project. I had to consider the political agenda of associating with a disabled or impaired identity for some participants, whilst also recognising that identifying with a disabled politics would not necessarily be on the agenda for other participants. The initial advertisement that I used to promote the research incorporated the terms 'disability, health, illness, impairment and chronic pain', highlighting the tension between labeling disability and simultaneously providing a focus for the research, without being too abstract.

Secondly, I began to realise that there were expectations placed on both the research and the researcher, as I faced challenges accessing participants in online and offline environments, as well as getting people together. While there is an additional set of ethics to consider when carrying out online research (See Brownlow and O'Dell, 2002, Madge, 2007, Orton-Johnson, 2010), I received the

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<sup>17</sup> I draw further on relationships of power in Chapter 8: '*Becoming (un)comfortable*'.



following comment on the blog as a result of posting in an online forum for spinal cord injury:

“Normally, SIA [Spinal Injuries Association] members respond to questionnaires because we are all aware that any research may help us in our everyday lives so are keen to help”

(Comment from disidentities.com research blog, July 2011).

As Mark, a spinally cord injured man had joined the research project, I was interested in the stories of other spinally cord injured adults. Therefore, when I posted in the SIA forum, I provided a summary of my participatory research and its aims, as well as a link to my online blog, inviting SIA members to participate. However, this was not the first time a potential participant had requested a questionnaire, as a man at a chronic pain support group (**Box 3.2: Responses to the newspaper**) was also keen to be involved in the project in this way. This demonstrates the expectations that participants have about the research process and might also reflect their own personal experiences of being involved in research in the past. The way that values are often placed on “researcher’s positionalities [which are] read and interpreted by the research participants” (Hopkins, 2007a: 387), illustrate the specific challenges that were shaped by my participatory framework. My feminist and participatory methodologies were (re)producing a paradox that, on the one hand was informing a more ethical approach to working with disability (Kitchin, 2000, Valentine, 2003b) and on the other, was causing some participants in my research to question its legitimacy. The legitimacy of the research and my positionality as non-disabled became particularly apparent when trying to work with a local organisation that supported people who were blind and visually impaired.

In May 2010 I began to attend a regular coffee morning at a support group for blind and visually impaired people, where a group largely consisting of

women over 40 years old got together for a chat. Once a month the support group ran a scone morning, the busiest of the month, selling scones that were made by other members, utilising the contributions in order to run the charity, whose lottery funding was due to finish. These mornings were my first point of contact with potential participants, however as my visits continued I became aware that certain relationships of power were developing.

Betty was not the only gatekeeper at this group; however, she was my main point of call and the person whom I emailed. Yet I started to get the distinct impression that Betty did not want to be involved with the research and subsequently I felt that had started to influence others. On this particular occasion I was arriving for about the fourth or fifth time over an eight-week period and I stood in the centre of a room, where about 15 people sat at four small tables, drinking tea and eating scones. Betty rang the bell to get everyone's attention and as the conversation quietened to a hush, she began to say:

**Betty:** So we've got, er, someone here who wants to ask you...

[Pausing she turns her body to face me, and asks]

**Betty:** What's your name again?

**Jayne:** 'Jayne'

**Betty:** That's right Jayne...

Betty may have genuinely forgotten my name, but there were other events that reinforced her position (by email), including that I might get a "little feedback" and "after thinking about this I think you should just come once a month if that is ok". I didn't know if these comments came personally from Betty or were relayed from the group, as I had received positive responses from members, who later took part in conversations and a two-hour workshop.

This example highlights the ‘relative power’ and ‘insider-outsider’ status (Mullings, 1999) that were produced during my encounters with Betty. While Mulling’s work outlines the transformative power of participants who are in elite positions when conducting interviews in Jamaica, in my research it is my positionality as a non-disabled ‘outsider’ that shapes my experience. While feminist geographers (and my research) critique narrow dichotomies between disabled/able-bodied, showing that concepts such as (dis)ability are marked by their fluidity (Butler and Bowlby, 1997, Butler, 2001), Betty uses her power to reinforce my position as an outsider. However, while Worth (2008) notes that the personal may be political in disability research, participants’ at the support groups (Box 3.1, Box 3.2) that I visited openly questioned my position in relation to chronic pain; but despite my disclosure that I have no personal experience of living with chronic pain, other than a relative’s chronic pain, this assertion did not prevent other participants’ participation in the research.

In the next section I show that despite these temporal positionalities (Sultana, 2007) and emerging ethical challenges, the production of more inclusive methods that are co-designed with participants illustrates the way that my research ebbed and flowed during and in between participatory encounters and in relation to the theme(s) set by participants.

### **3.2 ‘Doing’**

In this section I describe the process of ‘doing’ a participatory methodology, and describe how customised methodologies were used to suit participants needs, from an accessible blog for visually impaired users and a group photovoice session on chronic pain, to one-to-one and group conversations, individual timelines and diary writing. Using Mountz et al.’s (2003) work on methodologically becoming, I explore the “process of continuous negotiation[s]” (ibid, p.31), showing that these specific methodologies unfolded during my encounters with participants. By ‘doing’ the research in this way, I did not anticipate which topics would be important in the research but worked with participants to access new forms of understanding (Reason and Bradbury, 2001)

about the complexity of their lives. In section 3.2.1: '*Research Questions*', I show that through 'doing' the research with participants, the aims and objectives of the research developed rather than being determined prior to engaging with participants, as is the case in more traditional methodologies.

I provide an in-depth discussion of the four mini-methods that developed with participants between May 2010 and September 2011 - 'drawing' timelines (chapter 4), 'taking' photographs (chapter 6), 'talking' in conversations (chapter 8) and 'writing' a diary (chapter 10) are found in sequence throughout the remainder of the thesis, slotted in between empirical chapters in order to illustrate the becoming of knowledge production (Bourdieu and Wacquant, 1992, Gibson-Graham, 1994, Mountz et al., 2003, Cameron and Gibson, 2005). The concept of methodologically becoming also supports my use of grounded theory (Glaser and Strauss, 1965, Charmaz, 2006), which involves moving back and forth between engagements with participants, shaping methodologies and (re)visiting the conceptual, methodological and empirical literature on geographies of disability, health and illness in order to advance "theory development during each step of data collection and analysis" (Charmaz, 2006: 5). While this is discussed in more detail in section 3.4: '*Writing*', I provide an account of the importance of 'doing' feminist *and* participatory methodologies in disability research.

Feminist methodologies involve opening up the research to the voices of ordinary people and marginalised groups that may have been excluded from the 'detached objectivity' that pervades more positivistic research methodologies (Davidson, 2001b: 163, Pain et al., 2007). By incorporating reflexivity in the research process (England, 1994) feminist researchers question their own role in the politics of knowledge production, ensuring that participants become involved in the research as producers of their own knowledges. This illustrates that all knowledge is situated (Katz, 1994, Rose, 1997) and highlights sensitivity to the information gathered during exchanges with participants in feminist research.

In Chapter 8: *'Becoming (un)comfortable'* I refer to the inherent power relations that are (re)produced in conversations with participants, building on issues of reflexivity and negotiated positionalities that have already been raised. In Chapter 6: *'Taking photographs'* I refer to 'looking' as a feminist practice, challenging the "different gazes in our research practice" (Kindon, 2003: 142) as three photovoice users become the producers of these gazes, taking control of both the camera and the method. By using inclusive methodologies that emphasise the role of multiple knowledges and aim to move 'control' into the hands of participants, I demonstrate the connection between feminist and participatory practices, which are subsequently addressed within each mini-methodology chapter (4, 6, 8, 10). A relational participatory ethics of care incorporates these concerns by attending to the needs and desires of participants throughout the research process.

By using feminist and participatory informed methodologies, I explore the temporalities that emerged as I continued to interact with different people, investing intensive amounts of time building relationships (Klocker, 2012), some of which came to fruition as different participants fall in and out of the research process. Pratt's (2007) 15-year collaborative research project with Filipino domestic workers in Canada is significant as a long-term participatory project, however, my research focused on developing individually designed methods over a shorter period of time. Contrasting Pratt's work with my own highlights the fluidity and longevity of different researchers' networks (Cragg, 2003) in participatory research. As subsequent mini-methodological chapters show, the temporalities of my methods were shaped by multiple interactions with participants, including:

- conversations that can move beyond the space-time of an interview;
- photovoice demonstrates the importance of space-time snapshots;
- timelines are understood as non-linear drawings; and

- diary writing offers temporal accounts of lived experiences across the life course.

In Table 3.2: *'Levels of participation'*, I provide a summary of the participatory relationships that developed throughout the course of the research, demonstrating varying degrees of participation from working with blind and visually impaired students using existing contacts to developing specific methods with individuals in response to a newspaper editorial. Table 3.2 provides information about all of the participants that I worked with throughout the research process in different columns (1-8), to highlight: different groups (1) and individual participants (2). I have given pseudonyms to the eight participants, Mark, Sue, Robert, Steve, Hannah, Elizabeth, Simon and Victoria, who became more deeply involved in the research, and give details of their gender (3), disability, health condition or illness (4), my recruitment strategy (5), the timing of disabilities, health conditions and illnesses (6), the individual and group methods (7) that each participant used, and the empirical chapters (8) where I discuss each participant's accounts.

However, it was through these different types and levels of participation that 'research questions' based on participants' lived experiences of time and temporality developed, tying participants' stories together as an overarching empirical theme. In the following section, I outline the research question that shaped this participatory research.

Groups (1)	Participant(s) (2)	Gender (3)	Disability, health condition or illness (4)	Recruitment (5)	Timing of disability, health condition or illness (6)	Methods (7)	Chapter (8)			
							Becoming emotional	Becoming well	Becoming mobile	Memories
B & VI Group I	User A	M	VI	Existing contact at organisation	Developing	Conversations				
	User B	F	VI & cancer		Cancer					
	User C	M	VI		Developing	Timeline (s)				
B & VI Group II	User D	M	VI	Existing contact at organisation	Birth	Conversations				
	User E	F	VI		Developing					
	User F	M	VI		Developing	Sharing stories				
	User G	M	VI		Accident					
	<b>Mark</b>	M	Spinal Cord Injury (SCI)	Newspaper Editorial	Accident	Conversations Timeline	X	X	X	
	<b>Sue</b>	F	Congenital Dislocation of Both Hips (CDH)	Newspaper Editorial	Birth	Conversations; Timeline; Diary	X	X	X	X
	<b>Mike</b>	M	Partner	Snowballing	N/A	Conversations				X
	<b>Robert</b>	M	Multiple Sclerosis (MS)	Local club/ society	Developing	Conversations	X			

	<b>Steve</b>	M	Multiple Sclerosis (MS)	Local club/ society	Developing	Conversations	X			
<b>Chronic pain support group</b>	<b>Hannah</b>	F	Sclerotic arthritis	Snowballing	Developing	Photovoice; Conversations		X	X	
	<b>Elizabeth</b>	F	Chronic pain	Newspaper Editorial	Medical practice	Photovoice; Conversations	X	X	X	
	<b>Simon</b>	M	Spondylitis	Snowballing	Accident	Photovoice; Conversations	X	X		
	<b>Victoria</b>	F	Chronic pain	Snowballing	Developing	Photovoice; Conversations	X	X	X	
<b>B &amp; VI Group III</b>	User H User I User J User K User L	F M F M F	VI Blind Blind VI/diabetic VI	Existing contact at organisation	Developing Birth Birth Developing Developing	Conversations; Online Demo; Feedback; Signing up				

**Table 3.2:** Levels of participation



### 3.2.1 Research questions

What are the everyday practices and processes that shape disabled people's identities?

What are the roles of the past, the present, and the future in disabled people's lives?

How are these temporalities experienced on a day-to-day basis and over the life course?

How do everyday processes and practices challenge and change the temporal stability of disabled people's identities?

What is the potential of participatory research for uncovering everyday experiences of disability with disabled people?

### 3.3 'Feeling'

In this section I reflect on my own personal feelings about 'doing' the research and acknowledge the importance of participants' feelings throughout the research process. This relates to my feelings about the peaks and troughs of participation and to the way that participants demonstrated a mixture of feeling comfortable and uncomfortable. By focusing on feelings I address the role of emotions in fieldwork, as well as the role of emotions as a methodological theme, which I discuss in more detail in Chapter 4: '*Participatory diagramming: 'Drawing' timelines*' and Chapter 8: '*Becoming (un)comfortable*' and as an empirical theme in Chapter 5: '*Becoming emotional*'. However, as participants became involved to varying degrees I realised that there were expectations about what research should look like and feel like.

While I worried about whether particular methods would work, I was feeling my way through the participatory process for the first time, as were some of the participants. So whilst I could not say how long we would talk, write, draw, do or make for; how frequently; let alone which topic, I learned to read

situations, getting a feel for methods. However, when I was 6 months into meeting participants, I began to feel extremely low about the process I was going through, as I didn't feel like my methodology was working (although I had nothing to compare it to, other than what now felt like very structured qualitative methods I had used in the past). I was 'doing' the research and conversing with people at different locations (as outlined in Table 3.2: '*Levels of participation*'), yet I felt like I was spending significant amounts of time preparing possible methods for meetings with individuals and groups, but wasn't producing anything.

However, after meeting with one participant on multiple occasions as part of a larger group, she expressed her interest in the research but at the same time said it all sounded a bit 'airy fairy'. While this participant laughed about her description and had completed her own geography degree some forty years previously, this point further demonstrates both expectations about research (as discussed earlier in section 3.1.2: '*A relational participatory ethics of care*'), at the same time as expressing her feelings about participatory research methodologies. This example links to the politics of feeling (un)comfortable, demonstrating one of the high points of the research, which developed from the newspaper editorial (**Box 3.1: 'Responses to the newspaper'**). Box 3.3: '*Feeling comfortable*' describes the relationship that unfolded with Mark and his family as I built a rapport that was very different in nature to those participants I was engaging with at the time, especially at the support group where Betty was present.

### **Box 3.3: Feeling comfortable**

After receiving an email from Mark (Box 3.1), we decided that meeting face-to-face would:

"...suit me better, let me know when. [M]y wife says would you like to join us for tea?"

(Mark, Email Correspondence, 2011)

On my first visit to Mark's home he greeted me at the door to the bungalow and when I asked if I should take my shoes off, Mark's wife laughed from inside the kitchen, saying:

"Oh no, well Mark can't take his wheels off!"

(Mark's wife, First home visit, March 2011)

While I was invited back 'for tea' on multiple occasions, meeting Mark's son who lived in the same street, these encounters added to my understanding of Mark's experiences of spinal cord injury. Throughout our conversations Mark would refer to the way that his accident, becoming spinally injured had changed the way that he lived his life at home; and it was through being in Mark's home and getting to know his family that more and more stories were shared from different members of his family. The idea of feeling comfortable also relates to the degree to which participants became involved in the research process and the extent to which participants *felt* comfortable about choosing particular methods. However, feeling uncomfortable can be as much a part of the process, as Parr (1998: 31) describes being "uncomfortably aware of how my hair smelt of shampoo" when completing covert ethnography at a drop-in centre for people with mental health problems.

While Parr's study is about trying to fit in, unnoticed, feeling (un)comfortable in my research relates to the "embodied gender politics" (1998: 34) of working with male subjects. I have deliberated about whether or not to include this next example within my thesis and have avoided listening to the part of the transcript when typing up this participant's face-to-face interview. I think it is important to say that while I did not feel threatened by this participant (who will remain anonymous) I feel strange about reliving his joke about tying me up in his bedroom, when the interview seemed to be coming to a close. I think that it is enough to discuss this point without using the direct quote, which I am reluctant to listen to, and I think that I can analyse this one occasion as an

attempt by a male participant to make me feel uncomfortable in his own home as intentional.

As I had met this participant on multiple occasions at organised monthly meetings, I am apprehensive about my analysis of this event, as it is based on these meetings and the conversations we exchanged, however, what I can say is that this builds on his gendered identity and the assertion by a woman at the group, that:

“Well, the men sit over there...”

[pointing to where they are sitting]

“and the women sit over here”

[referring to her position in the room where we are talking]

“I think it’s because they want to talk about their sexual problems, because ... it makes men impotent’.

(Female participant, support group)

The same female participant at the support group smiles when she tells me the story, adding that she thinks the men don’t know that the women know why they sit by themselves. However, it is because of the exchange that took place whilst I was at this male participant’s home that I made the decision not to forward a written copy of the conversation to him for feedback.

In the final section of this chapter I describe the messiness of ‘writing’ up the research and the different challenges I faced when analysing and presenting empirical material from this particular participatory research project on disabilities, health conditions and illnesses.

### 3.4 'Writing'

“Because knowledge is co-produced with co-researchers and participants in particular places, those with whom we work can profoundly change our research practices and theoretical perspectives”.

(Pain et al., 2007: 29)

The opening quote of the final section of this chapter is significant because it demonstrates the profound role that participants can have and did have in my participatory research methodology. Pain et al. (2007) highlight the role of participants as co-producers and co-researchers, which is important as it enables me to demonstrate the complexities of 'writing' up the research, as well as exploring the messiness of using participatory methodologies. In this section I use four axes to show that it was only upon later reflection and 'thinking back' that I was able to recognise the messiness and emergence of the research process, as I thought about the tensions between analysing and writing up. These four axes include: the tension (and ethics) of choosing empirical material to analyse, providing coherence in a tangled up process, re-presenting emotional accounts through writing and re-exploring the conceptual literature 'after' the research is 'finished'. This final point highlights the ongoing analytical process, which took place throughout and in-between encounters with participants rather than at a fixed point at the 'end' of the 'finished' research.

The temporalities of writing and analysing the research are discussed in each mini-methodological chapter as I explain the process of analysing timelines, photovoice, conversations and diaries. However, I show that over the 14-month period of my research, by using a grounded theory approach the unfolding of theory, practice, outcomes and ethics became fuzzy and difficult to distinguish. In participatory research 'theoretical perspectives' (Pain et al., 2007) become 'grounded' both with and by the participants that are involved in the research, for example, in my research participants contributions, including what they say, photograph, write and draw, in turn shapes the research questions as knowledge

is co-produced by participants. Therefore, by shifting back and forth between the empirical material that is produced by participants with theoretical and conceptual literature in geographies of disability, health and illness, participants' accounts were analysed. The first tension that arises from this approach to research with my participants was learning to let go of the empirical material and to realise that whilst all of the material cannot be included, the research has still fulfilled a participatory ethos.

This leads to a second tension, overcoming the 'gold standard' that is often presented in participatory research and embracing the messiness of it through writing. In order to overcome the challenge of producing a written account of the ups and downs of participatory research, as well as the uncertainties of 'doing' and using different methods into a coherent narrative, I have used a less traditional structure for my thesis. By incorporating mini-methodological chapters I wish to demonstrate the churning back and forth between participants, theoretical literature, analysing and writing. A third tension involves writing about emotion, one of the unfolding themes of the research, as well as a part of my conceptual framework for understanding disability. This also highlights the tension surrounding the production of a written thesis, as Bondi (2005) argues that emotions in themselves cannot be represented.

The fourth tension, involves analysing participatory accounts using grounded theory by 'going back' to conceptual and theoretical literature in order to match up, compare or produce new knowledge based on participants' accounts of their disabilities, health conditions and illnesses. 'Going back' to the literature is significantly different to more conventional approaches to qualitative research, as the analysis of participants accounts emerged during and throughout the research process. As participants chose methods, research questions developed; as research questions developed and participants shared information about their lives, analyses also developed by going back to read conceptual material 'after' participants had shared their experiences related to disability, health and illness. The cyclical process between participants sharing

experiences, an analytical process in itself, and going back to the literature, took place repeatedly; however, this differed depending on the context, including the individual participants and the specific method that was being used. In this section my aim was to provide an overview of the analytical process in this research, demonstrating that the analysis of participants lived experiences was part and parcel of doing P.A.R methodologies, taking place during and after meetings with participants. Each mini-methodological chapter provides more specific details of the analysis and interpretation of empirical material in this research, including the role of participants as co-researchers and co-producers (Pain et al., 2007).

Finally, in the remaining chapters of this thesis I show that working collaboratively produces messy and emotional relationships, as I provide an open and honest account of the complexities, uncertainties, peaks and troughs and outcomes of participatory research. By writing up this research using a non-traditional structure, my aim is an ethical one, as I argue that writing should reflect the messiness of the process. I tackle the messiness of: not knowing what is or is not working, deciding when to continue and when to stop, thinking about who was involved and worrying about providing coherence in a tangled up process. I demonstrate that writing and reflecting on these tensions and not silencing or hiding them in our own research diaries, which are seldom aired, is an important resource for future participatory research projects.

In summary, in this chapter I have illustrated that by 'doing' participatory research, time and the temporalities of disability, health and illness unfolded as an overarching theme in the research. It was by using a politics of self-identification that the research was able to open up to a range of potential participants, and in the following methodological and empirical chapters I show how the temporalities of disabled people's identities bind all of the participants accounts together in this research.

#### **Chapter 4: Participatory Diagramming: 'Drawing' timelines**

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This chapter is the first of four mini-methodologies, which highlight the emerging (Mountz et al., 2003, Cameron and Gibson, 2005) nature of participatory methods in this research. Using feminist and participatory methodologies outlined in Chapter 3: *'The temporalities of participatory engagement: An unfolding methodology'*, I illustrate the methodological processes that took place with participants, as we explored the temporalities of living with disability, health and illness. By focusing on one method per chapter I show that 'drawing' diagrams, 'taking' photographs, 'talking' in conversations and 'writing' a diary illustrate the different visual and textual methods that developed through one-to-one and group interactions. The unfolding nature of these interactions and engagements shaped the methodological choices that participants made, as well as aiding new theoretical directions in critical social and cultural geographies of disability, health and illness, which developed through this practice. As methods were chosen with participants in order to 'represent' lived experiences, in this chapter I show that participatory diagramming emerged as a tool through the research, enabling participants to reflect on the emotionality of their lived experiences of disability, health and illness.

In this mini-methodological chapter I explore the importance of using visual methodologies in feminist research (England, 2006, Rose, 2011). By providing an account of participatory diagramming (Kesby, 2000, Alexander et al., 2007, Worth, 2009b, 2010) and mapping (Cornwall, 1992, MacKian, 2000, 2004, Giesecking, 2013), I discuss the practicalities of drawing timelines, a participatory diagramming technique that was used with two participants in my research. By offering contrasting accounts I will show how Sue and Mark engaged in different methodological processes based on individual needs (Valentine, 2003b), producing participatory diagrams that reflect their personal experiences of Congenital Dislocation of both Hips (CDH) and spinal cord injury (SCI), respectively. I use the phrase 'participatory timelines' to describe the method that emerged with Sue and Mark and through the use of audio



recordings taken during this activity and images of completed timelines (Figure 4.2.1; Figure 4.2.3; Figure 4.3.1; Figure 4.3.2) I show that 'doing' methods collides with both 'writing' and analysing participants' lives. I continue to discuss the importance of emotion in Chapter 5 '*Becoming emotional*', as such this chapter offers an introduction to the relevance of emotion as an empirical and methodological theme throughout this research.

#### **4.1 Visual methodologies: Feminist practice**

While geographers' claim to visual modes of representation have been well documented in the discipline from the history of geography (Driver, 2003, Ryan, 2003) and cultural geography (Rose, 1993, Nash, 1996) to physical geography (Thornes, 2004), visual methodologies have been increasingly significant to qualitative research across the social sciences, including sociology (Holliday, 2000) and anthropology (Pink, 2001, 2003). The 'visual' refers to the use of visual techniques such as film, photography, art and drawing, which is used in social research as a way to produce knowledge. However, the origins of geography as a visual discipline have been critiqued for re-presenting colonial imagery from the past through a masculine 'gaze' (Cragg, 2003) and re-producing power relations through other forms of visual representation (Rose, 2003). By combining feminist and participatory methodologies, the importance and use of visual methods as a feminist practice is illustrated in this chapter.

Feminist methodologies interrogate situated, relational and fluid perspectives by offering an alternative lens onto other interpretations and understandings of lived experiences. While feminist geographers such as Rose (2003: 213) highlight the way "visualities ... are always structured with power relations", this differs from "the history of visual technologies...in disciplining and controlling both the subjects of knowledge but also the modes of knowing" (Cragg, 2009: 5). The aim of visual methods as a feminist practice is to move beyond forms of 'discipline' and 'control' as participatory methodologies align

with a feminist ethics of care and responsibility<sup>18</sup> by attending to the needs and desires of participants throughout the process of the 'research'. In this respect geographers have used visual methodologies in an attempt to break down the inherent power relations involved when working with marginalised groups (Kesby, 2000, Alexander et al., 2007, Worth, 2009b, 2010, Giesecking, 2013) and to establish more suitable and appropriate ways to understand participants' lives.

By aiming to put the power or decision making into the hands of participants, participatory methodologies involve participants making decisions about the topic to be explored and the methods to be used, creating the potential to work with participants in ways that suit their needs, as well as destabilising traditional power hierarchies. When working with participants on topics related to disability, health and illness, this is particularly important, because it enables participants to be involved in their own way beyond traditional views of disability that tend to determine what they can do in relation to physical and/or sensory disabilities. However, by arguing for the diversity of disability it is possible to open up for a range of visual methodologies.

The visual methodologies used by geographers (Kesby, 2000, Alexander et al., 2007, Worth, 2009b, 2010, Giesecking, 2013) describe participatory diagramming, an all-encompassing term that includes the use of drawing<sup>19</sup> as a tool, method or exercise for illustrating various accounts or experiences, usually on large sheets of paper with marker pens (Worth, 2010). This often involves using the pens to draw images and write words, or using tactile materials (Kesby, 2000, Alexander et al., 2007, Worth, 2010) to produce visual representations in relation to a particular topic. However, participatory diagramming is about more than just creating a visual means of representing personal or collective thoughts, as Giesecking (2013) demonstrates through her discussion of mapping. While a map might be thought about as a visualised

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<sup>18</sup> See Chapter 3: *'The temporalities of participatory engagement: An unfolding methodology'*.

<sup>19</sup> See Kesby (2000) for a more detailed discussion on participatory diagramming in a developing world context that uses "locally available materials such as seeds, bottle tops, pebbles, sticks, straw, household objects or representations drawn in the soil" (ibid, p.425).

representation of space, Giesecking (2013) suggests that mapping enables critical social geographers to represent marginalised and oppressed groups (Brown, 2001). Mapping, as a participatory diagramming technique, enabled participants to map their own spaces, places and people in Giesecking's study of 'gender identity development on an elite college campus' (2013: 7). Using mental mapping as "another way of seeing [a participant's] world" (2013: 2), Giesecking's (2007, 2013) work illustrates the potential of feminist infused ways of knowing, putting her participants in control of the information that they 'map'.

While participatory diagramming may involve the production of a diagram (Kesby, 2000, Alexander et al., 2007), or map (Worth, 2009b, 2010, Giesecking, 2013), in my research diagramming was shaped by feminist and participatory ways of diagramming through the use of 'participatory timelines'. In the next section I provide an account of the visual methodology that developed when using participatory timelines in my research with two participants, Sue and Mark. In doing so I follow Kesby's (2000) support for Graham's (1999) work, which suggests that techniques should be discussed together *with* theoretical frameworks, highlighting the epistemological nature of participatory diagramming. While Alexander et al. (2007) emphasise that not all diagramming is participatory in nature, the audio recording made while Sue completed her timeline provides the first of many examples that illustrate her level of participation in the research. I outline the individual methods that were tailored to suit Sue and Mark's needs by exploring the different roles that each participant played. Using further examples from (life) mapping (Worth, 2009b, 2010) and arts-based methods (Bagnoli, 2009), I show that participatory timelines were used in order to map the temporalities of daily life and the temporalities of the life course, which is different to the spatialities mapped in Giesecking's (2013) work.

#### **4.2 Mapping temporalities**

In my research a participatory timeline, which is similar to a life map (Worth, 2010) was used as a visual tool, allowing two participants to explore the

temporalities of their lived experiences of growing up with CDH and becoming spinally cord injured in an accident. Following Mark and Sue's separate responses to the newspaper editorial, I accepted invitations to their homes<sup>20</sup>, explaining the purpose of this piece of participatory research. Upon returning to both participants' homes for the second time I suggested that a participatory timeline might be an appropriate method to use to explore Mark and Sue's experiences. This suggestion was based on the in-depth conversations that had already taken place with Sue and Mark, and as a method would enable both participants "to reflect on the different temporal dimensions of past, present and future in their lives" (Bagnoli, 2009: 560). By using paper to write down significant events and turning points (Worth, 2010) in their lives, Sue and Mark adopted this method for different reasons.

The methodological process that developed with Sue and Mark was inspired by Worth's (2009; 2010) work, which explores young visually impaired (VI) peoples' transition to adulthood using 'life mapping' in order to collect "stories of transition (important events, people and place)" (Worth, 2010: 3). In her study, Braille and large print content labels were added by participants to a central lifeline – a piece of string laminated to the centre of a large sheet of paper – as "self-defined 'fateful moments' of transition" (ibid, 1052) were mapped onto the paper. By incorporating turning points and significant events, each participant created their own personal life map indicating the spaces and times that were important to their lives in the move from childhood to adolescence. These life maps enabled Worth to understand "time as a lived experience" (2009b: 1050) as participants' added information thematically rather than sequentially, illustrating the fluidity of transitioning as a non-linear experience. Box 4.2: '*A guide to mapping participatory timelines*', provides a thematic guide to producing participatory timelines. This guide is written thematically, firstly, to reflect the non-linearity of the methodological process of engaging in participatory timelines, and secondly, to enable co-researchers' fluidity in the

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<sup>20</sup> See Chapter 8: '*Becoming (un)comfortable*' for more details about conversations in participant's homes.

process by not enforcing a chronological sequence, but enabling the method to unfold differently each time.

**Box 4.2:** A guide to mapping participatory timelines

**Method:** Agree a participatory diagramming method with your participant(s):

What will the timeline represent? (Agree a topical focus)

Why are you using a timeline? (This question might be answered after the process has taken place)

**Materials:** Choose appropriate materials with your participants: paper, pens, sticks, stones, and Braille labels. The use of materials might be shaped by context (Where are you facilitating the method (country, physical location), by participants (to meet different requirements - age), or by time (as a pre-arranged method that you agree to carry out in the future when working with participants, or as suggesting during a meeting).

**Control:** Give your participants as much control as possible, reassuring them as individuals or groups that it is their method/activity: what would they like to do?

**Plotting:** Ask participants to plot significant events and turning points in relation to the chosen topic (life course)

**Using layers:** Use additional labels or stickers for participants to expand or elaborate on points raised in the timeline.

**Analysis:** Analysis of the material presented by participants (written or spoken) is an on-going process that takes place as the participatory timeline is developing; however, analysis of the method may also take place in the same way. Personal reflections should be considered by all those involved in the method: Are your materials limited? How does or might this effect the process?

**Ethics:** What are the ethical issues that might arise before, during and after using the method? (It is important to consider the role of ethics throughout the process, not just before and after the data is collected)

By exploring differing methodological processes I show that Sue, who was born with Congenital Dislocation of both Hips, took control of the exercise and began drawing her own timeline. Mark, a spinally injured adult, instead directed me as I drew his timeline on a sheet of flipchart paper. Firstly, I illustrate what happened in practice as each participant produced a timeline – Sue of her life course and Mark of his daily life. I use the present tense in these accounts in an attempt to convey something more of these interactions. Secondly, I address the emergence of emotion as an empirical theme that developed as Sue and Mark both experienced the process of ‘drawing’ a participatory timeline. Box 4.2.1: *‘Feelings of a flipchart’* provides my own personal methodological reflection on some of the other moments in the research where I tried to integrate participatory diagramming.

**Box 4.2.1: Feelings of a flipchart**

Using participatory diagramming as a tool did not always feel right. Although I have provided an in-depth account of the participatory diagramming techniques that Sue, Mark and I produced, this was not my first attempt to incorporate visual methodologies. While Alexander et al., (2007: 119) suggest:

“[T]he claim to inclusivity may act to exclude and delegitimize those who decline to take part (Cleaver et al., 2001, Kothari and Cooke, 2001)”.

In much the same way that authors who write about the presence of a Dictaphone or audio recording device, in my research, the thought of producing a flip chart, and a rather large one at that, felt both awkward and inappropriate at times. In some respects it was the ‘power play’ that Alexander et al., (2007) discuss that made me hesitant to produce the paper and pens at meetings. After a period of carrying the flipchart on multiple occasions to a blind and visually impaired charity, I decided to leave it in the car, as it was beginning to feel like a hindrance<sup>21</sup>. Subsequently, this was the first group that I decided to give ‘drawing’ a go and it didn’t work out too badly in the end.

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<sup>21</sup> See chapter 8: *‘Becoming (un)comfortable’* for a discussion of the materiality of items.

In section 4.3: *'Expressing and analysing feelings on a page'*, I show that while 'feeling' and 'emotion' still emerged as a topic with Mark, it became more prominent through 'talking' and revisiting the topic whilst plotting his timeline, however, for Sue, emotions emerged through the process of mapping her life course.

#### **4.2.1 Sue: The temporalities of the life course**

After describing the process of using paper as a means to write and draw about her life, Sue agreed to complete a timeline exploring her life course, telling me:

"Well, I had been thinking about writing down all of the dates that things had happened to me since your previous visit"

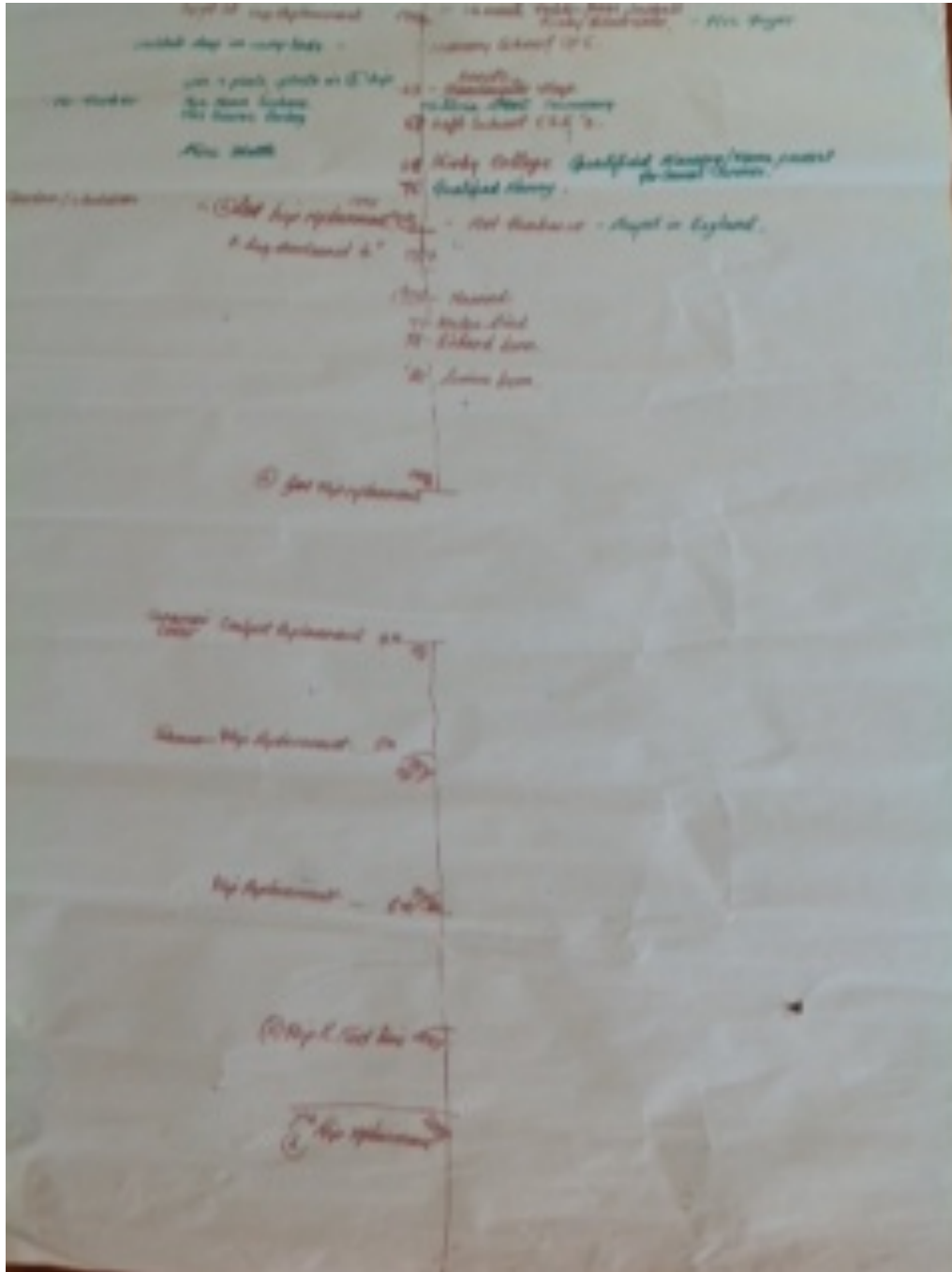
(Sue, Audio Recording Meeting 2)

Sue begins by plotting the dates that her operations took place, asking her partner for clarification and getting up to search in a draw for a medical card that shows information "for some of the hip operations, not all of them" (Sue, *ibid*). Once each operation is labelled from the 1<sup>st</sup> to the 7<sup>th</sup>, Sue moves back to an earlier turning point in her life and touching her writing on the page with her pen, she tells me:

"So, the second hip replacement...was a new one, it was copal (...) I think I told you that that replacement was extremely psychologically difficult for me (...) I was so upset"

(Sue, *ibid*).

This process continues, as Sue moves back and forth between writing on the page and filling in different parts of her life with stories, as each turning point reminds her of a particular event, person or place.



**Figure 4.2.1:** Sue's Timeline: Plotting Significant Events

Like the participants in Worth's (2009b, 2010) research, Sue plots important events thematically, from hip replacements and important family dates, to experiences of growing up on different hospital wards, having children and the year her younger sister died. Figure 4.2.1 shows Sue's participatory timeline



where she uses two different colours, firstly, to draw a line that runs vertically through the middle of the paper, plotting dates and important events (brown); and secondly, to plot details about secondary school, including the names of teachers, whilst reciting a few memories of childhood (green).

At this stage of the process Sue's timeline doesn't include a great deal of written information, instead the exercise of visually representing her life course becomes a tool that allows Sue to order her material and provide verbal accounts to support her story. In the following section I explore the different temporalities that are mapped when Mark engages in the production of his own participatory timeline.

#### **4.2.2 Mark: The temporalities of daily life**

The methodological process that took place as Mark and I completed his participatory timeline together differed from the one drawn by Sue in a number of ways. Firstly, as Mark was spinally injured as an adult in his mid-forties about 10 years ago, his timeline involved plotting a 'day in the life of' style participatory timeline, in order to discuss the temporalities of spinal cord injury. Secondly, while Valentine (2003b) suggests that traditional techniques might limit disabled people's participation<sup>22</sup> in research, after declining other alternatives such as 'typing' to compile diary entries, Mark's preference was for a timeline. Although Mark was unable to draw<sup>23</sup> I participated in drawing on Mark's behalf, inviting him to make decisions based on the visual representation of his 'daily life' and writing information that he conveyed to me.

After setting up paper and pens on the table, we are about to plot the start of Mark's timeline when his wife shouts from the kitchen, "6 AM!" indicating the time that Mark's routine begins in the morning. Mark's partner played a similar role to Sue's husband, interjecting with information or stories regarding the conversation that is taking place at the time. However, a very different process

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<sup>22</sup> See KITCHIN, R. & FREUNDSCUH, S. 2000. *Cognitive mapping: Past, present, and future*, Psychology Press.

<sup>23</sup> Mark tells me about the injury to his hand in one of our first email exchanges, reiterating this at our face-to-face meetings.

takes place with Mark as he provides a descriptive account of the activities that constitute his daily routine as they happen in a chronological timeframe. While it becomes clear that Mark's partner plays a significant role in this routine, I tried to pass 'control' back over to Mark, so that Mark is involved in producing knowledge and ways of knowing about his own life. Hence, after asking Mark "How do you organise your day?" we begin to plot the timeline, as Mark responds:

"How basic do you want it? Well 6 o'clock is usually wake up time - [my wife] makes a drink for us both because I catheterise myself, it's the first thing I do on the morning. Put, 'pass catheter'."

(Mark, Timeline Audio Recording)

We continue to build Mark's timeline in this way, at times with Mark directing me, as above when he tells me to use the label 'pass catheter'; whilst at others I try to write down as much as possible including the times, activities, places and people that were mentioned. Mark's methodological process takes place in two 'rounds'; in the first he describes his daily routine, offering an in-depth account of daily life at home, and a less detailed descriptions of his routine when he "[w]heels across to work" (ibid.), mainly discussing catheterising at regular intervals, every four hours.

The participatory timeline produced by Mark and myself relates to a working day and is representative of Mark's daily life Monday through to Friday at the time that the 'drawing' took place. While he provides information sequentially (Worth, 2010) in this 'round', Mark's accounts differ in the second 'round', as we begin to discuss the emotional impact that becoming injured through an accident has on Mark and his daily life since spinal cord injury. However, the second 'round' of participatory timelines also illustrates the significance of emotions to Sue's temporalities of the life course. In the following section I discuss the unfolding methodological process that took place as Mark

and Sue begin to use their own timeline differently to express their emotional experiences.

#### **4.3 Expressing and analysing feelings on a page**

In this section I explore the way that the analysis of participant's lived experiences was part and parcel of 'doing' participatory methodologies, taking place 'during' and 'after' meetings with participants, rather than as a distinct activity that took place solely 'after' methods were completed and the 'data' was collected. While MacKian (2004) notes that contemporary geographer's linguistic maps are burdened with language, leading to a "lack of visual representations" (2004: 617) in geographical work, in her own research on ME (Myalgic Encephalomyelitis) or Chronic Fatigue Syndrome (CFS) she aims to "map out' the discursive and material spaces of emotional experiences as they are lived by people in space" (ibid: 619). In her work, the use of mapping as an exploratory tool leads on from MacKian's (2000: 96) earlier work on the "spatially, temporarily and socially" situated nature of ME as a long-term illness experience. The process of producing these maps (one for each participant in order to represent the complex and multiple ways that different people experience ME) takes place in the analysis stage based on the pre-given narratives of participants. However, this differs to my research, where participants produced their own visual representations, producing and analysing their own lived experiences.

Bagnoli (2009): 549) notes that in socially-based research it is the process of completing the drawing that matters, "rather than interpreting drawings on the basis of some pre-existing theory". Bagnoli's quote emphasises the importance of enabling theoretical material to emerge by engaging with participants through 'drawing', whilst Kesby's (2000: 423) 'action research' epistemology "open[s] spaces in which researchers can facilitate participants' own reflection and action in the fieldwork arena itself". In my research I incorporated both of these points, enabling participants by putting them in charge of drawing and reflecting on their participatory timelines, working *with*

participants to produce new understandings of disabled people's lives. The process of completing participatory timelines enabled participants to reflect on their past experiences, taking part in 'action' through drawing, as emotion and feeling emerged as a topic by creeping into conversations and onto the paper. I demonstrate the emergence of emotion and feeling in the remainder of this chapter as I use quotes from the audio recordings that were made as Sue and Mark completed their participatory timelines.

An analysis of these conversations and the visual representations produced by Sue and Mark evolved throughout the methodological process and illustrate the blurring of boundaries between theory, practice and method (Pain et al., 2007). In this example I show that Sue leads the methodological process, highlighting the importance of emotions, which led me towards theoretical literature on emotional geographies of disability, health and illness, which I draw from in Chapter 5: '*Becoming emotional*'. In the first instance we are sitting at Sue's dining room table with a blank sheet of flipchart paper and marker pens, discussing the first stage (plotting significant events and turning points), which is still to take place, when Sue says:

"I'm going to put it probably three quarters, a third of the way down – that's because sometimes the timeline goes up and sometime it goes down – as in how I feel"

(Sue, Audio Recording)

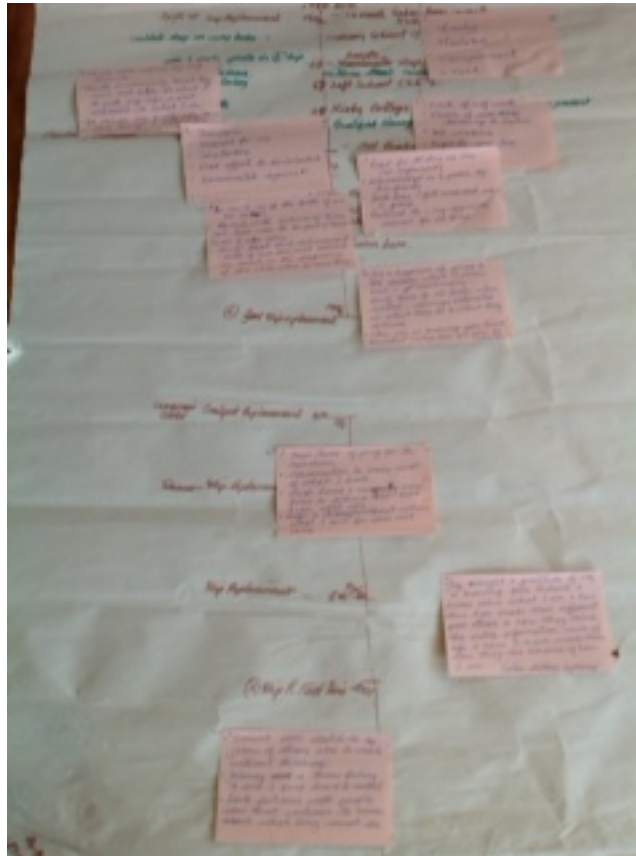
Although Sue discusses the position of her timeline on the paper, she doesn't end up drawing the line up and down; however, she laughs as I tell her:

"That's interesting because after you'd plotted those I was going to ask you to plot the emotions..."

(Jayne, Audio Recording)

The second stage of 'mapping temporalities' on participatory timelines involved Sue using post-it notes to describe how she was feeling throughout her life course at the time these different events were occurring. This time Sue picked up a normal (biro) pen, as I offered her different coloured post-it notes, rather than the marker pen she had used to draw the central timeline, and began to carefully write on post-it notes, sticking each one carefully to the flipchart paper. Sue completed this task in silence, as I sat and watched her fill nine small rectangular sized post-it notes with up to four lines of textual information. Pain et al., (2007): 28) suggest that visual methodologies have the capacity to reach beyond language and address 'non-verbal understandings', in Sue's case, providing a medium onto which she poured detailed accounts of her emotions.

Figure 4.3.1 indicates the position of these post-it notes on Sue's timeline, illustrating the way some of her feelings of living with CDH have mapped onto her life. However, the textual and visual account that I have thus far provided does not account for the moment that Sue became overcome with emotion, sobbing as she described memories of a friend she never saw again at the children's hospital. Sue provided a rich and in-depth account of her life in all of the methods that she used, providing nearly sixty years' worth of accounts relating to CDH. In the final empirical chapter of the thesis, Chapter 11: '*Memories*' I provide a more detailed exploration of Sue's memories, providing a case study of her memories across the life course to demonstrate the importance of emotional accounts and the multiple complexities that shape Sue life.



**Figure 4.3.1:** Sue’s timeline: Using layers

Giesecking (2013: 6) notes, “mental mapping is articulated as a way of visually speaking through places what words alone cannot articulate”. While this illustrates the importance of using post-it notes as a way to convey feeling in Sue’s timeline, the methodological process was altered in order to account for Mark’s needs<sup>24</sup> (Chouinard, 1997). As Mark’s timeline focused on his current routine, in the second ‘round’ of mapping temporalities I asked him to consider how he felt about the changes he had experienced since the time of his accident. This was a topic that Mark had discussed at previous meetings and asking him to consider his emotions as part of the timeline profoundly changed this stage of the methodological process. Mark began to relate to his feelings regarding living with spinal cord injury, and the post-it notes that we added together are shown

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<sup>24</sup> See Box 4.2.1: ‘Feelings of a flipchart’ for more detailed discussion and critique of inclusivity through visual methodologies.

in Figure 4.3.2. This illustrates the timeline that Mark and I completed, showing post-it notes labelled under two separate headings. The left hand side of the paper illustrates the 'PAST' and 'emotions related to injury', and the right hand side illustrates the 'PRESENT' and 'emotions related to 'normality''. As we discuss how things have changed, Mark determined these two categories, and we continue to follow a systematic process, moving between Mark's timeline and previously held conversations.

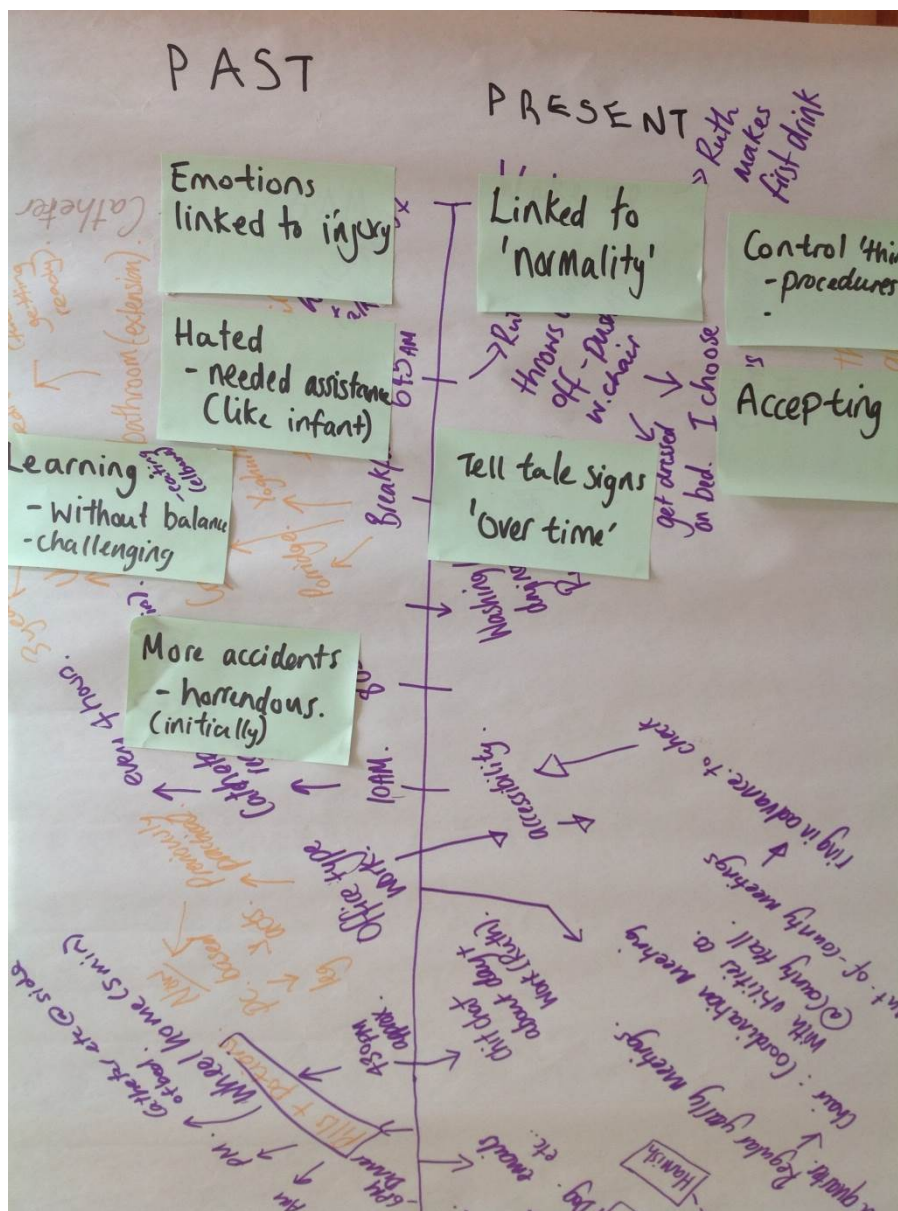


Figure 4.3.2: Mark's timeline: Mapping emotions

In summary, I have explored the unfolding of emotion as an empirical and methodological theme in this research, using two in-depth accounts based on 'drawing' participatory timelines. On the one hand, Sue took control of the method jumping straight in by drawing a (time) line representing her whole life down the middle of her page, writing important dates and events in chronological order, describing her wish to draw the line up and down to illustrate her changing feelings and eventually adding numerous post-it notes filled with her emotional memories. On the other hand, Mark also took control, as he appeared more in control of his emotions, providing a detailed step-by-step account of the changes to his daily routine since becoming spinal cord injured. However, Mark began to reveal his feelings, which had been raised by in previous conversations, as I guided Mark through the process of completing a participatory timeline.

In the next chapter, I provide a more detailed analysis of the emotions that shape participants everyday and lifelong experiences of becoming disabled.



### 5.1 The relationality of feminist and emotional geographies of difference

In this empirical chapter, the first of the thesis, I draw on five participants' first-hand accounts to explore the emotionality of the inception or beginning of disabilities, health conditions and/or illnesses, as well as their continuing emotional experiences related to becoming disabled. As I use time to structure my thesis, to analyse participants' accounts and to conceptualise the temporalities of disabled people's differences, the location of this chapter as the first of the thesis is significant. Firstly, it extends on the emotional accounts of becoming disabled given by two participants, Sue and Mark in Chapter 4, using accounts given by three other participants: Steve, Elizabeth and Robert. I argue that their feelings take place in relation to particular events or acts, reflecting their embodied identities. Secondly, participants describe their initial feelings and reactions to diagnoses of chronic pain and illness, as well as their feelings about everyday experiences related to their 'new' embodied identities. I show that time is an important analytical theme, as I discuss disabled people's 'first' accounts of their diagnosis through interactions with health care professionals, memories of accidents and of medical operations.

I locate my empirical findings within feminist and emotional geographies of "difference, exclusion and oppression" (Bondi et al., 2005: 8) and show that the relationality of emotion and the relationality of becoming connect the temporal accounts given by participants, with the spatial accounts that are currently emphasised in the discipline (Davidson and Milligan, 2004). Pain and Smith's (2010: 302) work demonstrates that "the 'emotional turn' ...insists on the place of emotions in analysis of the social, cultural, political and spatial world"; however, it is the following quote from Anderson and Smith that draws attention to the potential of the temporal world:

“At particular **times** and in particular places, there are **moments** where lives are so explicitly **lived** through pain, bereavement, elation, anger, love and so on that the power of emotional relations cannot be ignored”

(Anderson and Smith, 2001: 7, my emphasis).

Yet, despite explicitly addressing the *times* and *moments* where emotional relations are *lived*, in the literature on emotional geographies analyses of the temporal world remain largely unexplored. While I do not deny the significance of emotional spaces and the spatialities of emotional experience (Davidson and Milligan, 2004), I argue that emotions are undeniably fluid, transient, temporal and changing. ‘How are you (feeling)?’ is a question that is asked repeatedly and in number of different contexts, usually on a day-to-day basis and often referring to the particular moment when the question was posed, or in relation to a more recent period of time.

As feelings quite clearly shape emotional experiences, then there is also scope to explore the temporal capacity of feelings in relation to the emotional and feminist geographies of disability, health and illness. While there has been some discussion of the concept of becoming in relation to blind and visually impaired people and the life course, as well as the intensities and management of chronic pain, there is scope to explore the emotional temporalities of becoming disabled. While this whole thesis is concerned with the concept of ‘becoming’ disabled rather than ‘being’ disabled, this chapter addresses different events or acts in disabled people’s lives that shape or are shaped by emotional temporalities. By discussing the emotionality and temporality of participants’ experiences, firstly, I sketch out the fluidity and relationality of disabled people’s emotional temporalities to show that becoming emotional is different to being emotional (Ahmed, 1999).

By taking a relational view of becoming emotional, I argue that feeling[s] might more adequately describe the more personal ways that participants’ in my

research feel about subjectively lived emotional experiences, over collectively<sup>25</sup> felt emotion[s]. A relational view of becoming emotional (Ahmed, 2004, Bondi, 2005) is used to illustrate how disabled people's differences are *felt* across time and space and to explain how the emotional stories that participants tell about their experiences of disability, health, illness and chronic pain are understood through their relationship to other people, events and things. This approach opens "up the idea of fixed identities and fixed relations" towards identities that are "fluid, dynamic and continually (re)situated" (Thien and Del Casino Jr, 2012), providing a rationale for participants' stories in this research. The continually shifting and changing nature of disabled people's emotions are discussed in this chapter to illustrate the difference between emotion[s] and feeling[s].

In the remainder of this chapter time is framed in relation to the '*specious present*', highlighting the contested nature of *the present* (Dodgshon, 2008) and illustrating that a 'moment' cannot be completely removed or detached from the past just gone (Varela, 1999). I use three concepts of becoming to understand the emotional and embodied temporalities of disabled people's differences and to explore the complexity of these moments:

- becoming is contingent as disabled identities are understood through their *situatedness* (Bergson, 1910b, 2001);
- becoming is performative as disabled identities are understood through their *emergence* (Deleuze and Guattari, 2004); and
- becoming can be "open to futurity...and always becoming" (Worth, 2009 on Grosz, 1999) as disabled identities are understood as *anticipated*.

Source: Dewsbury (2000) and Dodgshon (2008)

The third concept of becoming emphasises futurity, reflecting a never-ending process and encompassing all of the accounts given by participants

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<sup>25</sup> However, in section 5.3 '*The emotional temporalities of everyday life*', I do draw on the significance of collective accounts when I discuss the performance of disabled people's differences and the power of socially felt emotions (Hochschild, 1975; 1979).

throughout the research. Becoming emotional (this chapter), becoming well, becoming mobile and memories are all open to change and to possibility (Grosz, 1999). In this chapter I show that five participant's differences and their experiences are not mapped out or fixed, but are renegotiated over time. In particular I focus on the (re)negotiation of feelings in relation to new forms of embodiment, as I discuss five participant's diverse chronologies in the specious present.

In the next section, I show that chronologies matter as I discuss Elizabeth, Mark, Steve and Robert's neurological differences<sup>26</sup>. I highlight the tension between the contingent (Bergson, 1910b, 2001) and emergent (Deleuze and Guattari, 2004) notion of disabled people's embodied identities. In section 5.3, I show that acts such as 'standing out', 'passing' and 'planning' are wrapped up in personal and collective histories that shape the way participants perform emotional temporalities.

## 5.2 Emotional (re)beginnings

In this section I use four participants' personal chronologies in order to highlight their subjectively felt emotional (re)beginnings, using Bergson (1910b, 2001) and Deleuze and Guattari's (2004) work on becoming in order to explore the role of time in participants (re)beginnings. This focuses on specific one-off events, demonstrating that the inception or (re)beginning of disabled people's differences is relevant to all of the participants in this research. However, not all participants discuss the emotionality of the contingent and unexpected nature of their beginnings, from birth, accident, injury or having developed for other reasons. Elizabeth, Mark, Steve and Robert's accounts illustrate the stretching and unfolding temporalities of diagnosis, accidents and medical interventions. I consider the *situated* nature of becoming provided in Bergson's account, as I show that time is (re)produced as linear in Elizabeth and Mark's chronologies, as events from the past flow into those in the present.

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<sup>26</sup> Here I am referring to the differences in their chronologies but also the neurological differences that binds their accounts together.

### 5.2.1 Stretching/expanding temporalities

Time is continuous in Bergson's concept of becoming, privileging the moment (Dodgshon, 2008) when events from the past flow into those in the present. By revealing "actual outcomes...only at each moment" (Dodgshon, 2008: 307), I show that while participants' (re)beginning are situated in time, at a specific point in the history of their disabled identities, time stretches and expands to encompass their emotional temporalities. As these experiences are situated at a point in time, the relationality of the time captures Bergson's "sense of succession...temporal flow...duration"(Dodgshon, 2008: 303), meaning that events such as diagnosis take place in relation to other events; and in Bergson's work this relationship is linear. In the personal chronologies of Elizabeth and Mark, time is fluid and framed by successive events in a linear fashion, reflecting Bergson's account as their (re)beginnings are situated in time through medical procedure, accidents and injury. However, over time these two participants reflect on their emotions in relation to other events and encounters throughout their life course, leading to the emergence of particular feelings.

Using a Deleuzian concept of becoming, participants' emotional (re)beginnings are expressed through moments where "different levels of what is past coexist with what is newly perceived in the present"(Dodgshon, 2008: 308). Therefore the relationship between the contingency and emergence of emotional temporalities adds to the way Elizabeth and Mark's feelings change over time, as the relationality of diagnosis, changing bodies and shifting feelings shapes participants experiences of becoming disabled. However, despite this relationship, Elizabeth and Mark experience very different emotional temporalities. In the accounts that follow I show that time is situated in the moment of encounter as Elizabeth's becoming takes place through medical procedure when she receives a routine injection that later is known to be toxic, while becoming spinally injured is contingently located in Mark's road cycling accident.

However, by considering their personal chronologies it becomes clear that both accounts encompass a Deleuze and Guattarian concept of becoming, as time is stretched in two separate ways. The stretching and expanding of time is demonstrated in Elizabeth's account of embodied time and Mark's account of going 'back in time', as the past and present come together (Grosz, 1999) to produce *emerging identities*. Significantly, it is the linearity of these personal chronologies that produces the relationship between identities as situated, the stretching of time and stories of emotional becoming. I explore the simultaneity of Mark and Elizabeth's disabled identities as *situated* and *emerging* through various emotional (re)beginnings.

### **(New) embodied beginnings: Elizabeth's story of chronic pain**

I met Elizabeth for the first time at a locally based chronic pain group<sup>27</sup> that she is closely involved with, and learned about her ensuing chronic pain, which developed following a visit to the hospital about back problems when she was in her mid-twenties fifty years ago. During this appointment a medical procedure was carried out and a "blue dye known as myodil" was injected into her "spine to make X-rays clearer" (Newsletter, 2011: 4); subsequently, it was discovered that the injection was toxic. Elizabeth is now in her seventies and has been living with chronic pain for over 50 years. Although we had spoken on the telephone, the support group meeting was the setting where we encounter one another face-to-face for the first time. I am sitting in a local hall with twelve other members of the support group who are sharing experiences of chronic pain<sup>28</sup>, when Elizabeth exclaims:

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<sup>27</sup> See Table 3.2: '*Levels of participation*', in Chapter 3: '*The temporalities of participatory engagement: An unfolding methodology*'.

<sup>28</sup> This is a usual conversation at the group and is one of the ways that members of the chronic pain group support one another in a face-to-face environment.

“I’d love to drive past GlaxoSmithKline’s office and throw a bloody brick through their window!”

[laughs]

(Elizabeth, Group discussion, April 2011).

The longevity of Elizabeth’s chronic pain becomes apparent in the embodied nature of her performance. It is not just the situated and contingent nature of becoming that signifies the emotionality of Elizabeth’s chronic pain, rather it is the simultaneous occurrence of multiple events that contribute to her account of embodied time. Elizabeth is referring to the British pharmaceutical company, GlaxoSmithKline, who produced the dye that was used in her medical procedure, subsequently leading to her chronic pain. The quote is significant for the way Elizabeth thinks about time in relation to her body, imagining time as it stretches to make space for separate yet interrelated experiences of chronic pain. There are two events that might be considered here; firstly, the timing of the spinal injection some fifty years ago and secondly, the accumulation of multiple experiences of living with chronic pain. While these events are not made explicit or even verbalised, they are nonetheless present in the moment of exclamation.

Elizabeth’s account embodies multiple temporalities as she performs her feelings, showing that the taking place and culmination of multiple experiences over time coalesce in the same moment, so that the past and present become melded together (Dodgshon, 2008). In this moment Elizabeth’s *emerging identity* becomes a performance, one that is disrupted by “new lines of flight, new becomings” (Anderson and McFarlane, 2011: 126) or (re)beginnings. Elizabeth’s account demonstrates how feelings over time are both embodied and performed, suggesting that becoming emotional cannot be located in one particular event or at one particular point in time, but that emotional encounters are (re)produced through a non-linear succession of events, as time stretches. In the following section I discuss ‘going back in time’ as Mark revisits memories of his spinal cord injury.

## Going back in time: Mark's personal chronology of spinal cord injury

Mark is a spinally injured adult who was injured in a road cycling accident on his way to work 10 years ago; at the time of the accident Mark was in his mid-forties. Mark had seen an editorial I had placed in a local newspaper and responded by telling me his 'brief resume', adding that he hoped he hadn't bored me. I met Mark on number of occasions as part of the research; however, our first conversation took place via email. Throughout this chapter I use Mark's quotes, details from a participatory timeline<sup>29</sup> and descriptions of Mark's home taken from my memories of visiting Mark and his family. These methodological details are important to my analysis, as I got to know Mark and the details of his life more closely through invitations to have dinner with Mark and his wife at their home. In both of the examples that follow Mark's emotions are located in the words he places emphasis on and the tone of his voice.

As Mark retells his story at various points in the research, he relives the events surrounding his spinal cord injury in a chronological timeframe, a linear progression through time. However, a closer, more detailed and in-depth analysis reveals that time stretches in his accounts. These events begin with memories of his cycling accident and 6 months rehabilitation at a spinal injuries unit. During this time Mark feels a sense of progression or moving on as he begins to adapt to his new body. During one visit to Mark's home we are completing a participatory timeline together, when Mark reflects on his first memories of becoming spinally injured, as he thinks *back in time* to his day-to-day life:

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<sup>29</sup> See Chapter 4: '*Participatory diagramming: 'Drawing' timelines*'.



“It’s completely changed from the first time I had my accident where I couldn’t do anything for myself, I needed help with literally **e v e r y** aspect - I couldn’t get dressed, I couldn’t do anything; I couldn’t get out of bed. They had to put me into the hoist to get me into the chair and allsorts. I was literally ‘learning to live again’.”

(Mark, Timeline Recording, 2011: 4, **original emphasis**)

In this quote Mark is comparing his different beginnings, thinking back in time and illustrating that there is “a capacity to add novelty or difference” (Grosz, 1999: 106) through the continuation of new or fresh perceptions from the past and into the present. While Mark’s cycling accident occurs at a point in the ‘past’, situating his new beginnings, the quote above also demonstrates how time stretches to include new practices or ways of ‘learning to live again’ with his new found embodiment, learning how to complete day-to-day activities, including getting dressed, getting washed and going to the toilet.

The emergence of a cyst on his injury site<sup>30</sup>, however, two years after his cycling accident moves him ‘back in time’ as time stretches to encompass multiple accounts of time as becoming disabled. If becoming in a Bergsonian sense is about the smooth process from past to present, then becoming is represented as more than just a point in time for Mark; while his accident situates his identity at a point in the past, the cyst becomes the focus of his feelings as he losses 90% of the power in his right hand:

“That really was hitting the depths; I think that hit me more than when I was in hospital after the accident initially. Thinking about it, if ever I’ve been depressed I think that would be it, that time. I had enough to lose and then I was losing what little I had”

(Mark, Timeline Recording, 2011: 8)

The cyst produced physical and emotional changes to Mark's body as time stretches to incorporate a Deleuzian account of difference out of repetition (Dodgshon, 2008). However, it is the development of the cyst and the changes this brings that move him back in time, emotionally, as the simultaneity of becoming disabled is illustrated through new forms of embodiment that are contingent and occur unexpectedly, as well as those that emerge over time as Mark gets used to each of his new embodied identities. This is further illustrated in the final section, that binds 'becoming' and emotional temporalities together illustrating the way participants' identities and their futures are entwined hand in hand and subject to change at any time.

However, in 2004, two years after his cycling accident, Mark lost 90% of the power in his right hand as a cyst developed. This event Mark moves 'back in time', as the cyst becomes the focus of his feelings. Having felt a sense of progression or moving on, Mark uses spatial metaphors (Bondi et al., 2005) such as hitting the depths to describe feeling low.

On first reading accounts of Mark and Elizabeth's stories their chronologies appear as a linear progression through time, yet a closer, more detailed and in-depth analysis reveals that time stretches in their accounts. Events such as medical procedures and accidents that lead to injury highlight the linearity of time, situating these disabled identities in time. However, time stretches to encompass multiple accounts of time, as the identities and becoming of these two participants emerge alongside the contingent nature of becoming disabled. The two accounts offered in the next section are produced by a different set of chronologies, as unfolding temporalities (Grosz, 1999) demonstrate the complexity of becoming.

### **5.2.2 Unfolding temporalities**

In this section I add to the literature on emotional geographies of disability, health and illness as I explore two participants' emotional experiences of time spent waiting for diagnosis. I use my empirical findings to show that time is experienced differently in the chronologies of Steve and Robert, as I explore

the unfolding temporalities of Multiple Sclerosis. By drawing connections between accounts of *waiting* for diagnosis, experiences of relapse, and fluctuating symptoms and feelings associated with bodily changes, I add to the literature on gender, emotion and health (Moss and Dyck, 1999, Valentine, 1999, Davidson, 2007, Thien and Del Casino Jr, 2012).

Phenomenological accounts of the temporality of illness (Toombs, 1990) focus on the subjective experience of time. The concept of time unfolding describes the way that “individual temporal configurations are never organised according to such a linear and one-directional flow” (von Peter, 2010: 19) and instead focuses on the way that temporalities “emerge in discontinuous and fragmented ways, being made and unmade as time unfolds” (2010: 20). I show that Steve and Robert experience *situated* and *emerging* emotional temporalities, which are located in continuing cyclical encounters with various health care or medical professionals, and in time spent waiting for diagnosis. Individual accounts are brought to the fore to understand time as it is experienced in the day-to-day lives of participants rather than the way it is perceived by medical professionals. While the latter views disability as a label, a categorisation of ‘being disabled’ (Crooks et al., 2008), I address the open ended process of ‘becoming’ disabled (Grosz, 1999).

I explore the difference between the stretching and expanding temporalities addressed in Elizabeth and Mark’s accounts, as they were aware of the emergence of their disabled identities over time because they are able to identify the contingency of their disabilities. However, Steve and Robert are only able to situate their identities with Multiple Sclerosis at a point in time, once their identities have emerged, illustrating unfolding temporalities. Their emerging identities allow them to make sense of the contingency of disability; this additional understanding of time is located in the lived experience of participants’ lives, adding to the complexity of becoming. However, the timing of diagnosis is different for both Steve and Robert; therefore there is a tension between how participants experience changes to their bodies and how these experiences are subjectively lived through time.

In the following accounts, Steve and Robert recognise the becoming of their disabled identities (Multiple Sclerosis), which are framed by contingency and shaped by diagnosis, in a series of encounters with various medical professionals.

### **Reflection time: looking back; looking forward**

Steve's journey with Multiple Sclerosis allows him to take a step backwards and reflect on his fluctuating emotions in relation to his personal experiences of relapse, diagnosis and symptoms of Multiple Sclerosis. The importance of spatial metaphors (Bondi et al., 2005) are evident in Steve's story, as he remembers and reflects on his journey at a distance, as his re-telling takes place in the extended present of the now 'reflection time' enables Steve to explore his journey with MS, using his personal timeline to consider a sequence of events based on – relapse, diagnosis and recognition of symptoms – as he looks back to relapsing for the 'first time' and forward to the 'next time'. However, in his lived experience this sequence is punctuated by discontinuous time (von Peters, 2010) as Steve's relapse occurs prior to diagnosis. The timing of the following account is significant as it shapes the emotionality of Steve's experience:

“Well my relapse, I was sat in my flat and I looked in the mirror and my eyes were moving, independently, I wasn't moving them. And at the same time, I looked like I'd had a stroke, my face had pulled down and it really freaked me out. I rang the Doctor but it took me two days to get in. I went to see a Neurologist and then the stroke part; my face had started to go back to normal. But my eyes were like that for about 3 months”

(Steve, in conversation, 2011: 1).

At this point Steve had not been diagnosed with Multiple Sclerosis and his feelings of being *freaked out* highlight how the contingency of becoming creates a sense of unease, at not knowing what is happening to his body. However, as

Steve reflects back on how he feels *now* (at the time of the conversation) about his 'first symptoms' prior to his diagnosis, his words are indicative of the knowing or emergence of his disabled identity. He explains:

“[It was] 10, 11 year...when I had the first symptoms, but I wasn't diagnosed for another year...I was driving, I was back on the road, driving [...] vehicles, which really looking back was crazy, but I felt okay”

(Steve, in conversation, 2011: 2).

While diagnosis confirms the way Steve feels about bodily changes he can only situate his MS in time after he recognises the symptoms. Robert also feels changes or shifts to his body that he cannot name until after diagnosis (Moss and Dyck, 1999). While Moss and Dyck (1999: 382) state that “the distinction between activities before and after diagnosis...did not exist in the lived spaces of [participants] daily lives”, Steve and Robert's accounts highlight how they begin to experience time differently once they know about their changing bodies or are preparing for their (re)beginnings. In the next example Robert's chronology highlights the (un)making of time in his account of Multiple Sclerosis.

Robert is in his mid-fifties and left his position as a manual labourer at a local factory when he was diagnosed with Multiple Sclerosis. Robert's story of living with Multiple Sclerosis is made up from a series of events, which began with a problem with his eyes, leading to a series of appointments and a diagnosis of MS. Robert's story is different to Steve's for three reasons. Firstly, at the time of our conversation Robert is experiencing more problems with his eyes (a potential relapse); secondly, his memories and feelings of relapsing are remembered differently to Steve's; and thirdly, his emotions are located in his gestures and body language. Robert's account also involves 'looking back' to memories of relapse, as the following quote shows:

“...the first time I had steroids I had a relapse and I had to go into the unit, **and** that was shit”

(Robert, in conversation 2011: 2)

However, while Steve’s first experiences of relapsing are contingent and occur at points on a timeline, he begins to experience time differently once he has been diagnosed.

“Looking back, others things that happened, if I’d known what I know now would have lead me to that direction of, well yeah, I’ve got a relapse coming.”

(Steve, in conversation, 2011: 1).

By ‘looking back’ and reflecting on his experiences, Steve’s diagnosis leads to recognition, allowing him to look back in time to the ‘first’ relapse and his ‘first’ symptoms, as well as forward to the next time. ‘Looking forward’ changes the way Steve’s feels about the uncertainty surrounding his body as he is freaked out, *before diagnosis*, to being more relaxed about future expectations of relapse and the sequence of events that are due to take place, *after diagnosis*. However, while Steve acknowledges and attaches certain emotional states to moments *before* and *after* diagnosis, in his personal chronology time unfolds organically. Looking forward Robert describes:

“The second time I went in to hospital and I felt like a new man and it was brilliant, but I don’t want to be on steroids all the time”

(Robert, in conversation, 2011: 2).

The order of Robert’s becoming takes place in a muddled up way as upon recognising chronic pain only then does it become possible to situate his ‘new’

identity and think through the emergence of his identity with Multiple Sclerosis. Steve and Robert's stories demonstrate how Multiple Sclerosis is a product of difference out of repetition, a disruption, as becoming disabled takes place at a moment prior to the emergence of their disabled identities.

In this section I focused on four participants emotional (re)beginnings, exploring the importance of becoming emotional, as Mark, Elizabeth, Steve and Robert discuss their embodied experiences of diagnoses, medical practices, accident and injury. When provided with a reason for bodily changes, for the 'first' time, these participants are able to acknowledge their disabilities, health condition or illnesses. Theories of becoming were applied to participants' stories in order to understand and explore the emotionality involved in the becoming of disabled identities. Emotions contribute towards participants' identities, *becoming* situated or emerging as they change over time. However, by exploring the complexity of participants' chronologies, these empirical findings disrupt and (re)produce new notions of becoming. Firstly, by exploring the emotionality of disabled people's (re)beginnings, I demonstrated the unfolding, stretching and expanding temporalities of becoming emotional. I used empirical material from participants' chronologies, to illustrate the connection between, and difficulty of, separating Bergson's and Deleuze and Guattari's work on becoming.

Secondly, using the accounts of Multiple Sclerosis offered by Steve and Robert, I have added to the paradoxical basis of the illness experience (Moss and Dyck, 1999). By providing an understanding of men's health, diagnosis and emotion, I have been able to highlight the ephemeral and temporal nature of becoming emotional. This material challenges Deleuze and Guattari's concept of becoming, where one particular event *emerges* in relation to a number of separate events that culminate and come together to produce tenseless time in the present, illustrating that as time unfolds, Robert and Steve are able to locate their 'new' identity at a point in the 'past'.

In the following section I show that three participants learn to control their feelings, their bodies and their emotions in everyday life, as well as in their projected futures.

### **5.3 The emotional temporalities of everyday life**

Using Davidson and Milligan's (2004: 523) work I show that "emotions take place within and around the closest of spatial scales" from the body as a site of emotion to the circulation of emotions between bodies (Ahmed, 2004). I argue that three overarching themes demonstrate the sites, scales and circulations of the emotional temporalities of disabled people's differences.

Firstly, I draw attention to the relationality of spatialities, socialities, bodies, histories and temporalities in four participant's accounts. I demonstrate that the relationality of collectively felt emotional experiences shapes individual subjectivities, as past histories produces socially acceptable ways for bodies to 'act', behave (Dear et al., 1997), feel or look (Hawkesworth, 2001). Secondly, I show that these acts take place in relation to the everyday, as I describe participant's everyday emotional experiences, from walking and falling in the street, to learning new embodiments and thinking about the future. Thirdly, I show that acts such as 'standing out', 'passing' and 'planning' are all shaped by temporalities that are mixed up in a complex web of power relations (Bondi, 2005). I show that these relations of power and temporality are trapped in personal and collective histories that shape the way Steve, Sue, Mark and Elizabeth control their feelings and their emotional temporalities, as there is an expectation to control feelings, control bodies and control bodily movements.

#### **5.3.1 Standing out**

In this section I show that personal and collective histories shape the way that three participants, Steve, Sue and Mark (re)negotiate their feelings over time, as I illustrate the emotional temporalities of 'standing out'. I highlight different 'acts' that illustrate the circulation of emotions between bodies, spaces, identities, histories and temporalities, where Steve, Sue and Mark's everyday



experiences refers to their initial feelings in the early stages of becoming disabled. I demonstrate the unpredictability and contingency of 'standing out' (Hawkesworth, 2001), showing that the 'active differencing' that takes place in Parr's (2008) work on mental health and exclusionary social relations is different to the unavoidable and unplanned differencing that takes place in Smith's (2012) work on epilepsy. I show that the latter illustrates the contingency of 'standing out' as Steve reflects back on getting to know his body following a diagnosis of Multiple Sclerosis; Sue discusses the emotionality of walking differently; and Mark refers to toileting accidents and the leakiness of his new body following spinal injury.

Parr (2008) suggests that people with mental health problems experience exclusionary social relations through public and active 'differencing'. This differencing is marked by particular social actions as people with mental health problems become known and recognised in the community because of their difference, ignored in the street, or marginalised within home space as friends no longer visit or because other people organise social events in the privacy of their own homes. While the recognition or singling out of particular members of the community in Parr's work leads to their differencing, the feelings that Sue and Steve experience in public or shared space are related to societal expectations of 'acting' in the street. Importantly, these expectations are not based on the recognition of Sue and Steve's individual bodies in public space, instead collective histories shape the way that they are made to feel different.

Sue and Steve both refer to 'acts' that make them stand out, as "feeling different is related to looking different from those around them" (Hawkesworth, 2001: 306). Hawkesworth's work focuses on facial disfigurement, showing that its association with 'teenagers' shapes the way that participants feel 'out of place' (Sibley, 1995) in the built environment. While this study is not located in the emotional geographies literature, it draws on participant's feelings, their spatiality and their temporality. In the same way that there is a societal expectation for acne to be connected to teenagers, Steve and Sue's emotional boundaries are shaped by a "system of normativities" imposing "a powerful urge

to behave in certain ways, to mark out the boundaries of the proper” (Shildrick and Price, 1999: 438). In the early stages of Multiple Sclerosis (Steve) and CDH (Sue), ‘acts’ such as, walking and falling in the street are related to behaviour in social space. Steve and Sue’s concern with the way they ‘look’ in spaces, as their actions are viewed by others, demonstrates how feelings are negotiated through bodily, socio-spatial and emotional boundaries that are maintained by ‘systems of control’ (Shildrick, 1997: 43). However, I show that control also relates to participants’ desire to control their own bodies and their bodily movements.

Steve is in his mid-fifties and was diagnosed with Multiple Sclerosis (MS) ten years ago; in section 5.2 Emotional (re)beginnings, he describes his feelings related to diagnosis, as well as recognising the symptoms of relapse. However, as Steve cannot predict ‘when’ or ‘where’ experiences of ‘standing out’ take place, the following account adds to Smith’s (2012) work on the experiential geographies of living with epilepsy, illustrating the contingency of ‘standing out’. While epilepsy is described as a “condition for which symptoms may be invisible and at other times distinctly visible” (2012: 342), Steve explains:

“I used to feel like a twat when that first happened to me, four years ago maybe. When I was bad with my face and my eyes, just before that and I had a couple of tumbles. But when that happened...I was knocking myself into the shelves in the shop and I was really apologetic and you tolerate that”

(Steve, in conversation 2011: 9)

Steve’s account of ‘tumbles’ and ‘knocking’ presents a temporary yet unpredictable ‘loss of control’ (Smith, 2012); he cannot control his bodily movements, producing feelings that are shared with those who occupy the space with him. However, this quote also illustrates something of Steve’s personal history as he describes feeling ‘like a twat’ when his differently mobile body<sup>31</sup> reveals his MS for the first time; subsequently ‘tolerating’ his bodily movements

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<sup>31</sup> See chapter 9: ‘*Becoming mobile*’ for a more detailed discussion of differently mobile bodies.

over the preceding years. Yet his apologies reflect past histories, which (re)produce socially acceptable ways for people to act, behave, look and feel, with Steve's feelings most prominently shaping his apologies in the example above.

In the following example I show that the relationality and spatiality of Sue's individual feelings occur simultaneously with collectively felt histories, as Sue discusses the act of walking. At first glance, such an everyday practice or activity might be marked by its normalcy, yet Sue feels different precisely because of her walking. Sue is now in her sixties and was first introduced in the thesis when I discussed the methodological complexities of mapping emotional 'temporalities of the life course' (section 4.2.1). Sue was born with Congenial Dislocation of both Hips meaning that as one hip was not formed in the same way as the other and throughout her life she has experienced multiple hip replacements. In the following quote, Sue talks about growing up at a time prior to her first hip replacement, in the 1970s, saying:

"I was more concerned with stopping the embarrassing way I use to nearly hit the floor after each 3<sup>rd</sup> or 4<sup>th</sup> step – making it look like I was drunk and unable to walk properly"

(Sue, in conversation 2011: 1)

Sue's feelings are shaped by societal expectations, as Sue talks about the embarrassment of falling over and desire to walk 'properly'. Sue's personal history is significant, as despite smaller operations, such as her first cup replacement at the age of two and a pin and plate, a hip replacement that was conducted when Sue was 11 years old, holding fragments of her fractured hip bone (femur) together<sup>32</sup>, the quote above refers to her experiences as a young teenager prior to her first major hip replacement surgery when she was twenty

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<sup>32</sup> [Hip Screw Compression Fixation for a Fractured Hip](http://www.orthogate.org/patient-education/hip/hip-screw-compression-fixation-for-a-fractured-hip.html) <http://www.orthogate.org/patient-education/hip/hip-screw-compression-fixation-for-a-fractured-hip.html>

and has resonance beyond this moment. At this stage in her life Sue's own personal expectations are shaped by past histories growing up in multiple hospital wards for children, spending prolonged periods away from her own family and her sister and therefore feeling different, socially, emotionally and temporarily.

However, this example also illustrates the expectation for Steve and Sue to control their bodies in public space, mimicking the actions of other bodies around them so that they do not stand out (Hawkesworth, 2001). In the third and final example I show that as Mark adapts to the bodily changes he is experiencing as a spinally injured adult, 'standing out' involves emotional and bodily control.

"In the earlier stages you had more accidents, for want of a better word... and emotionally that is just horrendous. I mean no one likes to wet themselves or mess themselves and it happens. When you get more into routine and bits and pieces you also learn to **control** things better either by procedures of by you being plumbed up or you just catheterise yourself and stuff. There are slight tell-tale signs, like if I start to feel particularly warm or I can feel my blood pressure rising, it's also an indication that I ought to go and empty my bladder. You learn because you can't feel it obviously"

(Mark, Timeline Recording, 2011: 5, **my emphasis**).

The tell-tales signs that Mark highlights in order to avoid toileting accidents, such as feeling 'particularly warm' or feeling his 'blood pressure rising', are similar to the steps that people with epilepsy take to "conceal the visibility of seizures...reacting to 'auras' which act as embodied 'warning signs' (such as an odour or feeling of sickness) indicating a seizure is imminent" (Smith, 2012: 348). However, as Mark's quote illustrates, in the earlier stages it wasn't always possible to avoid "accidents, for want of a better word". It is the leakiness

of Mark's body and the visibility of 'standing out' that shape his emotional temporalities, as he cannot control his bodily functions. While Steve and Sue cannot necessarily control unpredictable and contingent moments, Mark describes how he learns to control his bodily movements through the temporality of 'auras' (Smith, 2012), over time becoming more in control of his feelings.

The stories recalled by Steve, Sue and Mark show that social behaviour may be 'spatially and temporally contingent' (Parr, 1997: 436), as 'differences in bodily capabilities' (ibid: 439) shape the way these three participants feel, (re)producing embarrassing acts. While acts such as walking (normally), falling over and 'wetting' indicate a lack of bodily control, Steve, Sue and Mark's embodied accounts demonstrate the contingency of standing out.

In the following section I show that a Deleuze and Guattarian notion of becoming emerges through 'passing' (Ahmed, 1999, Titchkosky, 2003), which is intentional and potentially avoidable, unlike the accounts given above. I focus on societal expectations of control to show that over time the contingency of standing out leads four participants towards a desire to control their bodies and their bodily movements. In section 5.3.2 and 5.3.3 I show that emotional temporalities are (re)produced and felt through different performances (Butler, 1990, Deleuze and Guattari, 2004) with other people, supporting "how much more we *feel* in socially arranged ways than we thought" (Hochschild, 1975: 282).

### **5.3.2 Passing**

In this section I discuss the emotional temporalities of 'passing', showing that three participants perform different emotional, embodied and gendered acts in everyday life. These acts are shaped by spatialities, as three participants refer to the spinal injuries unit (Mark), the hospital (Sue) and the doctor's surgery (Steve). They are referred to by temporalities, as passing reflects a moment in participant's chronologies, or is more than momentary, reflecting a prolonged period of time; and by histories, as personal and collective social histories shape

participants feelings. This illustrates the relationality of becoming emotional, outlined in section 5.2, showing that as these performances are marked by their temporality, histories, feelings and emotions are temporally situated and may emerge differently at another time or in relation to another event or act, (re)shaping futures.

I use Deleuze's work on performance to show that "the ongoing repetition of deeply ingrained instincts, habits, and memories" (Dewsbury, 2003) shape personal and collective histories, as Steve, Sue and Mark (re)negotiate their feelings in everyday life. As their embodied identities shift over time from (re)beginnings, where spinal cord injury, MS and CDH are relatively new, these three participants begin to understand their feelings in relation to their (new) embodied identities, performing emotional temporalities. Therefore, as "time is the hiccupping that expands itself, encompassing past and present into a kind of simultaneity"(Grosz, 1999: 25), becoming emotional is conceptualised as performative and emergent.

During these performances participants' (re)produce controlled emotional responses to social situations (Hochschild, 1975, Hochschild, 1979, Hepworth, 1998)(Hochschild, 2009;, learning to control their emotional responses over time. I demonstrate how these emotional responses are connected to re-learning the materiality of bodies and re-learning feelings in certain places and at certain times, as emotional temporalities are shaped by societal expectations. These past histories (personal and collective) lead participants towards a desire to control their bodies, their bodily movements and their feelings, in order to pass as normal (Ahmed, 1999). Ahmed refers to the momentariness of passing, suggesting:

"acts of passing cannot be thought of as events: they involve encounters between others whose boundaries are not fixed"

(Ahmed, 1999: 94).

While this work on passing and identity focuses on two racial identities, the passing of a subject (as black or white, disabled or not<sup>33</sup>) is significant because it recognises that passing is transgressive. Yet, Ahmed highlights a tension around the boundaries of identity, in that, in order to pass a subject must assume a fixed identity. However, while disabled people's social and spatial exclusion has been well documented in the literature on geographies of disability, health and illness (Butler and Bowlby, 1997, Dear et al., 1997, Parr, 1997, Park et al., 1998, Imrie and Edwards, 2007), emotional and feminist geographies illustrate the fluidity of spatial boundaries (between public and private). However, as passing as normal is in part framed by histories of social exclusion, oppression and marginalisation, I emphasise the temporalities of these exclusions in everyday life, showing that three participant's relationships to their embodied identities shift as they perform emotional, gendered and embodied acts of passing (Ahmed, 1999). However, Hochschild's work is significant in these examples as each participant demonstrates how they control particular emotions over a period of time, performing acts of passing that are emotional.

Mark and Sue refer to the gendered space of hospital wards, despite their contrasting experiences. In the first example, the emotional norms surrounding spinal cord injury inform Mark's account as he discusses some of his time on a spinal injuries unit:

"I've never been a particularly emotional type of person, even when I was in hospital there was people weeping and wailing quite a lot and it is a lot to get over, but there'd be the occasional time where I'd think about something and I'd think about sticking my head under the covers and having a howl to myself but I'm not that sort of person"

(Mark, Timeline Recording, 2011: p.5-6).

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<sup>33</sup> Without wishing to present identity as a set of binaries, or essentialising identity but rather as a way to explore the performance of identities and the role of time in these performances.

Hochschild suggests that “[a]ctors must be seen as more than bloodless calculators or blind expressers of *uncontrolled* emotions” (1975: 283, my emphasis). As Mark was 44 at the time he became injured his quote is steeped in societal expectations about how he should be reacting to spinal cord injury emotionally. In this quote Mark recognises that a normal response to his situation should elicit a performance that involves sticking his ‘head under the covers’ for a ‘howl’; instead he describes himself as not ‘particularly emotional’. In the process of appearing unemotional, certain acts such as Mark’s actually involve being emotional (Hochschild, 1975), emphasising how Mark’s performance and his emotions are controlled. Mark’s story provides an example of how Mark should be ‘passing as normal’, i.e. passing as a spinally injured man, yet he chooses to pass differently, controlling his emotional state. This also illustrates how Mark’s performance may be gendered, as he tells me that the majority of spinally injured adults are men aged between 16-25, something he learnt from nursing staff on the spinal injuries unit. The ‘people’ he refers to are all men on a spinal injuries unit within a local hospital.

Mark’s account of controlling his emotions within the space of the hospital is linked to the second example given by Sue as she shares some of her experiences of growing up on various hospital wards. While Mark spent 6 months in a hospital recovering from his spinal injury, the length of his stay is relatively short in comparison to Sue who was ‘institutionalised’ in a children’s ward from the age of 14 months to 15 years old. Mark’s accident occurred in 2004, yet Sue spent her first night in a hospital in 1949 for a period of 14 years.

In the following account Sue reflects on her feelings during the years she spent growing up on different hospital wards for children, Sue states:

“There was just no thought about my body, at all; because there just was no use getting embarrassed... So you lost in a sense that ability to **feel** for your own body, or to **feel** anything good about it because everyone just looked at it for what was wrong with it...”



(Sue, Diary Entry, 2011: 8, **my emphasis**)

Sue learns to control and regulate her feelings, to pass as normal, emotionally, to think about her body, the way that others think about her body and her disability. While this example emphasises her subjective feelings about her personal history, Sue describes losing the 'ability to feel' for her own body, showing that passing takes place in relation to past histories that temporarily fix Sue's feelings, or feelings that she chooses to fix or control temporarily. However, in the previous section Sue talks about 'standing out' and the embarrassment of falling over and wanting to walk 'properly'. Walking 'properly' in Sue's account suggests the 'passing' described in Ahmed's work, as Sue must assume the identity of the other. The 'act' of falling is significant for both Sue and Steve, as it relates to the acceptance of her behaviours in the street (Parr, 1997). However, in Steve's account there seems to be a difference between falling in public space and falling at home.

In the first quote he describes publically falling (in the street), in the second, he discusses privately falling (at home).

"Yeah it bothered me, it bothered me that people might think I was drunk but then I'd think well if that's what they want to think, then it's up to them"

(Steve, in conversation, 2011: 9)

"I don't think twice about it now, I have a giggle because that's my thing. I fell over last week, I was laid in the bath with the shower still going and I was just crying with laughter because I think it's that ridiculously funny and I've got myself into this"

(Steve, in conversation, 2011: 9).

Both accounts demonstrate the performativity of Steve's feelings, linking to gendered norms and the acceptance of certain emotions associated with

'falling'. In the first instance he reflects on his initial memories and is 'bothered' about other people's reactions yet his thoughts soon change. This extends to the second quote where he describes the laughter associated with falling in the shower at home. Steve was an 'army man' during his late-teens and twenties and took pride in telling me about his trips round Europe and implied sense of masculinity in the sexual encounters that come to signify a 'real man'. The performance of Steve's gendered identity is shown in his references to 'laughing off' falling over unexpectedly and without warning, as a controlled emotional response to his Multiple Sclerosis: the way a working class man should.

Steve performs his gendered identity again when he describes the moment of diagnosis in the doctor's surgery, saying:

“...they suspected MS but they weren't sure. They did brain scans and that, sent them away, then the consultant got me back in for a little sit down and said, 'You've got MS' and I was on my own, I didn't take anyone with me. And I cried a little bit, I didn't [laughs].

(Steve, in conversation, 2011: 9).

However, as Steve was diagnosed while staying away from his home town, he learns to negotiate his feeling in spaces that are shared with other people; 'passing' through spaces by telling me that he “pretended that everything was okay” (Steve, in conversation, 2011: 2) when he returns home to see his friends. This demonstrates that passing can be more than momentary, as it can be prolonged over a period of time, as Steve passes in the process of pretending in front of family and friends.

### **5.3.3 Planning**

In this section I address the way that two participants discuss 'planning' in relation to their emotional futures. The future is understood in relation to the present and is conceived as a “moment suffused with intentionality...a moment

[that] is never complete but always reaching forward for completion” (Dodgshon, 2008: 302). I consider how “the imagined or projected substance of our future experience **will alter** in relation to our current emotional state” (Davidson and Milligan, 2004: 524, my emphasis). I show that while this quote signposts the temporality and fluidity of emotional states by referring to the ‘projected’ i.e. the yet to come and the possibility of change as future experiences ‘will alter’, the emotional geographies literature illustrates fluctuating boundaries between feelings, bodies, spaces and emotions, but not necessarily temporalities. Using Grosz’s (1999) work on *futurity*, where becoming is conceived of as an open ended process, I explore the temporality of Mark, Sue and Elizabeth’s anticipated futures. I show that participants’ experiences and their futures are entwined and subject to change at any time, using Adam’s (1990) work I highlight the complexity and uncertainty of participants’ anticipated futures

I show that emotional futures are linked to the control that participants have over their bodies and their feelings, extending on the accounts of control performing emotional temporalities outlined in section 5.3.2 ‘*Passing*’. In particular I draw on Mark’s memories of accidents, feelings and possible futures to show how they are tied up with the emotionality of becoming disabled. By referring to the cumulative present I show that becoming is connected by accounts of the recent past (the past present), as plans are realised, the current present during the methodological encounters (the present present) and the anticipated future (the future present).

This shows that at one stage these were all futures in Mark’s life, as all times “are never imagined outside their moment of narration” (Dodgshon, 2008: 302). Yet it is his changing body that tie these emotional futures together, as he cannot predict when and if his body will change.

Williams (2000: 54) refers to Brown and Harris’s (1978; 1989) work to discuss two types of emotion; emotions ‘arising from everyday activities’ and emotions ‘arising from motives and commitments (i.e. linked to human

intentionality)'. The latter may imply a connotation with the 'future'; however, the emotions re-presented in participants' accounts arise from both of these situations or encounters, making a division between the everyday and motives and commitments unclear. In the stories offered by participants, emotional futures are located in everyday activities such as attending appointments and trying measures to address pain, having children and dealing with familial relationships, and adapting to changing everyday routines. Emotional futures are also located in motives and commitments that cannot be separated from the everyday and are indeed informed by the everyday.

Elizabeth and Mark's accounts are re-presented to demonstrate how participants' anticipated futures are "open to futurity...and always becoming" (Grosz, 1999). A Bergsonian understanding is applied to two separate accounts to show how each present is experienced differently, incorporating more of the past into each present as time continues to pass. The cumulative present is used to illustrate how becoming is connected by accounts of the recent past (the past present), the present present (as plans are realised) and the anticipated future (the future present). However, while time is conceived as always becoming (Grosz, 1999), Latour suggests that change doesn't necessarily take place through this becoming but that "time passes or not depending on the alignment of other entities" (Latour, 1997a: 178). Futures are anticipated and emotional futures as the relationship between as the past present, present present and future present come together in a "moment suffused with intentionality" (Dodgshon, 2008: 302). Using these ideas I will present each account in turn showing how Mark's future is about the control he has over his body and his everyday routine; while Elizabeth's anticipated future without pain is shaped by the hospital appointments she attends to receive injections of sea snail venom.

In Mark's account, the recent past or past present (Adam, 1990) highlights the importance of becoming as contingent, emerging and anticipated. Mark's emotional memory from the time of his accident illustrates how becoming is located in the cumulative present, as he discusses familial relationships:

“You certainly think about what you have lost with regard to the physical relationship that you have with your partner that changes obviously. Mmmm... yeah. It’s devastating but with regard to your children the only emotions you [pause]

...one of the things that did upset me when I was in hospital was thinking that if [my daughter] wanted to get married, then I couldn’t walk her down the aisle and maybe she wouldn’t want me to go down the aisle even if she did get married. That really upset me, something as simple as that!”

(Mark, Timeline Recording, 2011: 8)

(Grosz, 2000: 223) demonstrates the inherent complexity involved in remembering and memory, showing that we “tend to believe that when the present is somehow exhausted or depleted of its current force it somehow slips into the past, where it is stored in the form of memories. It is then replaced by another present”. At one time Mark’s story is indicative of a present memory - how he felt at the time of his accident; however, upon retelling the story at a later stage, i.e. while completing a timeline for the research, Mark’s story becomes a past memory and an example of his anticipated future in the recent past.

However, Mark’s anticipated future in the recent past also demonstrates how once his identity as a spinally injured adult is situated as contingent, the emergence of his identity as a father begins to develop in relation to his accident. This leads Mark to draw on his emotions as he considers his future trajectory and the realisation that “I couldn’t walk her down the aisle and maybe she wouldn’t want me to” (*ibid*, 2011: 8). Mark’s future trajectory is also about his shifting and changing identity, particularly his changing body. Earlier in the chapter, Mark uses spatial metaphors to describe ‘hitting the depths’ (p.11, this chapter) as he discusses the development of a cyst “on the injury site” (Mark, Email correspondence, Oct 2010). However, his becoming is open to futurity and

may “alter in relation to [his] current emotional state” (Davidson and Milligan, 2004: 524).

When completing the timeline Mark described how his future altered as his body changed and his disabled identity began to emerge as something different, something new. Time is important in three ways. Firstly, Mark’s disabled identity is re-situated in time and emotionally this was unexpected; secondly, the experience takes Mark back in time, as he describes going ‘back to an infants’ stage’ (Timeline recording, 2011: 5). Thirdly, it demonstrates how the past culminates into the present, as Mark’s anticipated future is reshaped by emotions arising from everyday activities and human intentionality (Brown and Harris, 1978; 1979; Williams, 2001).

This second point is related to incontinence, which culturally is associated with a certain stage of life (Shakespeare, 1993), “with child-like status and consequent loss of social life” (Reeve, 2010: 2). Mark’s feelings are shaped by these cultural norms and at the same time as feeling he has gone back in time to an infants’ stage, his plans for the future involve emotions that are related to ‘going to the toilet’ and planning for further changes to his body in the future. While Reeve’s concern is that “worryingly, incontinence is being used as a reason to justify assisted suicide” (2010: 3), Mark’s intentionality, his purpose, is informed by his status, by his position in his own world. This is not to suggest that Mark’s world is detached from the rest of the world, but that his relationship to it is shaped by activities that take place in his everyday life. Following his spinal injury Mark learned to catheterise and with a medical professional his routine was focused on learning to catheterise on an evening, as it was Mark’s wish to return to full time work. Mark’s future was realised when he applied for a local job, working in an office and was successful. However, on one visit to Mark’s home when I am sitting with Mark and his wife he tells me how they have discussed the prospect of assisted suicide, if his anticipated future and his ability to control his body movements change again so that he can no longer ‘go to the toilet’ independently.

Reeve's states that "the anxiety associated with losing control over bladder and bowels is a good example of what Thomas (1999) has called psycho-emotional dimensions of impairment" (ibid, 2010: 2). Thomas' work may describe how Mark was feeling in spaces where his incontinence is 'revealed'; however, Mark's anticipated future is less about the concerns or exclamations of others and more about the emotions associated with his personal trajectory and ability to do things for himself, without the embarrassment of others doing it for him.

In the second example, Elizabeth's emotional future addresses everyday practice, as she refers to her *recent past*, which involves moments where she tries to control pain, using pain management, morphine patches as well as organising a support group for other with chronic pain. Yet her *anticipated future* is concerned with a series of on-going hospital appointments where Elizabeth has doses of sea snail venom administered to her spine, giving moments of relief from pain or times that Elizabeth describes as 'pain free'. Elizabeth emphasises particular words in the following quote to highlight the side effects of her treatment:

"The **awful** thing about sea snail venom is forgetting people's names, forgetting words. But if I'm getting pain relief from it"

(Elizabeth, Photovoice Discussion, 2011: 4, **original emphasis**)

Elizabeth's discusses how at the age of 20 a routine hospital procedure (going for an X-ray) culminated in her severe and prolonged chronic pain, this is more specifically known as adhesive arachnoiditis, "an incurable inflammatory condition affecting the middle (arachnoid) layer of the meninges...the membranes surrounding the spinal cord" (Smith, 2012). Since this event occurred Elizabeth has experienced repetitive operations including three on her spine, while more recently she has been attending hospital appointments as part of a clinical trial of Ziconotide. Elizabeth's story is about a series of on-going

hospital appointments, where injections of sea snail venom that block pain signals to the brain, are administered (Record, 2005) (NIH Record, 2005; Times Online, 2006; New Scientist, 2010). Elizabeth attends hospital appointments to have pumps implanted for the doctor to administer injections of sea snail venom, to relieve chronic pain as the injections block pain signals to the brain. While there are a range of temporalities present here, including the time that pain signals are blocked for, the variation in treatment, the 'successfulness' of the injections, and inherent temporalities of these successes, as I attend another meeting a few months later, Elizabeth tells me that the sea snail venom no longer works.

In summary, I have shown that disabled people's subjective feelings take place in relation to particular events or acts at different moments in their personal chronologies. Firstly, while time stretches or expands to incorporate Elizabeth and Mark's new beginnings and (re)beginnings, these are cyclical for Steve and Robert, who learn to understand their bodies and the embodied rhythms of MS. Secondly, at other times, participants refer to passing without being noticed and without standing out, yet as passing it isn't always possible participants learn to control their feelings about the success or failure of passing, leading to emotional and/or gendered performances. Finally, participants discuss the emotionality of futures, reflecting on past futures that have already come to fruition, or planning towards specific events, such as assisted suicide as a 'celebration', or injections of sea snail venom to relieve chronic pain.

In the next chapter I demonstrate the way that photovoice, the second participatory methodology chosen by a group of participants unfolded.



## Chapter 6: Taking photographs

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In this second mini-methodology chapter I explore the way that photography was used as a creative, feminist and participatory method with three members of a chronic pain support group. In order to illustrate the role of photography in this participatory project, there are three overarching themes that bind this chapter together. Firstly, I show that creative and artistic practices have the potential to engage participants in the research process in collaborative ways. Drawing on the work of artistic practices in qualitative geographical research (Dwyer and Davies) I show that the use of still and moving images, such as photography and participatory video share a similar feminist practice of looking (Kendon, 2003). A feminist practice of looking extends a broader critique to the masculinist 'gaze' (Crang, 2003) outlined in Chapter 4: *'Participatory Diagramming: 'Drawing' Timelines'* and recognises that knowledge production is not a singular activity that involves one viewer and one audience. Secondly, I show that a shared dialogue based on the daily and lifelong recoveries of ten participants emerged as I attended regular meetings at a chronic pain support group. I demonstrate the methodological process that developed as three participants, Elizabeth, Victoria and Simon used photovoice, a method that involves 'taking' and 'talking' about the photographs that people capture (Wang, 1999, Wang et al., 2000, Young and Barrett, 2001, Baker and Wang, 2006, Wang, 2006, Krieg and Roberts, 2007). Thirdly, I show that by using photovoice as a creative and participatory practice, with this particular group of participants, the task of documenting pain through images inadvertently overcame the challenge of representing pain.

I explore the potential of creative and artistic practices to shape the research process, as I demonstrate the emergence of participants' daily and lifelong recoveries as an empirical theme and the significance of photovoice as a visual methodology in this process. In the same way that drawing participatory timelines led to Sue and Mark discussing the emotionality of living with disabilities, I show that by 'taking' photographs Elizabeth, Victoria and Simon

provided specific time-space snapshots of their recoveries, providing an insight into their accounts of 'becoming well'. However, in the remainder of the chapter I explore the role of photovoice as a creative, feminist and participatory practice, contrasting the flexibility in my approach to photovoice and chronic pain with the more static framework used in other photovoice projects.

### **6.1 Creative and artistic practices**

In this section I show that creative and artistic practices have the potential to convey meaning through art (Kindon, 2003, Parr, 2007, Dwyer and Davies, 2010, Garrett, 2010, Hawkins, 2011, 2012), despite the continuing emphasis on verbal and textual methodologies in qualitative geographical research, which reinforce and reproduce more traditionally based data such as interviews, which are transcribed, coded and analysed. For example, while Hawkins (2011: 469) discusses the role of art to forge "relations with and within the community", where activities including gardening, knitting, walking and a summer festival are produced through artist-participant relations on a campsite in Cornwall. This particular example shows that research that involves art as a medium does not necessarily produce participatory engaged forms of working together, as Hawkins (2011) work presents a subtle yet underlying critique of the haziness of the 'viewer' and 'audience' through the above mentioned artist-participant relations. However, more participatory infused ways of knowing through creative practices are illustrated in Kindon (2003) and Parr (2007) work with marginalised groups, where visual methodologies such as participatory video are used to engage participants' as knowledge producers. The relationship between- and potential of- participatory and creative practices to enable participants as producers of knowledge is reinforced in my work by adopting a third, feminist way of working with participants.

Hawkins' (2011) acknowledgement that more innovative forms of public art (See Lacy, 1995, Hall, 2007, Lovejoy and Hawkins, 2009, Toscano, 2009) can learn from the frameworks employed by participatory geographers refers to Kindon's (2003) work on looking as a feminist practice. This feminist practice of

looking reinforces the idea that knowledge is produced by multiple actors or participants, highlighting that “there are different gazes in our research practice” (Kindon, 2003: 142) that may be described as ‘adulterist’ or ‘colonialist’ depending on the research context (ibid). Therefore, while the role of both the ‘viewer’ and ‘audience’ are unclear in the artist-participants relations discussed by Hawkins (2011), both Kindon (ibid) and Parr (2007) are aware of the importance of involving participants in meaningful ways throughout the research process. By exploring the methodological process that developed with three members of a chronic pain support group, in the following section I show that in my research photovoice is informed by a feminist practice of looking, which is framed through participatory and creative practices.

While these studies (Kindon, 2003, Parr, 2007) set themselves apart from other geographical work that uses video<sup>34</sup>, in the next section I show participatory video and photovoice can enable participants as knowledge producers, as I describe how Elizabeth, Victoria and Simon were put in “control of [the] viewing technology” (Kindon, 2003: 145-6). By using examples from qualitative research I show that while various photographic methodologies have involved participants to varying degrees (Latham, 2003, Johnsen et al., 2008, Dennis et al., 2009), photovoice was adopted as a method that is relevant as both a feminist practice of looking and appropriate for working on issues relating to disability and health (McIntyre, 2003, Baker and Wang, 2006, Parr, 2007).

## **6.2 Photographing recoveries**

Geographers’ have used photography in a variety of qualitative research practices, frequently asking participants to document aspects of their daily routines, from community and recreational environments in participatory photo mapping (PPM) (Dennis et al., 2009) and time-space photo diaries which are used to document significant or interesting events or places in a week (Latham, 2003), to using auto-photography to capture the daily lives of homeless people

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<sup>34</sup> Parr (2007) suggests that film and video are used interchangeably in Kindon’s (2003) work and that the differences between film and video should be noted.

(Johnsen et al., 2008). However, while geographers' willingness to engage with photography as a 'celebrated method' has been noted for being "singularly situated" and relying on text, video is celebrated for both its visual and aural qualities (Garrett, 2010: 2). I argue that the potential to hear and see into the lives of participants' in this research was made possible by utilising photovoice as a feminist practice of looking (Kendon, 2003).

Photovoice is a participatory action research method with roots in feminism (Booth and Booth, 2003, Baker and Wang, 2006), as well as a visual method that enables participants' to add 'voices' to the photographs they take usually at a later stage and as part of a group process. In Krieg and Roberts (2007) photovoice project with marginalised Indigenous women in Saskatchewan, Canada, an initial meeting was held to discuss participants role in the Photovoice process, in the overall project, as well as the use of cameras, potential risks and the "opportunity to decide about the degree of their participation" (ibid, p.153), before reading and signing consent forms. However, in my research, the initial meeting with the chronic pain support group focused on building a theme, recovery, then deciding on the method that would be used to explore that theme. This differs from the emergence of emotion as a theme through the use of participatory timelines, as participants at the chronic pain group discussed the difficulty of describing pain.

Methodologically, there are two key events that developed with the chronic pain support group. Firstly, the theme of recovery emerged as a topic through a shared dialogue between multiple members of the support group, as participants narrated 'past' and 'present' issues relating to therapeutic care and pain management. In November 2010 I made my first visit to the chronic pain support<sup>35</sup> group, a locally based charity in the North East of England that provides face-to-face and telephone support to people living with chronic pain. The group agreed that 'recovery' was a fitting theme after I spent time listening

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<sup>35</sup> The support group held its first committee meeting in 2001, 50 people attended this meeting to show their support for one another and discuss their similar experiences of waiting (a topic that is revisited in Chapter 7: *Becoming well: A geography of recovery*) to see medical professionals at the same clinic.

to people share their experiences of chronic pain, from daily practices of forgetting (acupuncture, tapping and smoking cannabis); the organisation of daily routines, including spacing and breaking up of time to perform tasks from personal well-being such as drinking water, taking short sleeping breaks or placing a wet flannel over a face; attending a pain management clinic or hospital appointments for injections of sea snail venom; to the emotional memories associated with pain and recovery. These introductory themes are explored in more detail in Chapter 7: *'Becoming well: A geography of recovery'*.

Secondly, photovoice was adopted as a method to enable participants to think differently about their lived experiences of chronic pain, as they discussed the difficulty of describing pain. One by one participants began to discuss their lived experiences of chronic pain, sharing stories of pain, suggesting Elizabeth experienced the worst pain, that pain was impossible to describe and that medical professionals would frequently ask participants to describe pain on a sliding scale, from one to 10, or to draw the severity of their pain on a piece of paper. By putting Elizabeth, Simon and Victoria in control of photographing "aspects of their daily lives from their own perspectives" (McIntyre, 2003: 48), Box 6.2: *'Representing pain using photography'*, illustrates the photovoice method that developed with these three participants, as they took a disposable camera and agreed to photograph 'pain in the present'.

**Box 6.2: Photographing and representing pain**

Elizabeth, Victoria and Simon were given a disposable camera, an instruction sheet (Appendix 6.2.1), a sheet of paper to note down the reason they had taken each photograph (Appendix 6.2.2) and a self-addressed envelope to return the camera when they had taken their photographs. All three participants signed consent forms and asked any questions regarding the process. I telephoned each participant after one week to provide guidance and support, offering individuals advice and listening to them talk about the challenges and opportunities of taking photographs in order to represent pain. All three participants returned their cameras and notes within four weeks and we

arranged to meet together at Elizabeth's home, where participants would view their own photographs for the first time, sharing with the group if they wanted to. I describe the process that took place as participants organised their photographs into shared themes in section 6.3: *'Time-space snapshots'*.

Elizabeth, Victoria and Simon are non-housebound<sup>36</sup> members of the chronic pain support group and were present at the meetings where I introduced the research, contributing to the discussion based on daily and lifelong recoveries. Both Elizabeth, who is in her early seventies and has been living with chronic pain for fifty years and Victoria, a similar age, who has been living with chronic pain since an emergency spinal operation 5 years ago, have already been introduced in Chapter 5: *'Becoming emotional'*. However, Simon, the third photovoice participant is in his fifties and has been living with back pain since his early twenties that eventually led to his spondylitis. These three participants agreed to take photographs of their lived experiences in order to show what 'living with pain in the present' looked like in their daily recoveries.

“[T]here are generally few instances of explicit and self-professed methodological strategies that explicitly use the arts as a way to access social worlds of research subjects in geography”

(Parr, 2007: 116)

By using photovoice Elizabeth, Victoria and Simon were able to document their lived experiences of chronic pain, providing representations of their own social worlds by photographing different objects, journeys, important people and places, as well as, medication. Unlike earlier uses of photography to portray people with mental health problems through the use of visual imagery to creative negative stereotypes and to stigmatise people (Parr, 2007, 2008), photovoice offers participants the chance to take control of both the camera and the method. As a feminist and participatory practice participatory video creates a

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<sup>36</sup> A label given to these members by those at the chronic pain support group.

similar environment for participants to take control and to become involved in the research process.

"[M]ovements [in front of and behind the camera] have facilitated a more explicit recognition of the agency and situatedness of all participants in the politics of knowledge production associated with the project's focus and have contributed to a deeper level of trust and understanding within the research partnership itself"

(Kindon, 2003: 146-7)

By becoming both the viewer, who is taking photographs of their own lives, as well as the audience, in this case the other two members of the chronic pain group who view the photographs together at a later stage, photovoice becomes a "culturally relevant lens" (McIntyre, 2003: 47) through which to view issues relating to health and disability.

### **6.3 Time-space snapshots**

In this final section I discuss three participant's time-space snapshots, highlighting the different temporalities that are captured through the simultaneous task of 'photo' images and participants written and spoken 'voices'. Whilst Elizabeth, Victoria and Simon captured still images of 'living with pain in the present', from particular moments in the day, to weekly routines and a series of photographs showing a journey, I demonstrate that the flexibility of my approach to photovoice has the potential to enable more creative practices, as I illustrate that the researcher's trust in more traditional approaches may reproduce more rigid methodologies.

In my research photovoice was used as a creative practice with disabled people, allowing participants the potential to be creative by providing them with loosely based guidelines and enabling them to use art to explicitly get at personally defined issues (Krieg and Roberts, 2007). My approach to using

photovoice is different to the more structured formats used by Krieg and Roberts and Booth and Booth, which are based on Baker and Wang's methodological approach. Whilst I presented participants with 'control', which at times left them feeling uncertain, as they thought that I might have a particular direction in mind, Box 6.3: '*Flexibility in photography*' demonstrates that there is scope for "unfolding uncertainty into research practice" (Dwyer and Davies, 2010: 88).

### **Box 6.3: Flexibility in photography**

By using a participatory approach it was the process that was important rather than the 'doing' of particular methods, therefore while methods were not intended to uncover specific theories, the use of tools (i.e. the camera in photovoice) are noted for putting "people in charge of how they represent themselves" (Booth and Booth, 2003: 432). However, while participants at the chronic pain group were asked to photograph things that 'represent' pain on a daily basis, in this research their images were used as visual tools, subsequently conveying the importance of affective geographies of disability and health. Using photographs to talk about the management and negotiation of pain on a day-to-day basis, this method highlights the power of visual tools to produce meanings [ref] regarding the lived experiences of three participants' chronically pained identities, which wouldn't necessarily have emerged from just 'talking'.

By practicing photovoice as a participatory, creative and feminist method with participants in this research, new theories emerged (Pain et al., 2007) regarding disabled people's everyday lives. After sharing their photographs, the following six themes - 'other people', 'aids' such as walking sticks, 'medication' including prescribed tablets and morphine patches, 'hobbies/distraction therapy'<sup>37</sup>, 'recreation/exercise' and 'comfort/therapeutic' - were chosen by Elizabeth, Victoria and Simon as they created six separate piles of photographs, illustrating the importance of recoveries. However, while this empirical material led to new theories, which are discussed in the following chapter, this created a new methodological challenge when trying to (re)present participants' accounts.

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<sup>37</sup> See section 7.3.4 for a discussion of 'distraction therapy' in the process of recovery.



As all of the methods used in this research demonstrate the importance of affective temporalities to participants lived experiences of disability, health and illness. Yet, Bondi (2005) illustrates that for those in cultural geography who take a non-representational view of affect, the paradox lies between theories of affect and practices of writing non-representational discourse, further highlighting the challenge of 'writing' about this material in the research.

In summary, I have shown that allowing participants both control of, and flexibility in, a method that puts them in 'charge of the viewing technology' (Kendon, 2003), unexpected results unfold for both the viewer (in this research the photovoice participants) and the audience (the other photovoice participants' and myself). In the following chapter, I explore the photographs, conversations and written material produced through photovoice, to demonstrate the importance of daily and lifelong recoveries.

### 7.1 The temporalities of recovery

While there has been a prolonged engagement with the topic of well-being in geographies of disability, health and illness, this has addressed the sites, spaces and places where recovery takes place, rather than the temporalities. In particular I address this limited engagement suggesting that an analysis of the temporalities of recovery illustrates the complex and nuanced ways that disabled people's day-to-day lives are (re)organised by and through materialities, embodiment(s), (power) relations, rhythms, routines and seemingly mundane activities. In this empirical chapter, the second of the thesis, I discuss six participant's accounts of 'becoming well', illustrating the everyday and lifelong recoveries that participants experience in relation to chronic pain, multiple hip replacements, sclerotic arthritis, spondylitis and spinal cord injury. By 'recovering', participants are not aiming to achieve a status of 'well being' or recovering to a previously held mental or physical status. Instead, the chapter focuses on 'becoming well', conceptualising recovery in terms of its temporality and suggesting that recovery is always open to change (Grosz, 1999) and never complete.

In chapter 5: *'Becoming emotional'*, I discussed the emotional temporalities of (re)beginnings and of everyday life, highlighting the emotionality of diagnoses, medical operations, accidents, falling, walking, toileting and futures. However, in this chapter I show that a discourse of 'becoming well' is shaped by the rhythms and routines of participant's everyday lives, highlighting the emergence of participants' recoveries through various temporalities. In section 7.2: *'Becoming well'*, I focus on the concept and study of well-being within the literature on geographies of disability, health and illness, highlighting the challenges of conceptualising the term (Fleuret and Atkinson, 2007) without losing its complexity or specificity (Pain and Smith, 2010). However, despite the importance of 'everyday' geographies that are rooted in the

practices, activities, processes and experiences of 'being well' (Kearns and Andrews, 2010), the temporalities of well-being are difficult to locate in the literature. I argue that striving towards 'being well' as a fixed and attainable goal is both unrealistic and unachievable in most physical, mental, social, spatial, spiritual and embodied senses. Instead I suggest that the concept of 'becoming well' provides a more appropriate and critical understanding of disabled people's social and cultural recoveries by acknowledging the fluidity of these different relations. Significantly, it is the relationality of well-being in therapeutic encounters discussed by Conradson (2005) that has the most resonance to my concept of 'becoming well'. This highlights unfolding, transitory and continuously evolving relations that emerge through therapeutic effects (ibid), connecting to the fleeting temporalities of disabled people's recovery/recoveries in my empirical findings.

Using six participant's accounts, I discuss the recoveries of Elizabeth, Victoria and Simon, who I introduced in the previous methodological chapter on photovoice. These accounts are interspersed with Mark, Sue and Hannah's recoveries, in order to explore the temporalities of becoming well. While the topic of recovery developed methodologically during conversations with members of a chronic pain support group<sup>38</sup> and as part of a photovoice method with three members of the same group, other participants spoke about (re)structuring their daily routines to fit in around changing bodies, making physical adjustments and alterations to homes, completing tasks in order to feel 'less pain' and the importance of relationships with partners, carers and medical professionals in these recoveries. I explore the different temporalities that (re)produce participants' material, embodied and affective recoveries in two empirical sections, demonstrating that while people measure, perceive and experience time differently, it is these temporalities that bind all of their experiences together.

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<sup>38</sup> See Chapter 3: *'The temporalities of participatory engagement: An unfolding methodology'*.

In section 7.3 *'Renegotiating 'new' bodies, 'new' activities and 'new' relations'*, I explore the significance of materiality, embodiment and affect, showing that 'straightforward' and mundane activities are reclaimed in the process of learning 'new' bodies and 'new' identities. Firstly, I show that two participants re-learn the materialities of their 'new' bodies following post-op hip replacement surgery and spinal cord injury, as new and altered daily routines take place. Secondly, I demonstrate the significance of 'place' when participants return home from surgery, and the subsequent 'placelessness' of affective recoveries in accounts related to chronic pain. Thirdly, I show that 'practices of forgetting' enable participants to momentarily forget their pain as they experience the temporalities of comfort.

In section 7.4 *'Rhythmic recoveries'*, I show that in order to complete daily chores, from the seemingly mundane practice of sleeping or going to the toilet, 'new' tasks are added to participants' routines changing the rhythms of their daily and lifelong recoveries. I show that quotidian cycles and power relations (re)produce a particular synchronisation of social life (Edensor, 2010b), emphasising the normal rhythms of day-to-day life. However, I challenge the norms that are (re)produced through these synchronisations and in Lefebvre's (2004) rhythmanalysis, highlighting the regularity *and* discontinuity in participants rhythmic recoveries. The 'and' is significant as it highlights the normal rhythms in participants routines, rather than conceptualising them in opposition to quotidian rhythms.

## **7.2 Becoming well**

In this section I explore the concept of becoming well, highlighting the limitations of conceptualising disabled people's recoveries through well-being. I discuss the relationality of becoming well in order to understand individual and collective recoveries by providing an account of the complex arrangements that constitute seemingly mundane practices in participants' daily routines.

Kearns and Andrews (2010: 309) suggest that well-being is “anchored in the environmental and spatial contexts of everyday life”. However, there is a tension between the breadth of the everyday as a geographical term (Pinder, 2009), signifying a turn away from the temporalities of well-being towards the specificities of the socio-spatial aspects and place of the everyday. This is reflected by analyses of health and place (Atkinson et al., 2012), including those places that promote health inducing benefits, such as therapeutic landscapes of health and healing (Gesler, 1992, Andrews, 2004, Foley, 2012), to the spaces of health(care) and caring (Williams, 2002, Milligan et al., 2007, Milligan and Wiles, 2010, Conradson, 2011). Despite Atkinson et al.’s (2012: 3) suggestion that “well-being, or becoming ... are essentially and necessarily emergent in place”, an in-depth analysis of the temporalities of ‘becoming’ that constitute everyday life are missing from conceptual and empirical framings of disability, health, illness and well-being. While Conradson (2005) and Atkinson et al., (2012) both articulate a concern with the ‘moments’ and ‘emergence’ of well-being and care, acknowledging the transient relations between individual and collective life, the temporalities of the everyday merge into their accounts rather than standing out in their analyses<sup>39</sup>.

In this section I show that my work fits into an already present geography of recovery that addresses the role of well-being in relation to mental (ill) health (Parr, 2008, Laws, 2013), physical impairment (Conradson, 2005) and alcohol addiction (Wilton and DeVerteuil, 2006). In the following definition of recovery, a connection to time is implied and although this addresses the linearity of recovery, I use participant’s accounts to stress the unfolding and emerging nature of becoming well.

“Recovery: [A] return to a normal state of health, mind or strength”

Source: Oxford English Dictionary (2012)

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<sup>39</sup> While Conradson (2005) raises the theme of time in the closing section of his paper, temporalities are an addition to his analyses, rather than framing them, as is the case in my concept of becoming.

In the above quote the use of the word 'return' implies the possibility to go back in time; while 'to recover', is encased in a language of 'getting better' and reaching forward to recovery. However, the possibility of getting better and/or the task of 'recovering' to a previously held mental or physical status have been critiqued for their inappropriateness and assumed linearity. Tamas for example, suggests that recovery is an inappropriate metaphor for survivors of domestic spousal abuse, who do not fit "a series of interlocking, cumulative steps" (2011: 143) towards recovery. Here the critique is of the assumed ability or capacity of 'survivors' to recover from personally felt past experiences and to return to the person they were, before their abusive relationships. However, 'a return to a normal state' jars with the lived experiences of Tamas' participants, and with those participants in my research, who are always in a state of becoming.

Parr's (2008: 22) work goes one step further to provide an insight into "the non-linear, complex patterning of 'recovery'" in relation to mental illness. Using Moss and Dyck's (2002) work, Parr reinforces the undulating and fluctuating nature of chronic illness to show that "[r]escriptive recovery moments", which are embodied by those in the process of recovery, "are always incomplete" (2008: 21). While Parr's work explores some of the temporalities of recovery, highlighting the tension between representations of chronic illness as a long-term experience with the unexpected moments that punctuate lived experiences, her work provides an in-depth analysis of the socio-spatial recoveries of mental illness. However, using temporality as a means to emphasise and to move beyond clinical accounts that utilize the 'static mental patient' (ibid, 27) as a category or label is useful in my research.

My claim, in this section at least, is that recovery is best conceptualised as a product of continuously emerging relational change: always a '*becoming well*' (Grosz, 1999). Significantly, I address the daily (7.3) experiences and lifelong (7.4) process of becoming well, using recovery as a framework to understand the 'everyday' geographies that re-structure disabled people's time. I show that disabled and ill people's recoveries and hence their time is not shaped by a single "longer-term state-of-mind" (Kearns and Andrews, 2009: 311); instead, as we

shall see below disabled people's time becomes restructured by multiple temporalities of becoming well.

### **7.3 Renegotiating 'new' bodies, 'new' activities and 'new' relations**

In this section I address six participant's accounts of recovery to show the importance of materiality, affect and embodiment to their experiences of becoming well, discussing the temporalities of (re)negotiating 'new' bodies, 'new' activities and 'new' relations. As Mark, Hannah, Sue, Elizabeth, Victoria and Simon learn to live with their 'new' found embodiments, following diagnoses, accidents, medical operations and surgery, they also encounter 'new' activities and 'new' relations in the process of everyday recoveries. By making adjustments to daily living and completing 'new' and routines tasks, participants re-negotiate their bodily and material boundaries (Longhurst, 2001), as mundane activities such as lying down, sitting up, standing and walking are reclaimed in the process of accommodating and negotiating embodiment[s]. I connect participants' empirical accounts of becoming well to re-materialised social and cultural geographies (Jackson, 2000, Philo, 2000, Lees, 2002, Anderson and Tolia-Kelly, 2004, Colls, 2007), showing that the "landscape is now one of the key sites for an encounter with various materialist traditions" (Anderson and Tolia-Kelly, 2004: 669).

While there is a dominant literature on the everyday landscapes of care where well-being takes place (Williams, 1998, Andrews, 2004, Milligan and Wiles, 2010, Conradson, 2011), I show that the 'landscape' described by participants does not provide a therapy space or space of therapy per se, rather the landscape, described by participants and the relations that take place in this landscape produce moments of recovery. Therefore, the hospital, the doctor's surgery, physiotherapy sessions and pain management clinics become the sites of encounter where recovery takes place.

I illustrate the 'taking-place of practices' (Colls, 2012: 430) of becoming well, using the affective geographies literature to highlight the more-than-human

and bodily experiences (Pain and Smith, 2010: 303). Using non-representational theory, I provide an analysis of recovery as a series of affects that “are generated and quiesced through entanglements with people, physical locations, material objects, at different times and in different spaces” (Bissell, 2010: 83). I argue that in specific moments of encounter, more-than-human, post-human or non-human relations (injections, material objects used in recovery) and human relations (the bodies in recovery) interact with places or sites of encounter to produce space-time recoveries.

### **7.3.1 The bed**

In this section I show that Sue and Mark renegotiate their ‘new’ bodies in the process of becoming well, as the hospital becomes the setting where everyday activities such as lying down, sitting, standing and walking take on a new purpose. These everyday activities are related to exercising, hospital treatment and the addition of ‘new’ tasks that are added to Sue and Mark’s repertoires as they complete ‘new’ routines and renegotiate their ‘new’ bodies. Using Mattingly’s (1994) work on the relationship between an occupational therapist and a man with a head injury, where I focus on Sue and Mark’s accounts of accommodating a new body (ibid, 1994), showing that “interlocking and continuous set of actions creates a situation of emerging experience” (Williams, 2002: 145). However, their emerging experiences take place in different contexts; firstly, as Sue is aware of going into hospital for a hip replacement operation, while Mark’s cycling accident leads to his spinal cord injury and hospitalisation in a spinal injuries unit for 6 months. While Parr’s (2008) work attends to the spatialities of recovery, in this section I demonstrate that the temporalities of recovery or the temporalities of rehabilitation take precedence over the spatialities of rehabilitation (Dyck and O’Brien, 2003)<sup>40</sup>, as I explore ‘suspended time in bed’.

### **Suspended time in ‘bed’**

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<sup>40</sup> However, in section 7.3.2 ‘*The home*’ I use Dyck and O’Brien’s work to illustrate the blurring of boundaries.



As Sue and Mark re-learn the materiality of their bodies and their bodily boundaries, a distinct set of relations to material items, other people and new activities creates specific embodied temporalities of becoming well. In light of Sue's first hip replacement operation and Mark's spinal cord injury, they both spend long periods of time lying down in hospital beds. These temporalities of recovery show that whilst time, bodies and movements become suspended as Mark and Sue's hospital beds hold them in the space-time of recovery, it is the "processes of materialisations that matter" (Colls, 2007: 356), as they re-learn the materialities of their 'new' embodied identities. The embodied temporalities of becoming well highlight what happens in-between moments of 'sitting up', 'lying down', 'standing' and 'walking' rather than at the specific time of these tasks, as the process of becoming well is important, "not the end product" (Colls, 2007: 356). In the following accounts I show that this further emphasises the emerging and unfinished nature of disabled people's differences, as opposed to achieving a fixed status of well-being.

This section shows how Mark and Sue begin to re-learn the materiality (Longhurst, 2001) and boundaries of their 'new' bodies. In these examples of emerging experience time is important in two ways, firstly, temporality shapes the day-to-day activities that participants' complete as they negotiate re-embodiment and secondly, participants' personal histories dictate the type of negotiation that takes place. Sue was born with Congenital Dislocation of both Hips (CDH) and has experienced various medical procedures and operations associated with her changing body over the last 60 years.

During the occasions when I met Sue she relives numerous stories including those from her childhood, illustrating how her history is marked by multiple contexts of negotiation. Sue has experienced eight hip replacements in the last 40 years, as she was born with Congenital Dislocation of the Hips. In the following quote she describes the period following her first hip replacement surgery that took place in 1972, describing the relationship between her body and the Balkan beam that it was attached to; as Sue explains, it was used to:

“stabilise the hip and prevent movement...the femur is separated from the hip joint...in a tight cast with weights at the end of your foot with a pulley keeping the leg pulled tight and separating the ball from the hip socket”

(Sue, in conversation, 2011: 2).

Sue describes staying in this position, lying down for six weeks, as her body, in particular her leg is held still, to prevent it from moving. While stillness in this context might be interpreted through power relations, as Sue’s static position in the hospital bed in part renders her powerless, as she is moved inch-by-inch over the course of one week into a sitting position. Sue demonstrates multiple instances/moments of ‘control’, as a relation to power, throughout her life, as I discuss entanglements of bodies, spaces, times, practices and power in relation to medical professionals and ‘patients’ in section 7.4.1 ‘*Quotidian cycles, power relations and mundane activities*’.

Sue learns to walk again following her first hip replacement surgery and suspended time in bed, as she begins physiotherapy following the initial six weeks lying down horizontally. Her physiotherapist gives her exercises to complete, including:

“doing basic exercises in the ward - *moving* your ankles, *turning* them in circles *bending* and *stretching* my right leg, *tightening* muscles in both and *letting go*”

(Sue Diary Entry 2, 2011: 2, *my emphasis*).

The ‘moving’, ‘turning’, ‘bending’, ‘stretching’, ‘tightening’ and ‘letting go’ highlighted in Sue’s quote illustrate how she starts to understand what her body can do following the operation. While Sue’s right hip was operated on, she completes the set exercises using both feet/legs, understanding her left leg through its relationship to the other ‘new’ right leg. Recovery involves ‘doing’

basic exercises as multiple entanglements include renegotiating her new body by re-learn new boundaries and abilities through exercise<sup>41</sup>.

Significantly, this process of recovery and the time Sue spends suspended in bed effects the way that Sue feels in the future following her second hip replacement surgery. This takes place in 1972, where medical procedures and surgical practices have changed significantly and do not involve suspended time in bed, but in fact significantly less time in bed, as “patients are expected to get out of bed on the day following surgery” (Sue, in conversation, 2011: 11).

During the six months on a spinal injuries unit, following his spinal cord injury, Mark shows that a significant proportion of his time was spent lying down on a hospital bed, before he was helped into a sitting position. However, once this suspended time of lying down had finished, Mark begins to re-learn the materiality of his body. Mark was spinally injured when he was in his 40s and begins to understand his new body by renegotiating everything he knows about it. Papadimitriou (2008) states that following spinal cord injury physically disabled adults,

“redefine, re-examine or modify past experiences, abilities, lifestyles and habits in their efforts towards re-embodiment”

(Papadimitriou, 2008: 691).

For Mark, re-embodiment involves re-learning the boundaries of his body through its materiality, which includes learning his own abilities by testing his body. As Mark is spinally injured (C1 with T7 complete) he does not have any sensation from his chest or abdomen, down to his legs and feet. In the following quote he describes a few of the changes to his body, including:

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<sup>41</sup> This links to the discussion of Sue being in control in Chapter 11: *Memories*, as she later highlights her relationship to physiotherapists during her recovery, wheeling down to physiotherapy early to do extra exercises.

“Learning to live without balance - challenging. You don’t realise even down to your eating; you’ve probably noticed I’m nice and fat and I rest on the table at the same time, I can’t hang on.

“Simple things like that, I always use one arm to steady myself no matter what I’m doing. At work I always have hands free and then I can speak away ‘cause if I’ve got to bring anything on the computer I can type”

(Mark, Timeline Recording, 2011: 5)

While Mark is unable to use his legs and uses a wheelchair on a daily basis, he can use his arms and the upper part of his body including his head and neck. He describes the challenge of ‘learning to live without balance’, however, as he is speaking he also demonstrates how he leans on the table. We are completing a timeline at Mark’s home when I watch Mark lean the upper part of his body onto the dining room table, shifting the relationship between his back and the wheelchair he sits in, to his elbow and the table he leans on. Mark reconstitutes his position and therefore his balance, showing how he modifies one of his abilities in an effort towards re-embodiment (Papadimitriou, 2008) as he transfers his weight from one position to another. However, this example also extends to the work place, as Mark adapts to his new lifestyle in his office based job where he uses the telephone on hands-free.

As Sue and Mark continue to renegotiate their changing bodies, recovery extends into the home of participants or into their futures through life long recoveries.

### **7.3.2 The home**

In this section I use Tuan’s (1974: 4) work on ‘topophilia’, “the affective bond between people and place or setting” (cited in Williams, 2002: 146) to show that place matters in the process of becoming well. I show that materiality of participant’s homes and the relations with family members alter when Mark

and Hannah return home following periods on hospital. I show that affect[s] “the visible energetic outcome of encounters between human bodies and more than human objects in places” (Andrews, 2011: 878), are temporarily (re)made through physical, emotional and spatial adjustments, blurring bodily boundaries (Valentine, 1999, Dyck and O'Brien, 2003) and illustrating the affective temporalities of the ‘home’. In the following examples, the home is the place where recovery takes place, as participants continue to learn about their ‘new’ embodied identities. It is the temporalities of places, people and relations that matter as I show that recovery is an ongoing process, changing and emerging through different sets of relations in the process of becoming well.

Using accounts and descriptions of the physical layout of Mark and Hannah’s<sup>42</sup> homes, I show that they restructure their homes to accommodate the changes they were experiencing to their bodies, (re) producing different affects through new relations. While Andrews (2011) describes the spatial affect of needle phobia, which comes together as humans, needles, places and people collide, it is the temporality of these moments of collision that matter as I show that two participant’s homes and relations within them are temporarily altered, producing certain affects.

In the first example, Mark, returns home following six months on a spinal injuries unit, and as the materiality and spatiality of his ‘home’ alter to accommodate his new embodied identity, these changes produce new relations between Mark and his family. While Mark re-adjusts to his embodied identity, his home and his family, subsequently, his family face re-adjustments as the layout of their home changes. At the time of Mark’s accident he shared his home with his wife, daughter and son, however, upon returning home adjustments were made to the physical layout of Mark’s home. The adjustments to Mark’s Dorma bungalow took place at various intervals in the ten years following Mark’s spinal injury to suit his changing body and changing routine; these changes affected all

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<sup>42</sup> Mark has already been introduced on a number of occasions, whilst Hannah a member of the chronic pain support group who was present at the meeting where the theme of recovery developed.

of his family. During one visit to Mark's home he offered to give me a guided tour of the house he lived in with his wife, explaining the previous layout and location of rooms. Firstly, Mark and his wife moved from the bedroom upstairs into the room that was their daughter's bedroom on the ground floor. While the main bathroom was located upstairs there was a shower room next to his daughter's bedroom, helping Mark to adjust to his daily routine, most of which was spent moving around in a manual wheelchair during the day. Most of these changes were related to Mark's daily routine, as he had to learn how to do nearly all of the things he'd learned to do one way, a new way<sup>43</sup>.

Dyck and O'Brien (2003) discuss the way that the distinction between the public and private sphere becomes blurred in the home, as private spaces become more public as friends and health care professionals infiltrate the home of a man with HIV/AIDS and care, work and social life become intermingled and difficult to separate. However, in Mark's account it is the temporalities of rehabilitation that matter, as he must share his toileting routine with other members of his family. When Mark first returns home from the spinal injuries unit he hasn't yet been taught to train his bladder and needs to use the toilet for long periods of time. At one stage he discusses the humiliation and embarrassment of going to the toilet at home, as the door had to be removed to accommodate his wheelchair. As the bathroom was located on the ground floor next to his daughter's bedroom, Mark describes having to complete his 'toileting routine' for three hours. This room is also next to the dining room where the family sat to eat their meals, as the private act of going to the toilet becomes more public and open to the other members of Mark's family.

Hannah is in her sixties and has sclerotic arthritis, experiencing chronic pain for a number of years. However, when Hannah became a wheelchair user in 2000 following an operation where she had part of her left leg amputated, she needed to change the layout of her home to accommodate her electric wheelchair. Although I initially met Hannah at a disability support group I visited her in her own home at a later date, meeting her husband who she lives with and

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<sup>43</sup> As explored in Chapter 5: '*Becoming emotional*'.

is also her informal carer. Hannah and her husband made adjustments to their home, having structural work carried out to remove the ceiling between the upstairs bedroom and the dining room on the ground floor below. These adjustments were made using money from the local council in order to install a wheelchair lift, as there wasn't enough room to accommodate the equipment in any other space in Hannah's home.

### **7.3.3 Shoes, sticks, chairs, flannels and back stretchers**

In this section I explore the affective capacity of material items such as shoes, sticks, chairs, flannels and back stretchers to show that Simon and Victoria's relationship *to* and interaction *with* particular material objects determines the type and length of recovery, including whether it actually takes place or not. Using visual images, written text and extracts from conversations as part of a photovoice method, I show that the intensities of chronic pain experienced by Simon and Victoria fluctuate according to the affective capacity of material items. I demonstrate the inherent 'placelessness' of therapeutic landscapes (Andrews, 2004) and the sense of becoming well in Victoria's account of walking and in Simon's account of holistic therapies. Significantly, it is in these examples that affective temporalities (re)produce moments of recovery rather than the materiality of Victoria's 'aids', or the equipment in Simon's account of complementary and alternative medicine (CAM).

However, I also show that 'practices of forgetting' enable three participants to go to another space and time, Elizabeth and Victoria forget their chronic pain by completing hobbies such as gardening or cross-stitch, whilst Mark completes certain mundane activities such as standing and sitting in their daily lives. Using Bissell's (2008: 1701, original emphasis) work on "comfort as a *specific affective resonance* ... can circulate between and through both objects and bodies", I demonstrate that the processes and practices of forgetting lead to the temporality of comfort. I show that Elizabeth adopts a standing position to complete one of her hobbies, x-stitch, in order to forget about her chronic pain, while standing is a particular activity that is pertinent to Mark as he discusses

forgetting in relation to his spinal cord injury. In these examples the temporality of recovery is demonstrated by the comfort that certain body-object relations momentarily afford as Elizabeth and Mark transition through different bodily positionings depending on how they are feeling at any particular moment, temporarily 'forgetting' pain.

In Chapter 6: *'Taking photographs'*, I introduced Simon and Victoria, two members of a chronic pain support group that took part in representing aspects of their day-to-day lives through photography. Using Simon and Victoria's accounts I show that photovoice unearthed the varying intensities of chronic pain experienced by these two participants, including the practices of recovery that take place on a day-to-day basis in their lives. In section 7.4 *'Rhythmic recoveries'*, I explore Victoria's 'waiting time' as she sets out on her own journey to learn about her chronic pain for the first time, however, in the following account I show that while Victoria and Simon have different experiences related to chronic pain, including the type and length of time they have been 'living with pain', they similarly photographed material objects and discussed their significance in recovery. Using Bissell's (2009) work and visual images from photovoice, I show that it is the affective capacity of material items that produces recovery rather than the act of walking.

Victoria's photographs illustrate the significance of material objects in her account of 'living with pain', where 'recovery moments' are produced through the relationship between various human and non-human relations. It is the affective capacity of these relations that is important in her recoveries rather than the activities that take place. Victoria's chronic pain is associated with her spine and the time leading up to and following an emergency spinal operation, resulting in the daily measures she currently adopts. In Figure 7.3.3.1 below is an image of Victoria's National Health Service (NHS) shoes, however she also took photographs of her grabber and walking stick. In her accompanying notes Victoria refers to these three items as 'aids' saying that they:



“give me a psychological ‘lift’ enabling me to do more things with much less pain”

(Victoria, photovoice notes, April 2011: 1)



**Figure 7.3.3. 1:** Victoria’s NHS Shoes

While her shoes ‘facilitate walking’ by giving her ‘less pain’ (ibid, 2011: 1), it is the shoes and the affect produced when they are worn by Victoria that is significant in her recovery rather than the act of walking. This has resonance with Bissell’s (2009) work on the affectual intensities of chronic pain, demonstrating that pain is experienced through varying degrees of intensity, subsiding or intensifying. Using empirical material from his own personal accounts of living with chronic headaches, Bissell shows how “intensities of pain...become *refigured in relation to the body*” (Bissell, 2009: 921, original emphasis). In Victoria’s account she photographed material objects (shoes, walking stick and grabber), as a way to ‘represent’ the importance of objects in her recovery. However, it is the nonrepresentational ‘psychological’ affect that is

produced when she wears her shoes or uses her walking stick or grabber, that subsequently diminishes pain (Bissell, 2009) and enables her to 'do more'.

Victoria's shoes adjust the position of her body in the world as well as her relationship to the floor that she walks upon. While Andrews (2004) builds on the physical nature of Gesler's (1992) therapeutic landscapes, providing theoretical insights into the role of 'imagined places' (Andrews, 2004: 312) in complementary and alternative medicine (CAM). By focusing on the treatment and care practices of a wide range of therapies, Andrews (2004) highlights the imagined places that therapists encourage patients to construct as part of their treatment programme. Yet in Victoria account it is not the setting that shapes her recovery in Gesler's (1992) traditional sense of therapeutic landscapes or in the 'imagined' sense suggested by Andrews. Instead, it is Victoria's specific relationship to these everyday objects and the 'placelessness' of these experiences that produces particular affectual intensities as part of her everyday recoveries.

In Simon's account, his photographs are illustrative of those objects that he only uses in his own home as part of recovery. At the photovoice discussion group Simon begins to talk about the photographs he has taken, running chronologically through the images and explaining their significance as we sit together on a sofa in Elizabeth's living room. The two images that are presented in this section of the chapter show particular material objects that Simons uses, the first (Figure 7.3.3.2) is a photograph of Simon with a wet flannel over his face, the second (Figure 7.3.3.3) is of a Swedish back stretcher (made by a friend) and the third, not shown here, is a heated neck scarf. Simon begins to explain the affective capacity of these material items when I ask him about alternative medicine and the Chinese massage oil, telling me he just decided to walk into a shop one day and try it out.



**Figure 7.3.3.2:** Simon's hot flannel

By using photovoice it is clear that Simon tries to represent all of the practices he uses in recovery, however, complementary and alternative medicine (CAM) are particularly important, as Simon emphasised these on my first visit to the chronic pain support group, telling me about acupuncture and other holistic strategies he has tried to manage pain on a day-to-day basis. Simon's photographs clearly demonstrate the importance of material items in his recovery, as without the back stretcher, the needles in acupuncture or aromatherapy oil used with his heated neck scarf, Simon would not be in recovery. However, as "the materiality of CAM is vastly more than the materials of CAM" (Doel and Segrott, 2004: 729), it is the "differences that take place in practice" (Anderson and Tolia-Kelly, 2004: 671) that matter. While Simon's pain is related to his spondylitis, the relationship between his body and other material objects are at time directly related to the pain in his back, for example when he uses the Swedish style back stretcher, pictured below, or sits with a wet flannel over his face, however, at other times he uses a "hot shower" on the "pain areas".



**Figure 7.3.3.3:** Simon's Swedish backstretcher

However, it is exactly because CAM is unexpected (Doel and Segrott, 2004) and contingent that Simon, like the other members of the chronic pain support group try any measures, including holistic therapies in a sense of becoming well. One particular practice involves the use of Tiger Balm, which is known for its temporality; however, it is not just CAM that is unexpected but medical trials, as I demonstrate the temporality of medical interventions when Elizabeth discusses her ongoing hospital appointments to relieve chronic pain.

#### **7.3.4 Forgetting: Comfort-able relations**

In the following accounts I show that practices of forgetting highlight the temporalities of comfort, as I explore the day-to-day and mundane activities that three participants carry out in order to forget pain. 'Forgetting' has been explored in the geographical literature in the context of memory, health and dementia (Varley, 2008, Ramgard, 2011), focusing on the subtleties of remembering and forgetting. While Varley (2008) addresses the role of memory loss in relation to Alzheimer's and familial relationships, describing the emotional effects of her father's forgetting, Ramgard (2011) illustrates that

people's memories prior to dementia shape the same peoples experiences of dementia in residential care settings. However, Macpherson's (Macpherson, 2009a: 189) work provides a different approach to forgetting, illustrating that by walking in the countryside visually impaired people are immersed in "the momentary forgetting of other reflective coordinates of identity such as home, work, and life difficulties". While Macpherson focuses less on the importance of specific memories, her account contributes to an understanding of the way participants in my research are enabled by practices of forgetting.

The temporalities of comfort developed as a theme during conversations<sup>44</sup> with Mark and as part of a photovoice discussion with Victoria and Elizabeth. I illustrate the multiple temporalities discussed by these three participants, using Bissell's (2008) work on "comfort as an affective resonance [that] is understood through the relations between bodies and other objects". Significantly, I show that the affective capacity of non-human relations produces moments or temporalities of comfort, enabling participants to forget their pain; in two different yet connected ways. Firstly, I show that the intentionality of 'distraction therapy', a phrased coined by one of the members of the chronic pain support group, is demonstrated through the verbal accounts and photographs provided by Elizabeth and Victoria. Secondly, I show that comfort-able relations between Mark's body and other material items that he uses as part of his daily routine take place without intention. Yet, it is through seemingly mundane activities such as standing, sitting and lying down that all three participants accounts demonstrate the affective temporalities of comfort.

In chapter 6: '*Taking photographs*', I described the methodological process that took place as three participants Elizabeth, Victoria and Simon shared and discussed their own photographs of 'living with chronic pain'. However, as I gave each participant their photographs and they began to sieve through them individually, wondering what they would find, Elizabeth commented that when she is particularly ill she completes cross-stitch. The

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<sup>44</sup> See Chapter 8: '*Becoming (un)comfortable*' for a more detailed discussion of the methodological process.

following quotes are taken from the letter that Elizabeth returned to me with her disposable camera, adding some context to her life of chronic pain:

“I have often worked through the pain barrier...”

“I took early retirement as a result of my worsening pain. Now I am older it is more difficult to work through the pain barrier so my hobbies have changed”

(Elizabeth, Photovoice Notes, April 2011: 1)

Elizabeth’s hobbies change from gardening, decoration and furnishing of a Grade I listed building, after 17 years working on the home that Elizabeth and her husband owned together, “until it became too much”. However, cross-stitch is one particular hobby that Elizabeth completes standing up. Standing is significant to Elizabeth’s account, because the other activities she takes part in are either completed, sitting down, such as gardening, or lying down on the sofa, as I describe in section 7.4 ‘*Rhythmic recoveries*’. Distraction therapy, a phrase that numerous members of the chronic pain support group<sup>45</sup> use is described here by one individual and published in the group’s newsletter:

“[M]y personal method for achieving a little pain relief – and to me it means finding something worthwhile to do to help take one’s mind off pain. It developed when I realised that an enthralling film, a worthwhile discussion or an exciting day out could help take my mind off the chronic pain I have suffered increasingly...”

(Newsletter, March 2011: 2).

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<sup>45</sup> Introduced in Chapter 6: ‘*Taking photographs*’.



**Figure 7.3.4.1:** Elizabeth’s wool tapestry

Figure 7.3.4.1 represents the “wool tapestry and cross-stitch (which I still do when pain makes anything else difficult. I have drawer full of new knits)” (Elizabeth, 2011: 1). Wool tapestry and cross-stitch enable Elizabeth to go to another space and time, momentarily forgetting (Macpherson, 2009a) her chronic pain and feeling comfortable. Elizabeth doesn’t describe why standing is particularly important for this task, however, as her chronic pain is predominantly located in her spine, where the toxic injection, myodil was administered over fifty years ago, becoming comfort-able is possible through standing, enabling Elizabeth choices in her own practices of forgetting.





**Figure 7.3.4.2:** Victoria’s distraction therapy

Victoria provides two photographs of her living room, one which is shown in Figure 7.3.4.2 above, however, it is particular items such as her TV, radio and CD/music player that she refers to on her accompanying notes, telling me that these diversion activities enable her to:

“[F]orget pain, relax and feel refreshed”

(Victoria, Photovoice Discussion, April 2011)

However, while Mark’s experiences different pain to both Elizabeth and Victoria, who, Mark’s pain. Elizabeth and Victoria both refer to spinal problems and the use of ‘distraction therapy’ which enables them to forget their pain and feel comfortable, Mark’s spinal cord injury produces different types of pain, as his ‘practices of forgetting’ are not related to pain *per se* but rather address those



times when he cannot feel the shooting pain in his right arm or the feeling of sitting on glass. As my first encounter with Mark, an invitation to have dinner with Mark and his family began drawing to a close; he discussed how he continually experienced pain. Both of his painful accounts related to sensations; the first, a feeling of someone dragging a hot poker along the inside of his lower right arm (this was demonstrated through a motion, indicating the exact area where pain occurs); the second, was described as a feeling of continuously sitting on glass. In a similar vein to distraction therapy Mark tells me, at a subsequent meeting at his home:

“If you’re busy and you’re concentrating on something else your mind is occupied and you just forget it’s there or is it there to start with? Because it’s neurological pain so your brain thinks it’s there but it isn’t there. I suppose it’s not really, it’s just your brain. It’s like people who lose a hand or arm, their fingers still itch, even though their arm’s not there - same thing.”

(Mark Timeline Recording, 2011: 4)

While Mark’s refers to periods of concentration or moments when ‘you’re busy’ as time where you just ‘forget [the pain] is there’, he suggests that these painful sensations are phantom pains. In Chapter 5: *‘Becoming emotional’*, I discussed the specificities of Mark’s spinal cord injury, highlighting the damage to Mark’s spinal cord and subsequently illustrating the functioning capacity of his body and the limited physical feelings he has below his specific spinal cord injury site (C1 with T7 complete). Whilst I do not use this information as a means to reduce or limit Mark’s body through its capacities, it reinforces my argument that the temporalities of comfort produced in Mark’s account differ to those addressed in Elizabeth and Victoria’s account.

In Mark’s account the temporalities of comfort are (re)produced through a range of different relations between Mark’s body and other material items that

he uses in the process of becoming well. However, the specificities of Mark's spinal cord injury means that the materiality of his body is always (re)produced through particular body-object relations, including objects such as Mark's bed, wheelchair, shower chair and standing frame. Bissell discusses comfort as that which is desirable and achieved through bodily effort, as he refers to the chair as the "site of the practice of everyday life" (Bissell, 2008: 1702), suggesting that to be physically comfortable the relationship between the body-chair is negotiated. However, as Mark cannot feel sensations, as the quote above demonstrates, the (wheel)chair, (shower)chair, bed and standing frame are the multiple 'sites' of the practices of his everyday life. It is through these multiple sites that the positioning of Mark's body and his comfort is (re)negotiated; in the following example Mark talks about feeling the materiality of his body when he lies on his bed at night time.

"It's because I can't feel the pressure and because I can't move you really get stiff on the hip and it's nice to turn onto a different bit of your body, although I can't feel it! It is predominantly to help me move pressure because of a build-up of pressure and risk of pressure sores. Also to help with that I usually sleep with a pillow between my knees and between my ankles, which is obviously a lot different to what I used to do"

(Mark, Timeline recording p.3-4)

The feelings and relations that Mark describes here may at first appear contradictory as he states that he 'can't move', whilst also stating that it's 'nice to turn onto a different part of your body'. At night time Mark transfers from his wheel(chair) to his bed and from his bed to his wheel(chair) when he wakes up on a morning, however, in between these times Mark's bodily movements, his positioning and subsequently his comfort are (re)negotiated. Yet this (re)negotiation involves his partner who wakes him up:

“[A]bout two o’clock ish...if I don’t wake [...]

[I]t’s at that point that [partner’s name] has to get out of bed, throw back the covers and help me turn from one side to the other”

(Mark Timeline Recording, 2011: 3).

The (re)negotiation and (re)positioning of Mark’s body through his relationship not only with his bed, but with his partner as well, demonstrates that at times the affective and temporal capacity of bodily positioning, is at times constrained by choice. While Bissell discusses agency in sitting, for Mark the temporalities of comfort, the affective relationship between his body-bed when lying down or his body-(wheel)chair when sitting, are important and perhaps compulsory parts of his daily routine. In section 7.4.1 ‘*Quotidian cycles, power relations and mundane activities*’, I discuss the complex rhythms of Mark’s routine following spinal cord injury, as he moves between these different body-object relations on a daily basis. However, that is not to say that Mark doesn’t have control over his routine, because while comfort-able relations between Mark’s body and other material items are part of Mark’s routine and occur without intention, he states:

“[M]ost nights I try and get myself up in the standing frame”

(Mark, Timeline Recording, 2011: 3)

“Especially if Mark has a bad night sleep, it’s an indication that he needs to have a stand really”

(Mark’s partner, Timeline Recording, 2011: 3)

Whilst Elizabeth stands in order to forget her pain by concentrating on the pattern on her cross stitch, selecting different coloured wools and threading them through a needle and using the needle to complete various parts of the pattern, achieving comfort through the affective capacity of different material

items; it is Mark's standing frame and its supporting strap that hold him in the space and time of recovery, as he chooses to "get... up in the standing frame". However, the practice of sitting and not sitting in his chair for certain parts of his routine reflect times when Mark's agency has been taken away, for example, Mark must sit in his chair to make daily journeys to and from work (he wheels himself to the local offices not far from his home); to move around his home and work space; and to eat his meals. The agency involved in these **everyday practices** is limited, as the relationship between Mark's body-(wheel)chair is necessary in order to complete these tasks.

In summary, I have shown that it is the seemingly mundane activities, such as standing, sitting and lying down that produce these moments of comfort, through distraction therapy and everyday routines.

#### **7.4 Rhythmic recoveries**

This section focuses on the way rhythms (re)structure participants' routines in both daily and lifelong recoveries. Following Lefebvre I will use rhythm as a tool of analysis to explore "moments, cycles, tempo, repetition and difference" (Elden, 2009: 656) in the accounts of recovery expressed by six participants. These accounts highlight different rhythmic temporalities as participants' recoveries are made and (re)made through spatially- and temporally- based practices. Like Lefebvre I am interested in the historically bounded relationship between space and time. In my research this focuses on the conduct of medical practices and procedures, from institutional settings, such as the pain management clinic and the hospital, to the way that participant's translate similar medicalised practices at home, in non-institutional settings. However, while the "body serves us as a metronome" (Elden, 2004: xii) providing a regular beat and a place from which to conduct a rhythm analysis in Lefebvre's (2004) work, my empirical findings show that the 'disabled body' produces rhythms that are shaped by both regularity *and* discontinuity. Significantly, this is different to the body in Lefebvre's rhythm analysis, which is observed and analysed in relation to a capitalist framework, therefore the

temporalities expressed in Lefebvre's work are steeped in a language of norms and normal patterns of 'doing' daily routines.

In the two following sections I (re)present, discuss and analyse the temporalities of six participants' rhythmic recoveries using empirical material to providing accounts of the different, yet normal rhythms and patterns that constitute participants' daily and lifelong recoveries. Firstly, in section 7.4.1 '*Quotidian cycles, power relations and mundane activities*' I show that a range of temporalities frame participants constantly changing recoveries as Victoria, Robert and Sue (re)negotiate different relations of power in the process of becoming well. I show that three participant's bodily rhythms are punctuated by time 'waiting' and 'speeding up'. Secondly, in section 7.4.2 '*Becoming still*', I show that rhythms of 'pausing', 'slowing down' and taking the time to be 'still' do not take place in opposition or resistance to faster rhythms (Parkins, 2004); instead they provide an analysis of the 'pacing body', as Simon, Elizabeth, Victoria and Mark (re)negotiate new routines to suit the requirements of their changing bodies at home. While these temporalities are framed by a dialect of becoming still, other rhythms address becoming mobile, defining participants' stillness and mobility, as the relationship between the two unfolds through movement, flow, discontinuity, stopping, starting and slowing.

#### **7.4.1 Quotidian cycles, power relations and mundane activities**

In this section I contribute to the growing geographical literature on the spatialities and relationalities of power that shape the daily lives of women with chronic illnesses (Moss and Dyck, 1999, Crooks and Chouinard, 2006, Crooks et al., 2008). In doing so I argue that relationships of power are also bounded by different temporalities, which in turn shape the recoveries of three participants in my research. However, I add gendered and temporal accounts to this literature, as I discuss the spatially based practices of medical professionals and the encounters between 'patients' and 'practitioners' to show that bodies, space, time, power and practices are entangled with one another. While Victoria experiences 'waiting' time, as she recovers from an operation on her spine, both

Sue and Robert resist the structured time of medical professionals, taking control and 'speeding up' time. By addressing the spatial practices of medical professionals I use Simonsen's (2010) work to consider how "bodily doings and sayings...constitute meanings and identities and...establish social orders" (2010: 221).

### **'Waiting'**

Victoria begins to tell me about her personal history at the first chronic pain support group meeting that I attended, highlighting her role as an active person playing multiple sports, including badminton at county level. During the same conversation Victoria tells me that she had extremely good coordination, recognising that something is wrong when she begins to lose her coordination. Victoria sets out on a journey to find out what is happening to her body, making appointments to seek medical advice; however, in the process of this journey, Victoria describes multiple accounts of 'waiting'. The first account of waiting relates to a series of prolonged encounters with medical practitioners in various institutional settings, as Victoria recalls continual attempts on her own behalf to raise concerns about her health and well-being:

"I was going to the Doctor at [the] hospital *no one was taking much notice*"

(Victoria, Photovoice Discussion, 2011: 8)

Victoria's account is framed by a series of temporalities that are shaped by the biomedical model of disability; visiting her doctor's surgery, the hospital and a pain management clinic, in order to legitimate her feelings of becoming ill (Moss and Dyck, 1999, Crooks and Chouinard, 2006). Victoria is in her seventies and has spent the moments up until her diagnosis, without pain or injury, however, in the quote above, sounding resigned she emphasises that "no one was taking much notice of me", telling me she was sent for a MRI scan and later diagnosed with a life threatening condition. Acting upon this, a doctor at the hospital decides Victoria should have an emergency spinal operation, which takes place

less than a month after the diagnosis. By legitimating her chronic pain Victoria is seeking a label, a name, a diagnosis, so that she can justify feelings related to her physical loss of coordination, feeling empowered in the process of becoming well.

However, in the subsequent account of waiting Victoria is governed by the time imposed upon her through the tempo-spatial practices of medical professionals. In particular Victoria's account illustrates that encounters and rhythms within her own home are reinforced by traditional power structures (von Peter, 2010) that are usually assigned to medical spaces. Foucault's work on the disorder of maritime and military hospitals from the 17<sup>th</sup> Century onwards and on the surveillance of 'mental health patients' throughout the 19<sup>th</sup> and 20<sup>th</sup> Century is useful for understanding Victoria's bodily rhythms at home. In geographies of mental health Foucault's work is frequently used to discuss the spatialities of power relations in the (mental) hospital (Philo and Parr, 2003, Curtis et al., 2007), however, I argue that his claims provide significant historical insights into the temporalities of the hospital, which subsequently spill over into Victoria's home.

Firstly, Foucault's claims that the disorder that existed in the "hospital allowed its medicalisation" (Foucault et al., 2007: 148) and illustrates that as doctors began to adopt roles in treating and fixing injured soldiers the cost of recovery time and bringing soldiers back to health was a priority. Secondly, treatment and care regimes within the (mental) hospital have been repeated over time, reinforcing particular power structures that are bounded by specific space-time relations. The rhythms that are instilled within hospital spaces, including providing particular services at set times of the day as patients fit into the routines of medical professionals, including doctors, nurses and others, producing a particular social ordering. In the following example I show that Victoria's account of 'waiting' highlights the blurred boundaries "between what occurs inside and outside the hospital" (Curtis et al., 2007: 341).

“I came out of hospital after 24 hours, after an operation on the base of my spine and I could hardly move and I couldn’t go to the loo. I had to wait a week before they came to raise my loo”

(Victoria, Group Discussion, April 2011: 15).

The temporal rhythms of the hospital are informed by a regular beat as part of this social ordering, as appointment times and medical practices such as physiotherapy fit into a quotidian cycle. However, the temporal practices of the hospital extend into Victoria’s home when she returns after 24 hours following her operation. Crooks and Chouinard (2006: 347) highlight the way women with rheumatoid illnesses both “struggle to negotiate relationships of power” and feel disempowered either by spaces or places of health care in Canada, after becoming ill. While Victoria describes being in excruciating pain each time she tried to sit down to use the toilet seat, power is reinforced in Victoria’s account of *waiting* four days for her toilet seat to be adjusted to the correct height by medical professionals. For Lefebvre, Victoria’s body would be seen as the mode of analysis, as the relationship between Victoria’s spatial body and temporal body and others around her produce particular rhythms, as she is affected by “the bodily practices of the other” (Simonsen, 2010: 223). However, this case highlights the temporalised medical practices that shape Victoria’s rhythmic recovery at home rather than the predominantly expresses spatialities in Simonsen’s (ibid) account, as Victoria’s bodily rhythms, of going to the toilet, are interrupted as she is made to wait, pre-structuring her future (von Peter, 2010).

### **Speeding up**

In the following example, I show that Robert and Sue resist the temporal rhythms and quotidian cycles that are reinforced through medical practice, as they take control of their encounters with doctors and physiotherapists. As quotidian cycles highlight the “mundane in the everyday *and* the repetitive, or what happens everyday” (Elden, 2004), I discuss the rhythmic ordering of the



medicalised body by doctors, as Robert describes the time leading up to diagnosis of his multiple sclerosis. Robert is in his sixties and is a member of a locally based support group that I attended for a number of months where I chatted informally to men and women, building trust and rapport<sup>46</sup>. In Chapter 8: *'Becoming (un)comfortable'* I describe the research relationship that developed between myself and Robert, as well as the single visit I made to his home, despite multiple face-to-face encounters at the support group. In the following quote Robert explains the time leading up to his diagnosis, during our meeting at his home:

"I had a problem with my eyes and then I was going to [the] hospital for an hour or so but an appointment every three months, going regular".

(Robert, in conversation, 2011)

While Robert describes experiencing changes to his eyesight as he attends appointments that he must keep at regular intervals with the Doctor, who regulates his time, in the second quote Robert expresses a desire to take control, wanting to speed up time:

"Eventually, this Doctor said you need to see a Neurologist - I didn't even know what one was. I said, *'I'll pay to get to see somebody now...I'm not messing about, I will pay'* "

(Robert, in conversation, 2011, *original emphasis*)

The tone of Robert's voice changes as he is serious about 'paying', wishing to accelerate the 'normal', slower process that Robert presumably attaches to the

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<sup>46</sup> See Chapter 3: *'The temporalities of participatory engagement: An unfolding methodology'*, for a more detailed discussion of the relationships that developed with participants.

services offered through the National Health Service<sup>47</sup>. Whilst Robert's experience takes place within the last ten years, in the following account Sue begins to re-learn the materiality of her body once more. Sue demonstrates that she is keen to speed up her recovery following hip replacement surgery, in order to walk again:

“The main time in hospital is around going to physio and if you do not work at it, it takes longer to get out. So as time progressed I would wheel myself down to the physio and do my exercises going earlier and earlier so no one noticed and doing more time until someone did notice and then back to the ward”

(Sue, Diary Entry 2: Recovery and Time, 2011: 2).

In section 7.3.1 *'The bed'*, I discussed Sue and Mark's experiences of renegotiating a 'new' body in the space of the hospital, however, while they both provide an account of the everyday experiences and repetitive acts that shape medical practice, Sue and Mark's encounters with medical staff take place at different times. Sue's first hip replacement operation was conducted in the 1970s and Mark became spinally injured in the 1990s; together they provide a snapshot of the ongoing cycles that constitute everyday life in the hospital. Such repetitive cycles have instilled a particular rhythm or rhythmic ordering to medical procedures and treatments, which is still embraced by medical. However, Sue's account of speeding up time is shaped by past histories, in particular her childhood memories<sup>48</sup> of growing up on various hospital wards for children.

Sue's quote shows that she (re)negotiates the exercise regime set by her physiotherapist, resisting the rhythmic recoveries determined for her by

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<sup>47</sup> The National Health Service (NHS) provides certain free healthcare services for residents of the UK.

<sup>48</sup> While I provide a more in-depth empirical and theoretical discussion of Sue's memories in Chapter 11 *'Memories'*, it is important to highlight the significant role of her memories on her futures and the practices she carries out in future encounters.

wheeling herself down to the room intended for physiotherapy, 'going earlier and earlier' and 'doing more time'. However, the renegotiation of power relations in Sue account are not related to a straight forward power struggle between herself and the medical professional, as I illustrate in more detail in Chapter 11 '*Memories*', instead Sue recognises that "if you do not work at it, it takes longer to get out [of the hospital]". On the surface this quote appears to resonate with Sue's desire to get home more quickly, speeding up time by adopting her own rhythms, but at the time of this hip replacement Sue is married and since the hospital was her home from the age of 14 months to 14 years old, experiences of being away from home shaped the relations she built with her immediate family. Therefore, a more in-depth analysis suggests that her desire to 'get out' and return home are related to the close friendships she made with her husband.

In the following section I focus on the temporal rhythms that disabled people adopt in their routines, as they transition from the doctor's surgery, the hospital and the pain management clinic to the home. By doing so I demonstrate the importance of becoming still and slowing down, as four participants (re)structure both time and space in their daily routines.

#### **7.4.2 Becoming still: Pacing**

In this section I explore the different bodily rhythms that participants adopt as part of their daily routines, (re)producing their own rhythms in the process of becoming still. I use the word 'pacing' and 'pacing bodies' to refer to the relationship that each individual adopts as they restructure their daily routines, spacing and breaking up tasks and completing activities, which at times fall outside the circadian rhythms expressed in section 7.4.1. I use four participants' accounts to illustrate that Elizabeth, Victoria, Simon and Mark set their own pace, altering their daily rhythms to suit the way that they are feeling at that particular time. By exploring accounts of 'pausing' and 'slowing down' to 'movement and flow', I use Bissell and Fuller's (2011) work to connect all of these stories together, to show that:

“[M]etaphors of flow, liquidity, routes and complexity underscore a world that can no longer be squeezed into sedentary understandings of living”

(Bissell and Fuller, 2011: 3-4).

By addressing the relationship between the specific bodily rhythms of Elizabeth, Victoria, Simon and Mark, which are attached to diagnoses of disability and embodied identities, to the multiple ‘entanglements’ of bodies, material objects, places and relations with other people (Bissell, 2010) expressed in section 7.3 *‘Renegotiating ‘new’ bodies, ‘new’ activities and ‘new’ relations’*, I explore different ‘moments’ in participants’ rhythmic recoveries. As participants’ discuss habitual parts of their routine, I show that specific bodily rhythms shape ‘when’ certain activities take place, as participants express the rhythms and relations between stillness and movement. I suggest that while participants may be ‘sedentary’ (Bissell, 2008, Bissell and Fuller, 2011), ‘pausing’ and ‘slowing’ down in the process of becoming still, pausing is a form of stillness that is relative to movement. By exploring four accounts I move beyond the literature on resistant rhythms (Parkins, 2004) and normative accounts of the fast or slow rhythms of everyday life (Edensor, 2010b) to offer alternative accounts of rhythmic recoveries in (non)institutional settings.

### **‘Pausing’**

In the following accounts Simon, Elizabeth and Victoria indicate that patterns of sleeping and resting change from one day to the next in order to suit the requirements of their chronic pain. Using photographs, participants’ personal notes and snippets from multiple conversations I show that sleep as a rhythmic recovery produces synchronisation in the lives of disabled people as they temporarily alter their rhythms depending on how they are feeling. The

following quote from Victoria accompanies the photograph of her bed<sup>49</sup>, as she writes:

“[H]aving a terrible day of back pain - relief of frequent periods in respite lying down”

(Victoria, Photovoice notes, 2011).

While Victoria temporarily recovers using her bed for pain relief, Elizabeth uses her sofa for sleeping during the day either because sleep hasn't been possible at night, or because she has completed 'a bout of activity'. Yet, Simon discusses the way that he spaces up and 'pauses' tasks throughout the day, breaking up his daily routine by taking sleeping breaks, or lying on the sofa:

“When I was younger, say 35 years old, I would go out on a Saturday, out on the drink, down the town. The following day I would sit until 5 pm with my leg over the couch, because of the spondylitis”

(Simon, Photovoice discussion, 2011)

While pausing may be seen as a form of stillness that is relative to movement, pausing in this chapter challenges the role of sleep as a relative category to wakefulness and to sleep as a biological rhythm. As such I draw a connection between quotidian cycles and 'pausing', showing that temporalities of pausing relate to the alternative rhythms and patterns of sleeping in the recoveries of Simon, Elizabeth and Victoria. However, these examples illustrate a discontinuous pattern in participants' rhythmic recoveries challenging the biological rhythms of sleep (Elden, 2009) and quotidian cycles addressed in Lefebvre's (2004) work.

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<sup>49</sup> This photograph didn't develop, one of the challenges of using disposable cameras in photovoice.

There is an expectation that the act of sleeping should take place at a particular time of the day, following a set pattern and therefore situating sleeping as a normed account (Williams and Crossley, 2008, Meadows, 2010). While I have emphasised the difference between gendered, ageing and life course sleeping patterns (Meadows and Arber, 2012, Venn et al., 2012), there has been a limited consideration of the relationship of sleeping to well-being, other than the recommended number of hours sleep. Horton and Kraftl (2008) refer to the 'spaces of every-night life', discussing the association of a lack of sleep with physical and emotional geographies of ill-health (Driver and Shapiro, 1993); highlighting the rhythms and routines of sleeping and waking; as well as, the importance of embodied accounts of sleeping. However, by exploring possible directions for geographies of sleep, sleeping and sleepiness, the authors reproduce normative accounts of sleeping with 'anti-normative or anti-social' (Kraftl and Horton, 2008: 518) inabilities, despite acknowledging different cultures of sleeping, including the way that children learn 'when' to sleep.

Yet the accounts given by participants highlight the importance of alternative sleeping patterns that exist outside of circadian and normative rhythms and contribute to the process of becoming well. However, as a practice of becoming still, Victoria, Elizabeth and Simon's 'moments of pausing', reinforces Meadows (2010: 90) work, showing that the "eight hour sleeping block is indicative of the social organisation of life and work... [as] sleep is a performed social act". Meadows work on insomnia and daily rhythms is relevant to sleeping. He suggests that the insomnia despite adopting a rhythm that falls outside the cosmic rhythm of "circadian alterations between day and night" (2010: 88) where capitalist temporalities reinforce 'falling asleep' and 'awakening' at particular times, the insomniac is left with no other choice but to try and squeeze into a pattern or routine that does not accommodate him<sup>50</sup>. Like Meadows (2010) story of insomnia, Victoria, Elizabeth and Simon's accounts also

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<sup>50</sup> By referring to 'him', I am following Meadows discussion of one of the characters from *Withnail and I*, rather than implying a gendered and/or masculine terminology.

disrupt the concept of a normal cycle of activities that take place for a particular amount of time, at a particular time of the day.

### **'Slowing down'**



**Figure 7.4.2.1: Simon's utility room**

Simon's account of 'slowing down' highlights a deceptively straightforward activity (Hansen and Philo, 2007), standing, in order to demonstrate the complexities involved in standing. Rather than accepting standing as an ability or act of being 'able' to stand, 'slowing down' is more concerned with what is happening as part of a process of becoming still, when Simon is standing. Figure 7.4.2.1 is a photograph that was taken by Simon, as part of a photo voice activity that three members of a chronic pain support group completed, aiming to capture representations of living with pain on a day-to-day basis. The photograph was taken using a disposable camera and therefore the first time Simon views the image is during the subsequent workshop, saying:

“This is a photo of the utility room...leaning on a window. I can be still there for 2 hours doing nothing”

(Simon, photovoice , 2011).

Simon is in his fifties and he tells me about a series of events that began when he was in his early twenties and may have contributed to his back pain, leading to spondylitis. The photograph and quotation both illustrate that Simon’s time spent standing involves a relationship between his body and the windowsill he leans on; ‘doing nothing’ in the process of recovery. Simon’s body-windowsill relationship produces an interaction that Simon chooses as he leans on the windowsill producing a temporary relationship that finishes when he feels better or his back doesn’t ache as much. While Simon determines the frequency and the length of time he engages in this activity as part of his routine, producing particular rhythms of becoming still, for Mark, a spinally cord injured man, standing is an activity that contributes to Mark’s exercise routine when he uses a standing frame for one hour. Both activities have different affective and temporal capacities, resonating with the theoretical and empirical material discussed in section 7.3. Significantly, it is Simon who positions himself within the space between the windowsill, ‘doing nothing’, ‘leaning’ and subsequently slowing down. However, as Mark’s bodily rhythms are (re)produced through a series of different body-object relations, his movements and flows shift between becoming still and becoming mobile, which is explored in more detail in Chapter 9.

To summarise, in this chapter I have demonstrated that disabled people’s time is restructured in a number of ways, as they experience the unfolding process of recovery. Becoming well is the concept used in this thesis to illustrate the open-ended process of recovery, which takes place through everyday and lifelong practices. Significantly, this is different to the concept of well-being, which implies reaching a final point and recovering, which, I argue, is not possible and instead participants experience the temporalities of recovery.



Firstly, participants' bodily and spatial boundaries are important as they (re)learn and (re)negotiate the materiality of their new bodies. Secondly, the affective capacity of material items, such as sofas, shoes, sticks and back stretchers, (re)produces moments or temporalities of comfort. As participants forget their pain, it is the 'placelessness' of affective worlds that matter. However, place and material boundaries also matter as new relationships develop when other participant's return 'home' following surgery, temporarily adjusting the fabric of and familial relations in their homes.

Thirdly, recovery is punctuated by 'moments' of pausing, slowing down and taking the time to be still, the relationship between stillness and mobilities unfolds through movement, flow, discontinuity, stopping, starting and slowing. These individual moments come together producing specific rhythms, which alter to suit the requirements of participants changing bodies. In doing so, participants rhythms challenge the 'norms' surrounding the 'day'- and 'night'-time, as practices such as sleeping, standing, sitting and lying down, happen as and when they are necessary, rather than at fixed times in a routine.

In the next chapter, I explore the role of 'talking' as a participatory method, showing that the multiplicity and fluidity of different conversations shaped the entire research process.

## Chapter 8: Becoming (un)comfortable

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In this third mini-methodology chapter I focus on the role of ‘talking’, which in the social sciences frequently focuses on qualitative interviewing, a method that is used with individual participants. While all of the methods employed in this project involved participants contributing verbal accounts, from drawing timelines and adding to photovoice, to the process of writing a diary and talking on a one-to-one basis, in the remainder of this chapter I use Gibson-Graham’s reference to ‘conversations’. This addresses the ephemeral basis of conversations and of participants’ lived experiences, illustrating the temporality of the research encounter. Therefore, this chapter is less about the specific structure of one-to-one exchanges that took place within a fixed timeframe and more about ways to move beyond the space-time of a qualitative interview.

I show that conversations enabled methodological and empirical insights to unfold, and highlight the importance of materiality to the research encounter. Methodologically, this is illustrated by the concept of becoming (un)comfortable, as I demonstrate how the materiality of participants’ homes and of items such as a Dictaphone can potentially change the type of exchange that takes place. In Chapter 5: *‘Becoming emotional’* my understanding of the importance of some of these materialities was aided by visiting Mark’s home, while in Chapter 7: *‘Becoming well: A geography of recovery’* I discussed participants varying interactions with material objects in their daily and lifelong recoveries through photovoice. However, in this methodological chapter I provide an introduction to the empirical material that is discussed in Chapter 9: *‘Becoming Mobile’*, which zooms into the daily mobilities of participants and the rhythms of moving and walking across the life course.

Using a feminist methodology I show that issues such as reflexivity, positionality and power relations are intertwined and that shifting power relations may result in moments where those involved in the research become

(un)comfortable. Using the concept of becoming (un)comfortable I demonstrate my awareness of the similarities and differences that took place with Steve, Robert, Hannah and Mark during exchanges in their homes. However, becoming (un)comfortable also highlights the emotional exchanges that take place when participants reveal in-depth information regarding their lived experiences (Laurier and Parr, 2000, Bondi, 2003, McDowell, 2010), as was often the case when talking to people about disability, health, illness, impairment and chronic pain. Finally, I highlight the varying degrees of participation that took place throughout these conversations, which produced various discussions relating to 'action'.

### **8.1 Conversations: The fluidity of research encounters**

While I use Gibson-Graham's (1994) reference to conversations as I discuss participants' contributions to the research through talking, many of the feminist geographers whose work I draw on refer to qualitative interviewing, the interviewee and the interviewer (Valentine, 2002, Bondi, 2003). However, by addressing feminist practices such as reflexivity and positionality, within a participatory framework 'conversations' more readily describes the fluidity of encounters that took place both within and beyond the space-time of an interview. A large proportion of my time 'doing' research was spent listening to people talk, whether this was over the phone, at support group meetings, on the other side of a living room or across the table following a meal.

A qualitative interview is an encounter that is fixed in space and time, despite the fluidity of the relationships that take place in that space-time. Valentine's (2002) work suggests "we are constantly (re)producing ourselves so that both researcher and interviewee may be multiply positioned through the course of the interview". However, as I built relationships with participants over 14 months of fieldwork, my research allows me to draw insights into the temporalities of these positionings, and the roles and relationships that develop over the course of multiple research encounters. This addresses positionality, a fundamental issue in feminist geography, which is attentive to the possibility of

different perspectives or positions that exist in the world, including how these different positions shape the world we live in. Therefore, both my own positioning and that of the participants moved fluidly between different encounters in different space-times, but also within the same space-time of conversations, rather than just as and when the 'interview' was taking place.

Gatenby and Humphries (2000) suggest that 'research by correspondence', including photographs, letters and questionnaires sent by Maori participants in their feminist participatory project, resulted in individual files that developed "to specifically suit the uniqueness of [each participant's] life, more than a questionnaire alone or perhaps even an unstructured interview could" (Gatenby and Humphries, 2000: 5-6). However, in my participatory project each participant made choices about the methods they felt comfortable with completing, and for some this just involved talking. I had met Steve and Robert on multiple occasions over a period of months at a support group building up trust and familiarity, whilst I only had one encounter with Hannah prior to talking to her at home. In the next section I show that by choosing to talk at home, Robert performed a very different identity to the one he frequently adopted at the support group where I usually met him to talk as part of a group.

## **8.2 Becoming (un)comfortable**

By immersing myself into the research encounter, becoming (un)comfortable reflects on the role of different materialities, as Robert's level of comfort varied throughout our conversations at his home. Although I use examples from my encounter with Robert, the materiality of participants homes also meant that Hannah, adopted her normal rhythms and fell asleep during our conversation; Steve talked non-stop but at times made me feel uncomfortable; and Mark joked about his disability, showing me his 'party trick' on my second or third visit to his family home.

As a participatory researcher my knowledge of the importance of materialities was shaped by "interrogat[ing] the dialectic between our

understanding of the world, and the ways in which those understandings are themselves materially embedded” (Jenkins et al., 2003: 59). By reflecting on my exchanges with participants at different stages throughout the research I began to think about the role of power relations. While feminist methodologies aim to destabilise power relations between the researcher and participants, McDowell (2010: 156) suggests that “[r]elations of power and authority affect the nature of [interview] exchanges”. So while I felt that I knew Robert’s personality and was expecting him to perform the friendly joker that he usually did, Robert surprised me, as he was quieter, appeared more submissive and our entire conversation only lasted about 20 minutes. After arranging to meet at Robert’s home it wasn’t that he appeared uncomfortable in his environment, but perhaps he was more uncomfortable with the topic of conversation, revealing private and personal details about his neurological diagnosis and relapses of Multiple Sclerosis.

Although I was using a ‘relational participatory ethics of care’ throughout the research process, the materiality of certain items may have shaped Robert’s feelings during our exchanges. This was the first time that Robert had signed a consent form, as this was the first time that Robert had agreed to get involved further; on the other occasions we had spoken at the group sharing stories and talking about the activities that were organised for the men. Laurier and Parr (2000) caution:

“[g]iven the powerful and often medicalised interpretations of emotional states and performances, to which many people experiencing illness or embodying impairment may be subject to, researchers need to be careful of ‘emotional analyses’ within and beyond the interview”

(Laurier and Parr, 2000: 100)

I show that shifting power relations helped Robert to become (more) comfortable, and exchanges with other participants provided the context that shaped my ‘emotional analysis’ of the conversation that took place with Robert.

After arriving at Robert's home, he made a hot drink for both of us and we sat at a small table in front of a bay window at the back of his house overlooking the garden. We began talking after I explained the purpose of the consent form and asked for permission to record our exchange electronically; Robert agreed. During the recording we talked about Robert's life, including his garden, his wife and his grandchildren, as well as his diagnosis of MS and the difficulties he was facing not being able to drive, as a result of his illness at that moment. However, wrapping up the conversation and signalling that our talking was over (for now), Robert concluded our conversation with a story about a family holiday, saying:

"Come on then, shall I show you the garden?"

(Robert, in conversation, 2011)

Feminist methodologies highlight the potential to share more equal exchanges with participants, which can "validate the participant more fully as a knower" (Falconer Al-Hindi and Kawabata, 2002: 114). Yet, this may produce a shift in power relations, resulting in moments where those involved in the research become (un)comfortable. Once the Dictaphone was switched off Robert and I walked up the garden, which was broken into sections and divided by fences, before finally ending and backing onto open parkland. It is here that I learned more about Robert, as he spoke about sitting in his garden, relaxing in his favourite chair, a wooden bench shaped like a cartwheel with two curved seats - and it was very comfortable. As we walked into the garden in our movements away from the house, the consent form and the Dictaphone, the nature of the exchange that was taking place changed.

It was only after this exchange had taken place that I was able to reflect on the significance of the material items used in research, the temporality of Robert's feelings, and the way the conversation began to flow more fluidly as Robert adopted more of a role of authority (McDowell, 2010). Acts such as offering consent by signing the paper, providing in-depth accounts of personal

experiences that are being digitally recorded and taken away to be re-played and re-considered may have positioned me in a powerful role. However, at a later stage and in a different space-time I learned that Robert was experiencing a relapse<sup>51</sup>, a particularly emotional time where he couldn't drive and was missing out on activities with other men at the group and attending group physiotherapy sessions. However, becoming (un)comfortable also demonstrates the mixed feelings that were taking place as Mark, a spinally injured adult decided to show me his 'party trick' on the second visit to his home.

Mark was first introduced in Chapter 5, as I discussed the process of completing a day-in-the-life-of style timeline with Mark. However, on this occasion as Mark began leaning forward in his chair, I gasped thinking he was going to fall out, when at last minute he caught the sides of his wheelchair and sat up. Mark and his partner both giggled at his performance, but I didn't know how to respond. I was partially embarrassed, blushing as I wanted to laugh and join in, yet I was still caught in between, in a moment of shock, wondering what had happened, while they had clearly experienced this before. However, laughter was also present in other methodological encounters, including the chronic pain support group, where members laughed at their own experiences of pain or shared laughter regarding a shared or similar experience.

Davidson (2001b) explores humour<sup>52</sup> in her own work with participants at a self-help group for diagnosed agoraphobics in Scotland to “illustrate the manner in which the communicative distance between researcher and researched is brokered through group dynamics” (ibid, p.166). Davidson's feminist methodology is attentive to working within a close support network prior to, during and after talking to participants at a self-help group by “approaching local and physically situated groups” (ibid, p. 165). But, at times she is left feeling ‘out of place’ (Kitchin, 1998) at moments when certain jokes are shared and she is made to feel like an ‘outsider’. However, the group dynamics at

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<sup>51</sup> See Chapter 5: ‘*Becoming emotional*’ for a more detailed discussion of two participants’ experiences of relapse and multiple sclerosis.

<sup>52</sup> Although see Macpherson (2007) for an account of the role of laughter with blind and visually impaired walking groups.

the chronic pain group were different and I felt that participants shared funny stories as a way to include me rather than to exclude me from the group.

However, by giving participants their own roles as knowledge producers the textual analysis of conversations, involved giving 'material' back to the participants, so that conversations continued to flow beyond the moment the Dictaphone<sup>53</sup> was switched off. Conversations were used as part of textual analysis from the audio recordings taken whilst drawing timelines and during the post-photovoice discussion at Elizabeth's home, to the more structured conversations at participants' homes.

In the next chapter, I discuss the different practices that participants undertake in the process of becoming mobile.

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<sup>53</sup> A Dictaphone was only used to record some conversations and not others.



## Chapter 9: Becoming mobile

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### 9.1 Differently mobile bodies

In this third empirical chapter, I continue to draw on the mundane and banal activities discussed by participants in Chapter 7: *'Becoming well: A geography of recovery'*, to show that like everyday practices of sleeping, standing and sitting, moving and movement practices are also encased in a discourse of normalcy. As with other chapters in this thesis, I draw from the notion of becoming, arguing that the process of 'becoming mobile' involves a range of types, styles, cultures and rhythms of movement and moving that are not fixed but unfold and emerge through participants' daily and lifelong recoveries. In particular I tease out the different ways that participants' engage in various modes or methods of moving by focusing on the temporalities of walking, wheeling and limping. I follow Andrews *et al.*'s call for critical health geographers' "deeper engagement with movement activities" (2012: 1926), showing that the complexities of walking, wheeling and limping go unnoticed because normal modes of moving and movement take precedence.

Using conversations<sup>54</sup> with Mark, Victoria and Elizabeth and written extracts taken from Sue's personal diary reflections<sup>55</sup>, I demonstrate the often 'hidden' and overlooked aspects of movement and moving. In the remainder of this chapter I explore the concept of 'becoming mobile', addressing the unfolding nature of participants' movements and supporting a conceptual shift from the fixed and bounded notion of mobility and movements (Urry, 2002, Cresswell, 2011), towards the:

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<sup>54</sup> The importance of 'conversations' are discussed in Chapter 8: *'Becoming (un)comfortable'*.

<sup>55</sup> See Chapter 10: *Diary 'writing'* for a more detailed discussion.

“networks of people, ideas and things moving, rather than in inhabitation of a shared space such as a region or nation state”

(Cresswell, 2011: 551)

I discuss the importance of relations between participants’ bodies and the objects or ‘things’ used in the process of becoming mobile, highlighting the fluid and temporal ‘networks’ of ‘differently mobile bodies’. I use the term ‘differently mobile bodies’ to explore Mark and Sue’s movement activities, illustrating the ‘normality of doing things differently’ (Hansen and Philo, 2007: 493) and building on the relationships between stillness and mobility outlined in Chapter 7.

## **9.2 Hidden mobilities**

In this section I use Sue and Victoria’s accounts to show that participants’ engage in various modes or methods of moving, as particular types and styles of ‘walking’ reflect participants’ different bodily movements through space. I argue that disabled people’s mobilities are hidden in two separate and interconnected ways. Firstly, I address what happens ‘in-between’ when participants move from A to B (Spinney, 2009, Cresswell, 2010, Middleton, 2010, 2011) and become mobile. I uncover the complexities of these ‘in-between’ and hidden mobilities by exploring the different body parts (feet, hands) and things (wheels, shoes, sticks and frames) that are used in the process of becoming mobile. By focusing on ‘everyday practices of walking’ and ‘temporalities of rehabilitation’, I show that the daily and lifelong movement practices of differently mobile bodies remain unexplored in the mobilities literature (Lorimer, 2011). Secondly, it is by using empirical material that I tease out the way that the walking and movement practices of disabled people are hidden from view in the literature. I argue that the complexities of walking go unnoticed because “fragile entanglement[s] of physical movement, representations and practices” (Cresswell, 2010: 160) privilege normal modes of moving and movement.

In identifying the various ways that people and things move, how movement takes place and by which modes, a more detailed exploration reveals that a certain kind of able-bodied mobility dominates the mobilities literature. Geographers such as Imrie (1996b, 2004) and Kitchin (1998) have explored exclusionary spaces, considering who uses and moves through the built environments by focusing on physical disability and access. Feminist geographers have addressed landscape and gender (Rose, 1993), mobility, belonging and race (Tolia-Kelly, 2004, 2006), as well as, well-being and ageing (Schwanen and Ziegler, 2011, Ziegler and Schwanen, 2011). Yet these areas of research reinforce movement from one place to another, ignoring what happens in-between (Spinney, 2009, Cresswell, 2010, Middleton, 2010, 2011). In the following two sections I demonstrate the intricate relations that take place between bodies and ‘things moving’ in the process of becoming mobile. In section 10.2.1 *‘Everyday practices of walking’* I explore Victoria’s daily mobilities in relation to her chronic pain and in section 10.2.2 *‘Temporalities of rehabilitation’* I explore Sue’s lifelong mobilities in relation to multiple hip replacements and learning to walk following medical operations.

### **9.2.1 Everyday practices of walking**

In the Chapter 7: *‘Becoming well: A geography of recovery’*, Victoria recounts her journey with chronic pain, from recognising changes to her body and attending multiple appointments with medical professionals to her diagnosis of chronic pain and emergency surgery on her spine five years ago. The diagnosis and operation have subsequently changed Victoria’s daily mobilities and her walking practices. In Victoria’s photovoice notes she describes using things such as her NHS shoes and a stick, which both ‘facilitate walking’, a movement activity that she completes on a daily basis with her dog Barney<sup>56</sup>, who “ensures that I take exercise” (Victoria, photovoice notes, April 2011). While Lorimer describes the way that:

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<sup>56</sup> A pseudonym.

“new ‘walking studies’ have focused attention on what might be considered the founding, or constituent, elements of this most basic of human activities, namely: the *walk*, as an event; the *walker*, as a human subject; and, *walking*, as an embodied act”

(Lorimer, 2011: 19).

Victoria’s account of her daily mobilities demonstrates the relationship between the ‘walker’ as more than just ‘a human subject’ as she discusses her shoes, stick and dog, as well as the way that ‘walking’ as an act may be embodied differently in relation to chronic pain. The idea of the walker as more than just a human subject is explored in Wylie (2002; 2005) and Macpherson’s (2007, 2008, 2009a) work, as they each consider the body-landscape relations of the walk, the walker and walking. Using non-representational theories both authors aim to understand how different bodies interact in rural environments by addressing walking as an activity, from Wylie’s personal account of his own walking practices to Macpherson’s exploration of the experiences of blind and visually impaired walkers, when she acts as a sighted guide.

Wylie (2002) provides an account of ascending Glastonbury Tor, where a day out walking with various companions appears to lend itself to a romanticised version of walking in the countryside. The identity of Wylie’s companions is never revealed and despite the embodied practices it sets out to explore, gender, age, ethnicity and (dis)ability remain unknown. In the end I argue that Wylie’s account, like others in the walking literature *feels* both disembodied and disconnected from the broader relations between self and landscape that he hopes to achieve. Focusing on a single day walking, alone, Wylie suggests that it is not his intention to address:

“questions such as who walks, or why ... [but] [t]he accent is thus upon specific walking corporealities and sensibilities: moments, movements, events”

(Wylie, 2005: 236).

However, in attuning to the self, the ‘moments, movements and events’ that Wylie champions disregards the very diversities of walking corporealities of the body, suggesting that an intrinsic connection to embodiment or being embodied through walking is a false distinction. By ignoring the complexities of walking in relation to other walkers, human geographies of ‘walking corporealities and sensibilities’ (Wylie, 2005: 236) emphasise able-bodied mobilities.

On the other hand, Macpherson (2009b) uses innovative methodologies to learn about the embodied and haptic experiences of blind and visually impaired walkers in the countryside. Acting as a sighted guide while participants navigate their way in specialist walking groups, Macpherson engages in close proximity to the walking experiences of her participants, using mobile methods to understand the movements of these walkers through “relations between sighted guide and walker” (2008: 1080). This work pays closer attention to the movements of visually impaired walkers, understanding the relationship between bodies and the rural environments they move in and through. Macpherson’s work reinforces the specific organisation of walking practices through ‘the walk as an event’ (Lorimer, 2011) emphasising the importance of other types of walkers (Oliver, 1993). Yet while there are noticeable exceptions (Macpherson, 2009a, Andrews et al., 2012, Imrie, 2012) normalised accounts of walking continue to focus on the *ability* to walk normally. In this sense walking is represented as a mundane practice that is carried out by ‘fit’ and ‘healthy’ individuals (Solnit, 2001, Wylie, 2002, 2005, Ingold and Vergunst, 2008, Edensor, 2010c).

While I did not go out walking with participants, different conversations uncovered the hidden aspects of becoming mobile, as the following exchange took place between Victoria and Elizabeth as part of a photovoice discussion group:

**Elizabeth:** “It’s horrible in a wheelchair; the way people look at you; it’s just horrible”

**Victoria:** “The first time I was thinking I was looking *normal*, someone said to me, shall I go and get you a chair!”

(Photovoice Group Discussion, May 2011, *my emphasis*).

At this point in the conversation Victoria, Elizabeth and Simon all laugh together in recognition of similar or shared experiences, emphasising the emotionality of differently mobile bodies. In this section I have provided brief examples of participants experiences of becoming mobile, showing that participants walking corporealities are integral to rather than divorced from Wylie’s questions concerning ‘who walks, and why’, challenging normalised accounts of the ‘walk’, the ‘walker’ and ‘walking’ that are reinforced through cultural geographies (Lorimer, 2011). I continue to explore participants’ differently mobile bodies, adding to the “multiple ways different bodies move and inhabit urban and rural environments” (Andrews et al., 2012: 1927, Colls and Evans, 2012), as I explore Mark’s account of wheeling in section 10.3: ‘*Cultural styles of moving and movement*’. However, in the following section I explore Sue’s lifelong mobilities, showing that her ‘walking history’ is threaded together by a complex web of differently embodied walking practices, each one distinguished by different relations and different temporalities.

### 9.2.2 Temporalities of rehabilitation

Walking and lifelong mobilities form a central and defining part of Sue’s accounts, as she discusses the emotionality of ‘walking normally’ and ‘falling’, as

well as renegotiating bodily boundaries and relearning mundane practices such as walking in the temporalities of recovery (chapter 7). In this section I show that over the last 60 years Sue's Congenital Dislocation of both Hips and the role of medical practitioners have shaped what happens in-between (Spinney, 2009, Cresswell, 2010, Middleton, 2010, 2011) as I illustrate the process of becoming mobile. However, in the early stages of getting to know Sue she goes produces a participatory timeline (chapter 4) of her life and in the process explains her medical operations. From her first cup replacement at the age of two, a pin and plate (the original hip replacement method) at the age of 11 and a total of eight hip replacements, seven on her left leg and one on her right leg in the last 40 years; the first full hip replacement at the age of 20. While this list of operations may appear exhaustive it does not express the intricate relations between Sue's body and the 'things' used as part of the recovery or rehabilitation process.

In Chapter 7 I demonstrated the way that certain temporalities of stillness may shape participants recoveries, in particular drawing on Sue's accounts of lying down in hospital bed in the process of becoming well. However, in this section I explore the complex temporalities of rehabilitation as I show that Sue experiences different types of walking, using different 'things' in the process of becoming mobile. The style of Sue's shoes provides one example of the hidden mobilities and complex temporalities of rehabilitation that shape her walking practices:

"Whenever I needed new shoes they had to be built up ... It meant that shoes had to be bought at least a month before they were needed as they took 2-3 weeks...

They had to be up to the ankle and with shoelaces, as wood was used then and this type of shoe was the only one that would secure it to your foot.

Later cork was used but the type of shoe bought for me never changed until I was 16"

(Sue, Diary Entry 2, Recovery and Time, 2011)

In the account above Sue describes the moments prior to her first full hip replacement when she had shoes 'built up...until [she] was 16' and Victoria's account of her NHS shoes (chapter 7) they were designed for walking in a specific way, walking normally. In the following quote Oliver (1993) argues that the role of medical practitioners is to encourage 'patients' to walk 'normally', stating:

“Rehabilitation constructs the concept of walking uncritically in that it is never analysed or discussed except in technical terms – what surgical operations can we perform, what aids can we provide and what practices can we use to restore the function of walking”

(Oliver, 1993: 15).

In discussing 'the functioning of walking' Oliver's (1993) account reinforces the normalcy of walking her second diary entry, '*Recovery and Time*'.

Using my empirical material I have shown how participants' stories challenge the assumptions that are made about types of walkers, the way bodies move through space and the parts of the body that are used for walking. I provide a more detailed account of the literature that privileges people's movements by foot (Ingold, 2004, Wylie, 2002, 2005, MacPherson, 2007, 2008, 2009a, Middleton, 2010, 2011)

### **9.3 Cultural styles of moving and movement**

In this section, I show that the 'inhabitation of shared space', while overlooked in the mobilities literature, contributes towards specific histories and cultures of walking, shaping the acceptance of dominant forms of 'moving normally'. I demonstrate the complex rhythms that unfold as Mark wheels through everyday spaces in his wheelchair, as I explore the way that certain practices of mobility, including moving and walking normally have become established over time.



I show paradoxically how on the one hand, a spinally injured participant moves through space with “regular, normative rhythms” (Edensor, 2010a: 4), while his wheelchair is simultaneously marked by its difference as a cultural symbol of disability (Oliver, 1993). However, these rhythms of wheeling also connect to the previous section on the role of mediating technologies to show how the same spinally injured participant uses his hands and wheelchair to pass and move through space. In this example Mark re-materialises his wheelchair, making adjustments for different types of walking or wheeling, challenging the (ir)regular rhythms of walking (Edensor, 2010c, 2010a).

The cultural styles and rhythms of walking draws on the literature to develop a critical analysis of the normalised accounts of walkers and their bodily movements, addressing the gait, speed, pace and breathing of walkers. By locating walking in the city and engaging with the “often neglected, everyday experiences of urban pedestrians”(Middleton, 2010: 582), Middleton provides an interesting account of participants’ embodied experiences as multi-sensory. Participants’ diary entries contain reflective descriptions of walking in urban environments, from the rhythmic ‘momentum’ (p.583) of one participant whose “awareness of his body waxes and wanes” (p.584), to the ‘quiet’ (p.585) sounds of walking on a Sunday. The multiple relationships between those walking in or through the same urban spaces are used to understand walking “as a set of translations and a process in, or of, itself” (Middleton, 2010: 590).

“Auto-disabling spaces are reflective of oppressive social norms, beliefs, and values that seek to prioritise the movement and fluidity of the mobile body, or the body responsive to, and (able to be) interactive with, the flows and rhythms of the motor vehicle”

(Imrie, 2012: 2265).

Imrie uses this description of auto-disabling environments to explore the disembodied design practices of urban policy makers, who draw from fixed

identities ignoring “the complexities relating to the multiple embodiments of space, and the fluid, crosscutting identities of those that inhabit the built environment”(Imrie, 2012: 2266). Using the example of ‘shared space’, where pedestrians and motor vehicles rely upon the behaviour of individuals’ to navigate through urban space, Imrie argues that without visual clues such as tactile pavements and dropped curbs the environment becomes auto-disabling for blind and visually impaired users. By ‘prioritising the movement and fluidity of the mobile body [with] the flows and rhythms of the motor vehicle’ (ibid), Imrie’s discussion of auto-cultures, emphasises the acceptance of a cultural norm over time.

These cultural norms also extend to the “styles and cultural values of walking” expressed by Edensor (2010a), where the fluidity of the mobile body (Imrie, 2012) emphasises the ‘regular’ practices of walking:

“[A]n irreducibly social and cultural practice that is learned, regulated, stylised, communicative and productive of culturally orientated experiences”

(Edensor, 2010a: 74).

The ‘culturally orientated experiences’ of different types of walking and/or walkers addresses the rhythms and sequences of walking that are marked by a particular energy. This energy is framed by the intensity of movement, the ability to move intensely or with the potential to speed up and highlights slower rhythms, such as ‘loitering and dawdling’ as suspicious. These energies and rhythms emphasise the body of the walker, privileging “movements on foot” (Middleton, 2010: 585). While Macpherson addresses the embodiment of visually impaired walking considering the ‘other’ ways that people move through the landscape, her research findings show that participants’ are ‘thinking through the feet’ (2009a). In other research contexts (Wylie, 2002, 2005) this notion of moving on foot is problematic as the following quote highlights:

“We must, therefore, be wary of accounts of walking which continually ground understanding in a normative able body and assume that we will all be able to walk and be able to walk in the same ways”.

(MacPherson, 2007: 64)

However, while a certain rhythm, flow or speed is often acknowledged in accounts of the ‘normative able body’, one participant’s movements in his wheelchair shows paradoxically how at times the speed or pace of moving is not so different. Mark is spinally injured and has been a wheelchair user for 10 years and his movement practices might be seen by the way he flows between spaces, moving with a consistency and at times smoothness that is similar to other kinds of wheeling, including cars and bicycles. This type of movement reflects the regularity that Edensor highlights, however, it is also marked by its difference as a cultural symbol of disability. This brief exploration of Mark’s daily movements contributes to the mobilities literature by expanding on research that addresses the ‘wheels’ of cars (Merriman, 2009) and bicycles (Spinney, 2009) to consider the importance of wheel(chairs) and the concept of ‘wheeling’ as a cultural style of walking. Furthermore, Imrie’s (2012) work on auto-disabling environments emphasises the acceptance of certain cultures of moving and movement.

To conclude, in this chapter I have shown that the temporalities of walking, wheeling and limping express different mobilities, flows and fluidities, as I show that participants’ differently mobile bodies are marked by synchronicity, repetition and rhythm. Firstly, using participants’ accounts I provided a critical analysis of ‘walking’, showing that ‘moving normally’ is championed over other forms and practices of movement; challenging assumptions about how, when, where and by which modes people move. I offered a glimpse of the way Sue and Mark’s differently mobile bodies move in daily life and through lifelong recoveries, showing that ‘hidden’ aspects of moving are visible yet ignored. I demonstrated that feet, hands, wheels, shoes, sticks and frames help participants to become mobile, yet disabled people’s daily

movements and mobilities continue to be excluded or under-represented in geographical accounts.

Secondly, by focusing on the rhythms of walking, I suggested that 'wheeling' and 'limping' may be conceptualised as another form or cultural style of walking (Edensor, 2010c). Various practices of walking reflect a 'culture of acceptance', as movements of a particular mode or style become established as normal and ingrained within history, society and rehabilitation practices (Oliver, 1993). While disabled people's movements are often visibly marked through their differences, Mark's account illustrates the paradoxical nature of moving smoothly and fluidly through space, on the one hand, using 'normal' rhythms, whilst simultaneously reproducing and representing disability through the materiality of his wheelchair.

In the next chapter, I discuss the messiness of remembering, as I explore the methodological process that developed when one participant decide to 'write' about her memories.

## Chapter 10: Diary 'writing'

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In this fourth and final mini-methodology chapter I focus on the role of keeping a diary, which is still a relatively underused qualitative method in the social sciences and geography (Meth, 2003, Milligan, 2005a, Milligan et al., 2005, Latham, 2003, Worth, 2009a). The decision to write a diary was made by one participant, Sue, and developed following the use of other methods, including conversations and drawing a timeline. My aim is to show, firstly, that when used within a feminist and participatory methodology, writing a diary put Sue in control as she produced a mixture of solicited (directed) and private (self directed) diary entries. This illustrates her degree of participation in the research process, as I demonstrate that 'action' can take place at a small scale, involving personal change (Cahill, 2007a). Secondly, I show that in my research writing a diary moves beyond the idea of recording actions as they happen in sequence, either as chronological day-to-day log of events (Worth, 2009a) or as a longitudinal account of events that take place over a specified amount of time (Meth, 2003). Using Sue's accounts I explore the temporalities of diary writing, illustrating the methodological and empirical importance of writing, which enabled Sue to retrospectively look into her past from her position at the time of writing (April 2011 - October 2011), as she discusses the significance of memories to her lived experiences of Congenital Dislocation of both Hips (CDH).

In the remainder of the chapter, I explore the methodological process that developed with Sue as she completed diary entries based on her memories across the life course. I show that the significance of 'memories' unfolded as an empirical theme, as Sue explicitly states that the purpose of writing a diary was to instigate change. Sue's diary entries provide the context for Chapter 11: *'Memories'*, which explores the role of time in relation to memory, using Sue's memories from the last 60 years of her life to show that time stretches, expands, shrinks and unfolds, as memories are recalled and remembered differently on each occasion.

## 10.1 Challenging memories

Diaries have been used in geographical research to varying degrees but largely as a way to capture the research process through personal diary reflections or as a means to record ethnographies including “daily activities and bodily practices” (Thomas, 2007: 76). However, in this section I highlight the limited application of diaries as a qualitative research method in feminist research (Meth, 2003), especially in relation to disability and health (Milligan, 2005b, Milligan et al., 2005, Thomas, 2007, Worth, 2009a). All of these authors share a similar regard for the use of solicited diary writing in conjunction with at least one other method; however, methodologically Sue’s diary entries are different, precisely because they are drawn from Sue’s memories of past experiences, within her own distinct timeframe.

A solicited diary is one that is written for a specific purpose, usually determined by the researcher and “completed by participants in the full knowledge that the contents will then be analysed and written about by the research team” (Milligan et al., 2005: 1883). Alternatively, a private diary or private document signals that the contents are for personal consumption only (Meth, 2003, Thomas, 2007). Yet, this finite distinction emphasises the division between public and private and limits the role of participants’ in the production of knowledge. The use of a diary within a participatory framework is the innovative aspect of my methodology, shaping Sue’s justification for choosing to write dairy. Sue had drawn a timeline of the often emotional events and turning points that had taken place throughout her life course, whilst our conversations continued and we shared information about our lives, Sue was always keen to know ‘What’s next? When I suggested a range of other methods, including a diary, Sue responded:

“I’d like to keep a diary so that I can turn traumatic memories into more positive ones”

(Sue, in conversation, 2011)

This quote from Sue challenges the points raised by Meth (2003: 197) regarding “ownership and the politics of knowledge production”. Citing Elliot’s (1997) work, Meth highlights the unequal power relations that exist between the researcher and those writing diary entries when she discusses the purpose of a solicited diary. However, while participants are involved in writing entries in research where solicited diaries are used to the degree that they are the authors; by working within a participatory framework I provided summaries to Sue, involving her in the analysis. In the next section I show that the boundaries between types of diary writing become blurred and there is less of a distinction between solicited diaries and those for personal consumption, as Sue and I complete a three-stage process together. This begins with Sue’s wish to challenge the memories that she holds and explores the role of (self) directed writings.

## **10.2 (Self) Directed Writing**

Writing a diary was the third participatory method used by Sue, who became deeply involved in the research process, taking the lead and making decisions about her own participation from the moment she responded to the newspaper editorial. As Sue was the only participant who chose to write a diary, the following account explores the (self) directed writings that were produced by Sue and based on her lived experiences of CDH. Time is innately associated with diary writing and may be used as a specific frame of reference to acknowledge ‘when’ a diary is written, including the date, month, year or clock time of writing. For example, diaries are used by Milligan (2005b) and Worth (2009a) to understand participants’ experiences of transition; Worth uses diaries to ‘more intimately capture’ young visually impaired adolescents transition to adulthood using audio diaries, while Milligan (2005b) contacted care-givers in New Zealand using a pen-pal relationship to understand “informal carer’s experiences of the transition of care from the domestic to the residential care home” (ibid, p. 214). However, in contrast to Milligan and Worth use diaries to capture participants’ thoughts on the process of transitioning, Sue chose a diary as she wished to challenge her memories, in order to understand specific

events from the past differently. Significantly, this produced complex understandings of the temporalities of Sue's memories and shows that "diary writing is a discontinuous process" (Meth, 2003: 198), emphasising the temporal basis of diary writing as a method with the empirical accounts given by Sue. This demonstrates that through various face-to-face encounters, time became woven into conversations rather than as an a priori framework that tied the research together from the start (Milligan, 2005b, Milligan et al., 2005, Worth, 2009a). However, while diary writing is a broken or 'discontinuous' process that involves stopping and starting, and even leaving the 'writing' to come back to it another time, which differs from the fixed timeframe of an interview<sup>57</sup>, in this research diary writing was a reciprocal process.

A dialogue developed between Sue and myself as we exchanged information, which took place in three-stages. It began with Sue choosing self-directed writing (stage 1), through the use of additional guidelines to help to focus Sue's entries (stage 2) and finally I emailed a summary of the main points I thought Sue was making (stage 3). Sue completed three diary entries on 'first memories', 'recovery and time', and a 'timeline of achievements', with themes unfolding in response to our verbal exchanges over the course of the research. I explore these entries and the process that developed both face-to-face and via email exchanges, showing that whilst a diary is a method that aims to capture longitudinal data (Meth, 2003, Milligan et al., 2005), Sue's entries shift between memories of the experience of the event as it took place (Worth, 2009a) and her current thoughts on those memories. This highlights the complex temporalities of memories, which are discussed in more detail in Chapter 11.

Sue's accounts illustrate that memories are stretched over time, as her diary writing on 'first memories', 'recovery and time', and her 'timeline of achievements' challenge the idea that a diary is often written in, and so of, the present (Elliott, 1997). One of the aims of this thesis is to destabilise fixed notions of time, such as the meaning of the 'present', and Sue's diary entries do

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<sup>57</sup> Although see Chapter 8: '*Becoming (un)comfortable*' for a discussion of the temporality of verbal exchanges.



just that, discussing the way certain lived experiences shaped her future, whether that future has passed or it is still anticipated. However, 'first memories' (Appendix 10.1.2) is a topic that Sue and I had discussed during our first face-to-face conversation, which focuses on her childhood memory 'going home'. Sue recalled writing about her first memories in an O-Level English evening class that she had attended as an adult 30 years ago and was certain that this would be the first entry. Despite being unable to locate her original entry from the O-Level class, Sue had already highlighted this memory as a significant turning point in her life (See chapter 4).

As noted, the participatory basis of this method developed through a mixture of face-to-face exchanges and electronic communication, and in March 2011 I provided Sue with her first written guide (Appendix 10.1.1), at her request. In geographical health research that utilises diary writing, participants' are often provided with written prompts. In Milligan's (2005b) research she did not come face-to-face with participants', using written communication only to engage with carers at a distance. Upon noting their interest, participants were sent an information sheet and a summary about their "experiences of caring for an elderly partner, relative or close friend" (ibid, 2005: 216), along with some questions. While Milligan notes that this may reduce the hierarchy that is often prevalent in face-to-face settings, this exchange was important with Sue, as each guide was produced differently and without the initial face-to-face meetings I feel that I could not have suggested compiling diary entries, based on Sue's lived experiences of CDH.

In Chapter 5: *'Becoming emotional'*, emotion unfolded as a theme through the use of a timeline as well as in Sue's first diary entry, however, like Thomas's (2007) work, where dairies are used as a way to access the role of emotions in HIV/AIDS, Sue's second diary entry, was a directed piece of writing that focused on the theme of 'recovery and time' (Appendix 10.2.2). Recovery was a theme that had developed with the chronic pain support group, as well as addressing Sue's lived experiences of multiple hip replacement operations. In the guide produced for recovery and time (Appendix 10.2.1), I focused on the stories that

Sue had already discussed in verbal exchanges, including her feelings about different operations and the daily activities and exercises she had to carry out as part of this recovery process.

Sue's third and final diary entry developed in response to my feedback from the second diary entry on recovery and time and as I suggested focusing on recovery at home, Sue's emailed the following response:

I am OK with answering questions about the recovery at home since I married [partner's name]. I am concerned about what I can remember though. My lack of recall does to only stay within the realms of child hood. Is this a form of selective forgetfulness?

With talking about what I have done in my life and how really I am doing so little in comparison now - I would like to make a 'time line' of my achievements. Would you be interested in this if I do it?

It was one of the bad days of depression that I wonder what I had achieved and if I had made any difference -something I have always wanted to achieve and wonder now if I have?

I await your questions

(Sue, email correspondence, July 2011)

This third extract is the shortest one produced by Sue, totalling five pages; yet Sue begins this entry by saying that she “needs[s] time to get the dates right in the time line I have started and I will get it done one day – having the list in my diary is already of benefit to me so I will not rush the next part” (Appendix 10.3.2). Worth suggests that “one reason paper diaries were not chosen is that writing often seems to steer participants into a linear record of experience” (2009a). However, the memories that Sue explore in all three diary entries “challenges the issue of diary keeping as an act of current sequential record

keeping” (Meth, 2003: 168), which is further illustrated by Sue’s third extract, as she writes:

“I decided to make a list, trying to keep them in order, and realised how much I had done and how difficult it actually was to keep them in order”

(Sue, Appendix 10.3.2)

Sue’s ‘timeline of achievements’, demonstrates that she achieved action Cahill’s (2007a) action through writing, and while the analysis of Sue’s diary entries has already been outlined, as I moved between discussions of the three-stage process (from choosing a theme and providing a guideline to offering summary feedback before moving onto the next diary entry), themes emerged from the ground up. In Sue’s accounts, the action comes from taking control of all of the methods and finally realising what she has done with her life, as a few months ago, she tells me that she is making a scrapbook of her life. Subsequently, the act of writing a diary in this research, also adds to Tolia-Kelly’s (2006: 213) work that, highlights the missing ‘engagement with the act of writing itself as an experiential and emotional activity’.

In the next chapter, I bring the whole thesis together by expressing the temporalities of remembering and the role of memories.

## Chapter 11: Memories

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Memories by their very nature are fuzzy, blurry and fluid, slipping in and out of our minds with varying degrees of intensity, clarity and vision, whilst other memories are more clear and distinct. Memories are directly connected to time and to temporality, even when remembering is sometimes difficult, traumatic and unexpected it is hard or even impossible to say 'where' a particular event took place, 'when' the memory is from and 'why' it is remembered at a particular moment. Memories are not tangible, although certain material items, such as photographs, may be reminders of people that are no longer alive and of events that have taken place, or participants' bodies may serve as reminders of their disabilities, health conditions and illnesses. However, in this final empirical chapter, I emphasise the importance of one participant's memories, using a case study of Sue's experiences of becoming disabled, as I highlight the limited contribution of geographical work to the literature on memory, social identities, disabilities, health and the life course. I suggest that whilst accounts of childhood, adulthood, later life and the life course have gained attention, the emphasis on memories shaping disabled people's identities across *and* throughout the life course is missing.

I discuss the temporalities of remembering and focus on the way memories shape the more personal and subjective social and cultural identities of becoming disabled. I argue that this is different to studies that focus on collective and social memory, which are assigned to cultural research on memory and place (Jones, 2011). Social and cultural geography has focused on memory as a collective attribute, often representing the history of a place using social or collective memories, memorialisation and material culture. Yet memory "at the individual and personal level" (2011: 881) makes few explicit links to the literature on social identities, health and the life course. While research that addresses memories on a personal scale focuses on childhood and emotion (Jones, 2005), as well as, memory, grief and later life (Hockey et al., 2005), the emphasis on these memories shaping disabled people's identities is missing.

All eight participants in this research referred in one way or another to memories in the process of discussing their disabled identities, from emotional memories of ‘standing out’, diagnosis, relapse, rehabilitation and planning for a different future (chapter 5); to memories of ‘becoming well’ as participants renegotiate ‘new’ bodies and ‘new’ activities and try complementary and alternative medicine (chapter 7); and finally to accounts of becoming mobile (chapter 9). However, in this chapter I provide an in-depth case study of Sue’s memories from her participatory timeline (chapter 4), multiple conversations (chapter 8) and her diary entries (chapter 10), as I stitch together the material on emotion, recovery and mobilities, drawing connections between all three empirical chapters into one overarching analysis of memories.

In the remainder of this chapter, I use Sue’s accounts to illustrate the way that memories of the ‘home’, memories of becoming well and the messiness of remembering, demonstrate the temporal boundaries of becoming disabled. I show that through remembering, memories are fixed in time, memories are stretched through time and memories can be timeless and placeless. Using Sue’s accounts I examine the linearity and sequential nature of memories and the way memories disturb temporal sequences, as well as critiquing the geographic literature for privileging childhood memories that remain within the realms and boundaries of childhood (Philo, 2003, Jones, 2005).

### **11.1 Memories of ‘home’**

The concept of ‘home’ is a complex notion and holds an important place within the geographical literature; however, the multiplicity and ambiguity of the ‘home’ also has resonance with Sue’s memories. In this section I use an extract from Sue’s first diary entry, to show that one particular childhood memory, ‘going home’ to illustrate the significance of temporal boundaries stretching. Firstly, I show that Sue’s memories are marked by multiple meanings of the ‘home’ and begin within the hospital, where this ‘first’ memory takes place<sup>58</sup>.

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<sup>58</sup> While I later highlight the problems associated with conceptualising a ‘fixed’ starting point of becoming, for the purposes of this example Sue labels this as her ‘first’ memory.

Secondly, using Sue's accounts I highlight the temporalities of the 'home', adding to the feminist and emotional geographies of disability, health and illness.

### 11.1.1 Going 'home'

Sue was born with CDH, which describes the way "the ball and socket joint at the hip does not stay locked together" (BBC Health, 2012). While I have already discussed the way hip replacement surgery has shaped her life course in multiple ways, producing a complex history of medical operations<sup>59</sup>, the following account is taken from Sue's diary entry (2011), written when Sue was in her sixties, as she recalls going back to her parent's 'home'<sup>60</sup> for a visit. In this memory Sue is 5 years old and has been living in a children's hospital since the age of 14 months; the hospital is about 20 miles from her parent's home, yet her parents seldom visited, usually once a month.

#### Box 11.1: Going 'home'

"Having spent some time in Hospital X for crippled children... I was now about to go home.

This trip 'home' I remember being very excited about, as going out in the cold was not usually allowed for children with my condition (...)

Everything was white and although I had seen snow, I had not seen so much and anyway I had not left the hospital grounds (which were small) and therefore I had no conception of this amount of space; empty space with no nurses, doctors or other children in; big empty space.

The journey was long and once I arrived I was taken into a house that looked big but upon entering it got smaller and narrower.

As the walls closed in on me I got more scared and upon been passed to a person who I occasionally saw at hospital I saw the ambulance man turn to go.

<sup>59</sup> I discuss Sue's medical history in Chapter 7: *'Becoming well: A geography of recovery'*.

<sup>60</sup> Sue uses quotation marks to describe her parent's 'home' in her original diary entry.

This was the last straw and I cried – loudly.

(Sue, Diary Entry 1: Childhood Memories, 2011).

On this day in Sue’s memory she is leaving the hospital for a few hours, taking a journey to visit her parents. Sue’s feelings both in and of space demonstrate her awareness of the materiality of spatial boundaries as she describes ‘the amount of ... big empty space’ on leaving the hospital building compared to the ‘smaller and narrower’ space of her parent’s home. Yet this is compounded by feelings of ‘the walls clos[ing] in’ when she is inside their home and in particular translates into Sue’s future practices, as she later suggests in the same diary entry:

I cannot say for sure if this memory shaped any of my future – but what it did do is make me understand why I did some of the things I did later in life; like not be able to go into a cupboard without someone holding the door open (...) making me almost claustrophobic.

(Sue, Diary Entry 1: Childhood Memories, 2011).

Sue’s second quote illustrates that her memories from childhood draw her forward as the temporal boundary stretches time away from this experience in the past to connect with subsequent feelings of claustrophobia in smaller spaces in the future and ‘later in life’. This resonates with Bergson’s (1910b) work where ‘events from the past flow into those in the present’, which was first introduced in Chapter 5: *‘Becoming emotional’*. In Sue’s account, the event is her particular memory of going home and experiencing the feeling of the smaller space of her parents’ home compared to the hospital, while the present, in this account, reflects the sequential ordering of another event, such as going ‘into a cupboard’ in the present. The relationship of the present to the past in this example is important as Bergson’s understanding of time and of temporalities

emphasises the relationality of one point in time to the next point in time in a linear<sup>61</sup> fashion, highlighting the chronology of memory (Mantel, 2003).

Sue's account of being 'almost claustrophobic', which is taken from the quotation above, also has resonance with some of Anderson's (2004) work on the role of non-representational theory and memory. Anderson's work is useful here because it focuses on the emergence of memory by exploring the complex interconnections between affect, time, recorded music, memory and participant's daily lives. While participants in Anderson's study discuss the role and ability of music to invoke particular memories at unexpected moments, one participant is 'transported' (ibid, p.10) back to her Mum's home in the past when sitting at her own kitchen table listening to a piece of music before going to work. In this account "the temporal sequence of past/present/future [are] disturbed", as the boundaries of this participant's home "are twisted and deformed" (Anderson, 2004: 10) being stretched through time by memories.

Yet Sue's memory of going from the larger space of the hospital and back to the smaller space of her parent's home, produces a reaction that makes her feel both scared and wanting more space. However, while space as a physical container might appear to be of utmost importance to Sue's phobia, it is time and the memories of this event that remind Sue of these feelings. In Sue's account, temporal boundaries stretch, as her feelings of claustrophobia or refusal to go into a cupboard unless 'someone [was] holding the door open' are a reminder of 'going home' to her parents in her childhood. The temporal sequence becomes disturbed in Sue's account as her memories of 'going home' stretch into her future practices and throughout the rest of her life.

While the literature on phobic geographies provides a small (in number) yet significant contribution to social geography, including agoraphobia (Davidson, 2003, 2010) and obsessive compulsive disorder (Segrott and Doel, 2004), these studies tend to explore the significance of spatial boundaries.

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<sup>61</sup> However, in section 11.3: *'The messiness of remembering'* I use the work of feminist theorists to show that time is not always linear and distinct, but complex and unfolding.



However, while Sue’s account illustrates the shrinking of spatial boundaries related to ‘home’, it also addresses the simultaneous stretching of temporal boundaries from childhood memories and into future practices. This highlights the temporality of phobias, as Sue explains:

This outcome took years to combat and still comes back if I am not in control of the situation I am in.

(Sue, Diary Entry 1: Childhood Memories, 2011).

While Sue explains that it took ‘years to combat’ her claustrophobia, she also addresses the temporality of this experience, which ‘still comes back’ unexpectedly at other moments. In referring to agoraphobics’ bodily boundaries, Davidson (2010: 371) describes the embodiment of these experiences using Marks (1987) work:

“[O]ne feels temporarily strange, unreal, disembodied, cut off or far away from immediate surroundings”

(Marks, 1987: 342, cited in, Davidson, 2000: 641)

Yet despite addressing the temporality of phobias Marks’ quote frames the embodied agoraphobic’s temporal feelings of ‘not being there’ and is used throughout Davidson’s work to emphasise the socio-spatial relations of agoraphobia, however, Sue’s account suggests that time is just as profound in shaping phobias. In the next section, I show that Sue’s memories and experiences of CDH demonstrate the temporalities of the ‘home’.

### **11.1.2 The temporalities of the ‘home’**

In geographies of disability, health and illness there has been a wealth of research that explores the importance of the spatialities of the ‘home’ (Dyck, 1995, Moss, 1997, Dyck et al., 2005), however, the temporalities of these

experiences is less well documented. Sue's memories of 'home' illustrate the shrinking, stretching and folding of spatial boundaries, as her accounts describe the way boundaries become stretched to encompass other spaces that are less traditionally conceived of as 'home', such as the hospital. The hospital is one space in Sue's life that she considers as home and although 'it was never explained', Sue was "taken from [her] mother" at the age of 14 months, subsequently moving from institution to institution<sup>62</sup>, which became Sue's home for the next 16 years of her life. Sue was moved between different children's hospitals in the North East of England, from the 1950s to the late 1960s, when she left to train as a qualified nurse.

While emotional geographies of mental (ill) health, refer to the home as "a place of relative safety" (Segrott and Doel, 2004: 606) for people with obsessive-compulsive disorder (OCD), there is an underlying notion of the importance of temporalities in Parr et al.'s (2003) research. Parr et al., demonstrate the relationship that a former patient still has with a Scottish asylum, choosing "to sleep rough in the woods behind the old hospital site because they retained such meaningfulness for the individuals concerned" (2003: 350). However, in Sue's account hospital wards indicate a sense of familiarity and safety, as her experience of growing up in hospital wards where the volume of space is noticeably bigger than in most 'private' homes, shapes her feelings in her account of 'going home', as the following quote demonstrates:

I was now about to go home (...) and until that time home to me was a very long wooden ward, with a fire stove in the middle.

(Sue, Diary Entry 1, 2011: 1)

While Sue's spatial and emotional boundaries are disrupted as she feels space shrinking and folding (Honkasalo, 1998) as she enters her parents' home, this quote illustrates that these feelings might be shaped by the size of the hospital ward that Sue was used to living on. While the accounts in this section

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<sup>62</sup> See Sue's timeline for an indication of the multiple 'home' spaces she has experienced throughout her life course.

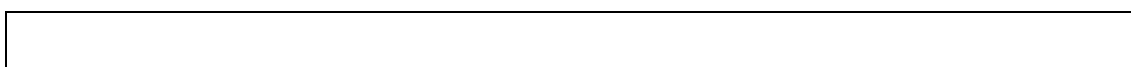
provide a glimpse of the importance of the temporalities of the 'home', it illustrates a new direction for future research into accounts of disability, health and illness across the life course.

In the next section I show that Sue's memories of becoming well also stretch through time, as Sue recalls memories related to recovery following her first hip replacement surgery, which extends on the initial discussion from Chapter 7: *'Becoming well: A geography of recovery'*.

### **11.2 Memories of becoming well**

Sue's entire life could be analysed as a series of different moments that contribute to the process of becoming well, from the moment Sue was taken from her parents and placed in a children's hospital, to the succession of different hospitals that she subsequently 'grew up' in and the multiple operations for hip replacement surgery. However, in this section I draw on the time associated with Sue's first hip replacement surgery at the age of twenty, using specific memories to highlight the emotionality of becoming well and the emotionality of becoming mobile.

Sue's first memory, which is taken from the audio recording of Sue's participatory timeline (chapter 4) is used to demonstrate the way that she re-negotiates her position as a patient in relation to the medical staff on the ward, as she recalls her feelings associated with the following memory from over 40 years ago, saying:



“You see no level of consent [...] I did the same thing [as other patients] by saying yes you do what you think but I want to know why, I’m interested. It’s my body; I want to know why.

Those were the days in the ward when you had curtains that came round on wheels, erm, and when a surgeon came round, he would just get hold of the bed covers and pull them back and ... would get hold of your nighty and pull it up. There was just no consent to it; there was no thinking about your feelings. You were there to be tret<sup>63</sup> and to be tret as quickly and as soon as possible so you know there was no thought to asking you, were you on your period and did you have pants on. Or sometimes it was even done with a load of youngsters around and the sister had been called off to an emergency”

(Sue Timeline Recording, original emphasis).

It is at this point that Sue continues to discuss losing ‘that ability to feel for [her] body’, (discussed in section 5.3.2 ‘*Passing*’), however, she also highlights the gendered nature of the hospital ward in this memory, saying that ‘there was never a nurse [...] but if the sister was called away, there was a good possibility that the rest of them could all be male, which in that case you’d just have to get on with it’. Sue’s account and her memories of the events surrounding her first hip replacement demonstrate her embodied emotional investment, as ‘it’s [her] body; [and she] wants to know why’. Yet the actions of the medical professionals, including the (male) surgeon and the (male) trainees, treat Sue and her body as an object of medical knowledge (Foucault et al., 2007) highlighting their disinvestment and disembodied practices.

Sue’s second memory relates to one particular relationship with a female sister, who failed to take notice of Sue’s ‘*swelling and itching*’ beneath her bandages, as Sue describes:

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<sup>63</sup> This quote is taken directly from the audio recording that I made when Sue was completing her timeline, in this particular example *tret* is replaced with the word ‘tret’, a word often used in this region.

This was the only time that I found that there are people who take an instant dislike to you and want to make you not only feel small but not worthy of compassion or consideration and for some reason want to punish you for what you are and who have the power to do so.

You are very venerable<sup>64</sup> when depending on others you do not know and this was the first time that I had been in an adult ward. I constantly told this particular one that the Elastoplast's was driving me crazy because of the itching.

She never passed it on and it was nearly a week later when my surgeon ... came round and upon seeing the swelling and irritation when taking the covers off me (the few I had on!!) that something was done.

(Sue, Recovery and Time)

However, this created friction between other members of staff when this 'swelling and itching' was not communicated and resulted in the sister, doing things like:

You see she use to do other things like leave the meals just out of reach, take longer to wash me so that I got cold, leave my bed cloths wet, when I tipped a bed pan or washing myself I spilt some water, making me wait for a bed pan and again to come and collect it saying she forgot because she got called to do something else.

(Sue, Recovery and Time)

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<sup>64</sup> As Sue wrote all of the diary entries on her computer, emailing me electronic copies, I have not corrected or changed any grammar, spelling or punctuation. Therefore, any errors in this regard have been left intentionally.

At just 20 years old these things stayed with Sue, who recognised the nurse outside of the hospital, stating,

[W]hen I eventually came to live [here] 3 years later, I used to see her often; each time I felt physically sick, but she never recognised me.

(Sue, Recovery and Time)

While these memories demonstrate a particular period in Sue's life, where the actions of different medical professionals shaped her feelings of belonging on the hospital ward, Sue's third memory, relates to the expectations placed on her during recovery and the role of physiotherapists. One particular practice still remains with Sue, as she recalls:

The Physio department made a film of the way I walked and did this as a teaching aid for Doctors and physios too.

The time between the parallel bars walking toward a mirror, with large dots on my hipbones trying to keep these dots level as I walk towards the mirror are ingrained in my mind and probably gives reason to why I do not like to look at myself walking toward a mirror in any way!!

(Sue, Diary Entry 2: Time and Recovery, 2011: 2)

Sue associates this memory with a particular place, the hospital ward, however, the image of 'walking toward a mirror with large dots on [her] hip bones' stretches through time, as she refers to her dislike of repeating a similar practice in the future.

### **11.3 The messiness of remembering**

Remembering is significant to participants in this research as they continuously dip in and out of their own memories at different points in time,

demonstrating the way remembering “is folded into the world” (Thrift, 1999, cited by Anderson, 2004: 4). For Sue, memories of becoming disabled have been ‘folded into [her] world’ since childhood, as she discusses numerous memories of ‘institutionalisation’<sup>65</sup>, from growing up on various hospital wards for children to her experiences of negotiating with medical professionals before, during and after multiple (8) operations for hip replacement surgery, showing that past informs her future (Bergson, 1910b, 2001). However, in this final section of the chapter, I demonstrate that while remembering may be chronologically organised, remembering is a messy process.

Firstly, I show that the participatory methods chosen by Sue demonstrate the messiness of becoming as Sue questions her ability to recall memories and uses her diary entries as a way to challenge, control or change particular memories. In section 11.1 ‘*Memories of ‘home’*’, I discussed the way that Sue’s memory of ‘going home’ is bounded by a specific timeframe, as Sue labels it as her ‘first’ memory. Whilst the (self)directed writing process that took place with Sue when she decided to keep a diary to turn ‘traumatic memories into more positive ones’ is discussed elsewhere in this thesis<sup>66</sup>, the opening paragraph of her first diary entry is significant, as she writes:

With very little memory of my younger days I wonder now how much of what I will tell you about are actual memories or imports of perception that I have engraved from what others have told me, by looking at photos, by listening to others perception of how they thought I managed.

(Sue, Diary Entry 1, 2011: 1)

As Sue makes the decision to write a number [4] of diary entries based on her memories of becoming disabled, she questions the accuracy and legitimacy of her ‘first’ memory as she begins to write her diary entries. By doing so, while

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<sup>65</sup> A phrase used repeatedly by Sue in our first meeting together in her own home. I subsequently asked Sue to elaborate on its meaning, at a later stage in the same conversation.

<sup>66</sup> See Chapter 10: ‘Diary *‘Writing’* for more details on this process.

this 'first' memory appears to be located at a specific point in time, in Sue's past, as her 'first' memory, Bergson's work shows that each present is 'different precisely because it has accumulated more memory into it' (Dodgshon, 2008: 307). However, this idea of the accumulation of 'more memory' seems to imply that a memory, any memory will or can become clearer and more distinct, as time passes chronologically.

Yet, Sue highlights the subsequent role of this memory as "a sequence of events that came back to [her] when forced to remember 'what [her] first memories were' when taking an O' level English Evening Class" (Sue, 2011: 1) as an adult learner during the 1980s. Sue's own reflection of the reality of these 'actual memories' is significant, as Legg (2007) reminds us that "the way in which memories are formed and valued change as one moves through time". This demonstrates the messiness of participatory methods, of writing and of becoming, as Sue compiled diary entries to 'challenge' her memories. By taking on the task of writing a diary Sue is inevitably challenging her own ability to recall her memories, which can only ever be a partial representation or a partial account, yet while Sue acknowledges the role of material items (photographs) and aural accounts (other people's stories through verbal exchanges), it is through the act of writing down and cementing her memories that Sue hopes to challenge or change them. Grosz's (2005) understanding of Bergson demonstrates the potential to change these memories:

"[T]he fracturing and opening up of the past and present to what is virtual in them...to what in them can bring forth the new"

(Grosz, 2005: 4).

This quotation is used to illustrate that while Sue's memory is fixed at a point in the past, at the evening class, since recalling this memory on a number of occasions since this class, Sue's memory may continue to 'bring forth the new' with each recollection. By assigning this particular memory as her 'first', Sue



allocates significance to this memory of going home and the subsequent emotional ties she associates to it, however, I return to the (re)beginnings outlined in Chapter 5: '*Becoming emotional*', to demonstrate the complexity of remembering and the difficulty of locating beginnings within Sue's personal histories.

While there are particular memories that Sue locates in time, as her participatory timeline and examples in this chapter demonstrate, a more in-depth analysis of the temporalities of Sue's life course challenge the illusion of a fixed or static starting point(s), reinforcing the concept of becoming as a process of continuous change. However, as our conversations develop, Sue later draws from memories that she cannot locate at linear points in her lifetime but instead to a periods of time on the hospital ward for children, including memories of sleeping in wooden cots, and memories that are marked by 'huge amounts of anaesthetics'. These were administered in the hospital, sending Sue into a deep sleep when she had been in theatre having surgery. Sue remembers being accompanied by a nurse, who ensured you woke up every 15 minutes, including 'a short, sharp slap if you were falling asleep!'

Probyn's (1996) work shows that memories of childhood "throw us into a present becoming, profoundly disturbing any chronological ordering of life and being", emphasising the temporality of remembering. Unlike many of Sue's other memories that she locates at specific points in time or in relation to significant events where she provides rich and in-depth details, this memory reflects a "profusion of entangled events" (Winterson, 1991). It is not about a one-off event but rather it reflects a number of seemingly similar memories that are "marked by the huge amount of anaesthetics' that were administered" (Sue, in conversation, 2011). Yet as these memories become blurred and tangled up, it becomes more and more difficult to separate Sue's subjective memories into more distinct and categorically defined temporalities.

This is important as it indicates that memories and identities do not take place in isolation but are shaped by their relationship to other people's

memories. While Winterson (1991) suggests, “there are not origins but numberless beginnings” (cited in Probyn, 1996: 113), all of the memories presented in this chapter and during the participatory methods completed by Sue illustrate the role of memories shaping her multiple identities and ‘numberless beginnings’ across the life course. Sue’s rich, in-depth accounts demonstrate some of the intricacies of time, from growing up and adolescence to getting married and having children. Sue discusses the way that her adulthood<sup>67</sup> and her future are directly shaped by her past memories -of familial relationships<sup>68</sup>; -of claustrophobia; -of always keeping her children close by and having a closer relationship<sup>69</sup> with them and never leaving them in hospital if they needed to stay in overnight. These decisions are shaped by her memories of recovery in the hospital that I have outlined in this chapter, demonstrating that:

“The self - the identity - is always in flux, the present **altering** the past even as the past **informs** the present”

(McConkey, 1996: 315, cited in Jones, 2005: 208, my emphasis).

While McConkey (1996) addresses the singularity of identity in this quote it is used in the context of Sue’s story to highlight the significance of two keywords ‘altering’ and ‘informing’. This describes the way Sue’s memories continue to shape both her ‘past’ and her ‘present’, however, in highlighting ‘identity’ as something which is singular whilst also in ‘flux’, McConkey contradicts the idea that identity may be subject to change. This draws us back to the importance of participants’ multiple and fluid identities, outlined in section 2.3 ‘*Accepting differences*’, demonstrating that accounts of disability, health and illness are more appropriately theorised as identities.

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<sup>67</sup> See VALENTINE, G. 2003a. Boundary crossings: transitions from childhood to adulthood. *Children's Geographies*, 1, 37-52. for a more detailed discussion on the way that childhood and adulthood are not distinct categories or parts of the life course.

<sup>68</sup> While there is a more detailed literature on the role of young people as carers for ill or disabled parents (Stables and Smith, 1999), as well as, the lives of parents with disabled children (Goodley, 2007). See BLOCK, P. 2002. Sexuality, parenthood, and cognitive disability in Brazil. *Sexuality and Disability*, 20, 7-28. for more on “the need for research to challenge common stereotypes about parenting with a disability”.

<sup>69</sup> However, Sue’s partner reiterates a similar story as he describes feeling left out when Sue thinks in the singular about ‘their’ children although she often talks about ‘her’ children.

In summary, I have shown that memories are not simply a revival of past experiences that are reiterated in chronological succession, but that personal and subjective memories stretch and shape experiences across the life course. Memories of childhood, shape the way that one participant, Sue acts upon her own future, as Sue recounts personal histories, illustrating the emotionality of remembering 'past' experiences. Firstly, these past experiences refer to memories of the 'home', providing new empirical material that illustrates the temporalities of phobias, as the linearity of temporal sequences are disturbed and new meanings that challenge the spatialities of the home and illustrating the temporalities of the 'home', as a concept. Secondly, emotional memories of becoming well provide historical accounts of the treatment of patients by medical professionals in the 1950s and 1960s, adding to the temporalities of disability, health and illness using in-depth qualitative accounts.

Finally, this chapter has examined the messiness of becoming disabled, a concept that I have tried to explore throughout the thesis, showing that as memories of disabilities, health conditions and illnesses continue to unfold, they opening up to new possibilities and new futures. In the next chapter I bring together all of the empirical, theoretical and methodological findings to demonstrate the temporalities of disabled people's identities.

## Chapter 12: Becoming

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At the start of this thesis, I identified the unexplored temporalities of disability, health and illness, arguing that their analysis might enrich geographical accounts. In this final chapter, I use the concept of becoming as an umbrella term, in order to bring together the multiple and complex temporalities of disabled people's identities which the research has uncovered. The research suggests that becoming is an ongoing process, that not only binds the research process together, occupying a position at both the centre and the margins, but filters through and connects disabled people's accounts of their disabilities, health conditions and illnesses. The idea of becoming has wound its way through the analysis, as an underlying, always present and unfolding process of continuous change.

In this concluding chapter, I draw together the findings of the thesis. Firstly, I demonstrate and contrast the concept of 'becoming disabled' with the more static and fixed concept of 'being disabled', as I come full circle to illustrate the different temporalities that have shaped both disabled people's identities and *this* research process. Secondly, I return to the four axes - embodiment/materiality, emotion, relationality and fluidity - that were presented in Chapter 2. Through drawing together the findings, I suggest that that the everyday, mundane and banal experiences of becoming disabled are framed by participants' lived experiences rather than by their disabilities. Thirdly, I reflect on participatory approaches and methods, which have been the driving force in this thesis, considering how far they have worked to develop research questions and empirical themes from the ground up and therefore open up the research to the temporalities of becoming disabled.

### **12.1 Becoming disabled: The temporalities of disabled people's identities**

The key contribution of this thesis is to understand disability through everyday and lifelong temporalities. The concept of becoming disabled has been informed by an examination of the in-depth, qualitative accounts of eight

disabled people. These accounts, from spinal cord injury, Congenital Dislocation of both Hips, spondylitis, multiple sclerosis, sclerotic arthritis, spinal operations and adhesive arachnoiditis, demonstrate that the diversity of disabled people's differences are bound together by the temporalities that frame lived experiences of disability, health and illness. Each empirical chapter has explored different types of time, from daily routines, one-off events, histories and futures to the stretching, expanding, shrinking and unfolding of time, providing key contributions to understanding disability through everyday and lifelong temporalities.

In Chapter 5, we saw how disability and time are inextricably connected. The analysis here centred on the important emotional dimension of this relationship, which has also tended to be underplayed in previous research. The inception of disabilities, health conditions and illnesses signals an important time in participant's trajectories. All of the participants in this research experienced different bodily and emotional changes, and the inception of disabilities occurs at different moments in these trajectories. One-off events such as a medical intervention or an accident enable some participants to pin point the 'beginning' of their disabilities at a specific point in time, while for others, feelings and time stretch as they wait for 'new' and unfolding diagnoses. Secondly, their experiences show that societal attitudes towards disability and disabled people (re)produce certain histories that shape the way that disabled people learn to control their emotions over time. At times this involves the performance of feelings associated with everyday acts such as falling (in the street and at home), walking (normally) and learning to 'go to the toilet'. However, these feelings stretch into the future; showing that the lived experience of disability is marked by its fluidity, as bodies and emotions, unfold at unexpected moments.

In Chapter 7, I documented the different speeds that time is experienced throughout the recovery process, as participants (re)negotiate day-to-day and lifelong recoveries. For some, day-to-day routines change following surgery as they negotiate a specific set of practices within the hospital, subsequently

shifting to negotiate another set of practices, which are marked by a different set of temporalities, upon returning home. However, as participants' disabilities, health conditions and illness fluctuate, lifelong recoveries take place through everyday practices, such as sleeping, standing, sitting, walking and lying down, as time also fluctuates to accommodate these changes. In this, research participants with chronic pain are able to simultaneously forget pain and to forget time through the process of distraction. However, at other times, time is much more prominent, as time pauses, slows down and speeds up in the process of becoming well. The acceleration and de-acceleration of time does not solely reflect the linearity of time, but highlights the rhythms of disability. As participants try to control their rhythmic recoveries, they are also controlled by their own specific bodily rhythms, as demonstrated by Mark's account of becoming spinally cord injured. Yet, significantly it is the circadian rhythms of the day and night that this chapter challenges, showing that both regularity and discontinuity frame disabled people's normal patterns of 'doing' daily routines, at times that are the most appropriate for them rather than at set times in a fixed routine.

Thirdly, in Chapter 9, I examined the modes and rhythms of moving and movement, focusing on the temporalities of walking and wheeling, as I discussed the overlooked and hidden aspects of disabled people's everyday practices of moving and movement. This chapter of the thesis demonstrates that the pace, speed and rhythm of disabled people's movements are not so different to accounts of the 'normative able body'. Finally, in Chapter 11, I demonstrated the importance of temporalities of remembering, showing that memories are not simply a revival of past experiences that are reiterated in chronological succession, but that personal and subjective memories stretch and shape experiences across the life course. As the linearity of temporal sequences is disturbed, new meanings that challenge the spatialities of the home illustrate importance of the temporalities of the 'home', as a concept. Subsequently, while memories of disabilities, health conditions and illnesses continue to unfold, they

opening up to new possibilities and new futures, shaping all of the empirical material in this research.

Overall, these findings contribute towards understanding disability through a range of temporalities, adding important insights into the role of disability in everyday life and across the life course (Anderson, 2004, Hopkins and Pain, 2007, Pinder, 2009, Worth, 2009b, Edensor, 2010a, Meadows, 2010).

### 12.1.1 Emotional, embodied and affective temporalities

The most salient temporalities are outlined in Table 12.1 *'The emotional, embodied and affective temporalities of becoming disabled'*, which is discussed below.

	<b>Embodied temporalities<sup>70</sup></b>
<b>Emotional temporalities</b>	<ul style="list-style-type: none"> <li>• Performing temporalities and controlling feelings;</li> <li>• Stretching, expanding and unfolding temporalities;</li> <li>• Sequential, (dis)continuous cycles of time;</li> <li>• (Re)openings and (re)beginnings.</li> </ul>
<b>Embodied temporalities</b>	<ul style="list-style-type: none"> <li>• Rhythmic recoveries - the temporal patterning of routines;</li> <li>• (De)acceleration of time;</li> <li>• Temporalities of wheeling and walking.</li> </ul>
<b>Affective temporalities</b>	<ul style="list-style-type: none"> <li>• Affective recoveries and bodily rhythms;</li> <li>• Moments of comfort, stillness and pausing;</li> <li>• Distraction and forgetting time;</li> <li>• Placelessness of affectual intensities.</li> </ul>

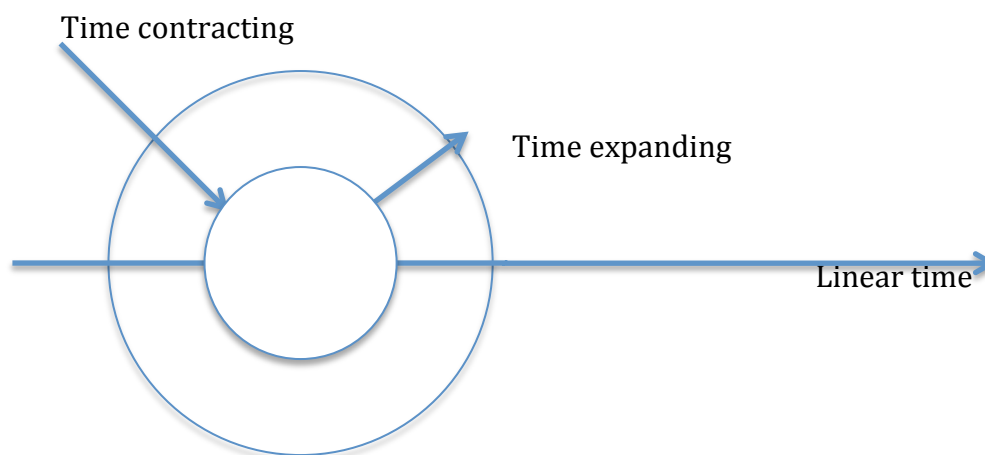
**Table 12.1:** The emotional, embodied and affective temporalities of becoming disabled

Table 12.1 illustrates three overarching temporalities of becoming disabled, which I discuss demonstrating the synergies between different

<sup>70</sup> Significantly, embodied temporalities shape all of the accounts given by participants, as illustrated by Table 12.1 and discussed in the remainder of this section.

accounts of time and the inter-relations between emotional, embodied and affective temporalities. These temporalities connect the various accounts given by participants in this research, who shared their pasts, presents and futures and in doing so provided everyday and lifelong experiences of disabilities, health conditions and illnesses.

*Emotional temporalities* show that as disabled people relive particular memories of the banality of everyday acts, which may appear mundane, such as falling and walking, as well as memories of diagnosis, operations and accidents, these emotional attachments shape participants temporalities. Firstly, performing temporalities demonstrates the way that feelings control certain experiences or enable participants to control certain feelings, as they perform emotional and gendered temporalities. Secondly, the stretching, expanding and shrinking of time, highlight the way that time also becomes embodied through emotional temporalities are illustrated in the following three diagrams (Figure 12.2.1, Figure 12.2.2, Figure 12.2.3).



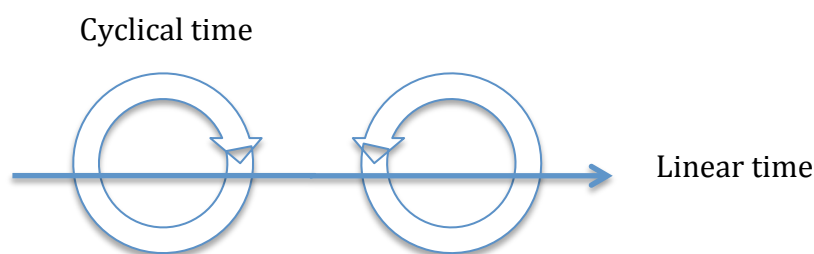
**Figure 12.2.1:** 'Stretching and expanding temporalities'

In chapter 5, memories of diagnosis revealed the different ways in which time is experienced. Figure 12.2.1 'Stretching and expanding temporalities' demonstrates the simultaneous experience of lived time as embodied and emotional. Feelings located at a specific point in time i.e. at diagnosis, often stretch through time along with a number of other 'felt' experiences, which come



together to erupt as multiple fissures coalesce, (re)producing emotional temporalities. Figure 12.2.1 shows that whilst linear (clock)time continues to pass and participant's chronologies move forward, time expands to incorporate the emergence of different becomings or contracts, shrinking as embodied and material changes to disabilities, health conditions or illnesses creates 'feelings' which (re)situate participants in the 'past'.

Thirdly, the emotional temporalities explored in this thesis provide specific insights into the temporal boundaries of certain experiences of disabilities, health conditions and illnesses. Figure 12.2.2 'Unfolding temporalities of multiple sclerosis' highlights the way that men experience continuing cyclical encounters with various health care and medical professionals, in time spent waiting for diagnoses of multiple sclerosis.

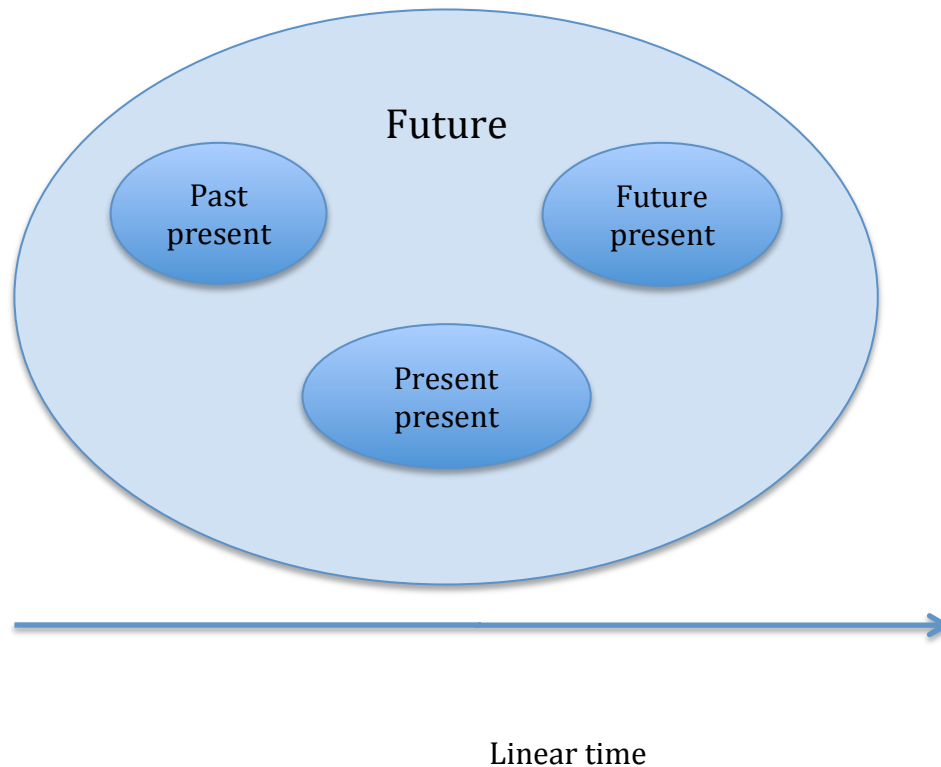


**Figure 12.2.2:** Unfolding temporalities of multiple sclerosis

While participants embody cycles that fluctuate between relapse, diagnosis, appointments times and bodily changes, although not necessarily in the same order, the (anti)clockwise cycles in Figure 12.2.2 demonstrate the progressive, sequential and (dis)continuous basis of becoming through MS. Multiple sclerosis may be disrupted by temporalities that challenge and unsettle the order of 'becoming', affecting the 'good' and 'bad' days (Charmaz, 1991) that participants experience. These insights offer further scope for future research on the temporal boundaries of MS (See 12.4 'Future becomings').

Fourthly, (re)openings and (re)beginnings also incorporate multiple fissures, showing that (childhood) memories shape and stretch into the 'future' and may also change in relation to the 'present'. While the 'present' and the

'future' are both contested terms, which have been discussed throughout this thesis, they are expressed in diagrammatic form in Figure 12.2.3: '*Emotional futures*'.



**Figure 12.2.3:** Emotional futures

Figure 12.2.3 shows that futures are connected by accounts of the recent past (the past present), as plans are realised (the present present) and the anticipated future (the future present). Whether futures are expressed through (re)opening memories or embodied in emotional (re)beginnings, they are often unexpected or anticipated, open to chance and to becomings. Therefore, the futures expressed in this thesis are not 'fixed' in linear time but lived in relational 'felt' time and experienced in the cumulative present of the 'now'.

*Embodied temporalities* connect with all of the accounts outlined in Table 12.1, demonstrating the continuous (re)negotiation of disabled people's fluid and changing bodies. Firstly, rhythmic recoveries explore the temporal patterning of routines within the hospital and the 'home', highlighting the

relations between movement and stillness within the context of individual and collective recoveries. Disabled people alter and (re)negotiate their own specific temporal rhythms, as they become attuned to and embody their own recoveries. Secondly, these rhythms are shaped by different speeds, as accounts of 'pausing' and 'waiting' demonstrate inherently different power relations and signify the (de)acceleration of time in disabled people's recoveries. 'Pausing' indicates autonomy, as participants choose to slow down or speed up the rhythms of the day in order to become mobile. Yet participants refer to 'waiting' as a practice that is enforced by medical professionals, slowing down diagnoses and hindering daily recoveries. Thirdly, the temporalities of wheeling and walking illustrate the fluidity of disabled people's movements, as the pace, speed and mobile rhythms of disabled people are not so different to the normative accounts of able-bodied mobilities.

*Affective temporalities* involve the temporal affects that take place as material relations with other people, objects and things (re)create moments where participants 'feel better'. Firstly, feeling better relates to affective recoveries that involve others, shaping the bodily rhythms of disabled people and of family members. As the materiality of the home and 'normal' familial patterns are disturbed, (un)expected changes to routines have the affective capacity to (re)shape the emotional and embodied temporalities of others. Secondly, moments of comfort are (re)produced as disabled people 'pause', creating moments of stillness between different body-object relations at different times of the 'day'. These 'affective recoveries' challenge the circadian rhythms of the every 'day' and every 'night' time. Thirdly, the materiality of different body-object relations enables affective temporalities as disabled people forget 'real' time through moments of distraction, as recoveries are temporarily shaped by the placelessness of these affectual intensities.

In summary, the emotional, embodied and affective temporalities listed here, (re)shape and (re)produce different lived experiences of time, producing a range of complex moments in the *process* of becoming disabled. I make

suggestions for further research based on these findings in section 12.4 '*Future becomings*'.

## **12.2 Accepting differences**

In Chapter 2, I introduced a feminist conceptual framework, 'Accepting differences', arguing that the temporalities of disabilities, health conditions and illnesses tie together disabled people's identities in this research, rather than the categorical markers of physical, mental or sensory impairments. This framework has four key axes: embodiment/materiality, emotion, relationality and fluidity. These flow throughout the empirical accounts in this thesis and, I have argued, are fundamental in shaping disabled people's identities.

Firstly, disability is a lived experience that changes over time, and as these experiences are grounded in the lives of disabled people, they are both embodied and felt, taking place in relation to each person's life course. Disabled people express their embodied identities as they re-learn their bodily boundaries over time, as we saw in chapter 7 where Sue and Mark described recovering from medical operations following accidents and as a result of multiple hip replacements. However, in chapter 5, Steve and Robert experience fluctuating bodily changes, as their balance, eyesight and mobilities alter, for reasons unknown to them. Yet they are able to legitimate these emotional and embodied feelings, as they are diagnosed with multiple sclerosis. While disabled people feel these changes, the materiality of their bodies and the materiality of other items go hand-in-hand with their embodied experiences.

For example, the materiality of disabled people's bodies matters, as they discuss feeling changes, such as re-learning the materiality of the body when recovering from hip replacement surgery, or through temporary pain free moments when injections of sea snail venom are administered. However, Mark talks about moments of comfort despite having no feeling and not physically feelings changes to his body. In Chapter 9, I illustrated the materiality of the different body parts (feet, hands) used for walking and wheeling, as well as the

relationship to particular objects used, such as a wheelchair, NHS shoes and walking sticks. We also saw the importance of materiality in items used in the process of becoming well in chapter 7, through photographs of flannels, back stretchers, heated neck scarfs and the equipment used in cross-stitch, demonstrating the affective and temporal capacity of material items.

The arguments around the embodiment and materiality of disabled people's experiences in this research build upon recent literatures in social and cultural geography on time and identity (Jones, 2005). In particular Hockey et al., (2005) suggest that:

"[w]e need a synchronic view of time which can reveal the capacity of material items to mediate time in complex and ambiguous ways"

(Hockey et al., 2005: 138)

Their work highlights the role of material objects "for private grief, bereavement and continued social relations with dead partners" (Lorimer, 2007: 93), signifying the importance of time and non-human relationships in everyday life. In my research, the material objects used in recovery demonstrate the capacity of these material items to mediate time, as recovery is punctuated by 'moments' of pausing, slowing down and taking the time to be still.

Secondly, disabled people's affectual experiences connect to the second axis of the conceptual framework, emotion. The emotional and affective experiences of disabled people have been a dominant and binding theme in this research, unfolding through and in-between all of the encounters with participants. However, as my analysis of the temporalities of disabled people's lives contributes to the complex social web of multiple and criss-crossing identities that constitute disabilities, health conditions and illnesses, I provide a brief summary of these relations to becoming disabled, which cross over into the previous section on embodiment and materiality and next section on relationality.

The performance of emotional temporalities in Chapter 5, the non-representational affect of becoming well in Chapter 7 and the way that emotional memories stretch through time in Chapter 11, all challenge the temporal stability of disabled people's identities. Davidson et al., (2005) state:

'the emotional geographies of our lives are dynamic, transformed by our procession through childhood, adolescence, middle and old age, and by more immediately destabilising events such as birth and bereavement'

(Davidson et al., 2005: 1)

However, analyses of the temporal world remain largely unexplored in the emotional and affective geographies literature, therefore, the empirical findings in this thesis add to understanding the temporalities of everyday life and the life course. While I have also shown that there are certain challenges built into researching the intangibility of emotional and affective experiences, this research has also gone some way to addressing Colls's critique (2012: 433) that: "[t]he sparse reference to feminist theoretical work on affect or the body across non-representational geographies is indeed highly problematic and indicative of how affect has not been utilised to explicitly engage with bodily difference(s)'.

Thirdly, in Chapter 2, I argued that relationality draws a delicate balance between the "specificities of individual impairments" (Hansen and Philo, 2007: 494) and the wider social, material, emotional, cultural, economic and political processes that shape disabled people's identities. While I have shown that a range of events and acts shape disabled people's identities across the life course, from day-to-day routines to historical and personal acts, it is the relationship of these experiences to one another that contributes towards becoming disabled. In Chapter 5, we saw that understanding disability is shaped by the relationality of feeling, including the relationality of histories of social and spatial exclusion and oppression, which shapes the way that some participants feel at particular times. Participants discuss the relationality of feeling 'like a twat' or 'embarrassed'

when ‘standing out’, as acts such as falling in ‘public’ (re)produce the disabled body as not normal. However, emotional boundaries are stretched when Mark describes ‘going to the toilet’ at home, an act that is shared with other members of his family as the spatial arrangement of his home is temporarily altered and the bathroom door has to be removed to accommodate his wheelchair. In Chapter 5 and Chapter 11, the relationality of feeling shapes past, present and future feelings, as memories of childhood and memories of changing bodies stretch temporal boundaries.

All of the empirical material discussed by participants in this research, reiterates the identities of disabled people, rather than a singular identity. It is the coming together of gendered, emotional, material, affectual and disabled identities that matters, as identities become embedded in relations. For example, in chapter 7, members of the chronic pain support group measured the intensity of neurological differences (spondylitis, spinal problems and adhesive arachnoiditis) by emphasising the importance of other people’s pain, or by comparing pain in the present, to pain in the past. The findings in this thesis also demonstrate the relationality of affect:

“Attending to the affects that are going on performs a radical decentering of the body by taking a more *relational* ontology where neither the figure of the singular body nor individual, reflective subjectivity take centre stage”

(Bissell, 2010: 80, my emphasis)

While this research has shown the disabilities, health conditions and illnesses are undeniably shaped by and through disabled people’s embodied experiences, the affective capacity of material items, such as sofas, shoes, sticks and back stretchers, demonstrate that becoming well is about more than just the materiality of the body. The findings in this research, contribute new understandings to research that centralises analyses of the disabled body,

showing that both non-human relations are as integral to disabled people's lives, as demonstrated by the affective capacity of everyday activities such as standing, sitting and walking.

Fourthly, in Chapter 2, I demonstrated that rather than being a fixed condition or identity, disability and disabled people's identities are experienced as fluid and shifting set of conditions that often unfold unexpectedly in the accounts given by participants. Fluidity challenges the idea of fixed identities, and being disabled, as I have shown throughout this thesis by using the concept becoming disabled. For example, the complex temporalities of remembering illustrate the fluidity of the past, the present and the future, through memories. In Chapter 5, Mark revisits his memories at the time of his spinal cord injury, showing that what was once a present memory (the thought that he couldn't 'walk' his daughter down the aisle at her wedding), 'slips into the past' and becomes a past memory. However, in Chapter 11, Sue's childhood memories of growing up on various hospital wards for children stretch into her future, shaping her experiences of claustrophobia and her future identities as a woman, a daughter, a mother and a patient.

The fluidity of disabilities, health conditions and illnesses, is also addressed as disabled people take on 'new' identities, as we saw in Chapter 5, as they renegotiate new feelings about their bodies following diagnoses, and in Chapter 7 as they trial and error new practices, like injections of sea snail venom that eventually do not work, or CAM. On a day-to-day basis disabled people (re)negotiate new activities, new bodies, new feelings and therefore new identities. However, what is significant about this fluidity is that it challenges the bio-medical and social models of disability, showing that disabled people's lived experiences are constantly changing and in flux, shifting between one fluid set of conditions to another.



### 12.3 Methodological becoming

In this thesis, participatory approaches and methods were the driving force that shaped the four empirical themes emotion, recovery, mobilities and memories. In Chapter 3, I demonstrated that the fluidity of methodological and empirical temporalities contributed to the concept of becoming disabled.

Through using a grounded and participatory approach (Charmaz, 2006, Pain et al., 2007), the findings and the methodology itself unfolded *during* the research process, demonstrating the messy and fuzzy nature of weaving emerging ideas together with empirical evidence (Law, 2004, Tamas, 2009, Askins and Pain, 2011). In Chapters 4, 6, 8 and 10, we also saw how the analysis of the empirical material moved back and forth between the 'data', before, during and after face-to-face encounters with participants, whilst ethical temporalities unfolded in a similar way. Fundamental to this process of methodological becoming was the decision to use a 'politics of self-identification', leaving the definition of disability open by allowing it to develop by 'going to' participants at pre-organised groups associated with disability, health and illness, and enabling participants to 'come to' the research. However, whilst an important goal in this research was not to label disabilities, for some 'disabled' people, particularly in relation to sensory disabilities and impairments, labelling disabilities or health conditions is an acutely political issue. For example, D/deaf people represent their own culture (Skelton and Valentine, 2003), those on the autism spectrum promote acceptance and respect of their own neuro-diverse label (Davidson, 2007, Ortega, 2009), while the word 'crip' is reclaimed as a personal politics.

In Chapters 4, 6, 8 and 10, I have shown that placing a certain degree of 'control' in the hands of participants (Kindon, 2003, Parr, 2007), as well as valuing and learning from participants' experiences, produced different degrees of participation. For example, in Chapter 4 and Chapter 6, participants took control of drawing timelines and taking photographs. This was particularly important for the non-representational accounts that unfolded in this research, as illustrated in Chapter 6, as despite the critique of affective geographies as apolitical, it was exactly the political purpose of using participatory methods that

enabled findings on participants' affective recoveries to develop. Yet, we saw in Chapter 8, how the materiality of certain items made some participants feel uncomfortable, whilst others decided to opt out of the research because their expectations about 'research' unfolded differently, as discussed in Chapter 3.

In Chapter 10, I illustrated how 'deep' participation developed with one participant, Sue, who wanted to write diary entries, in order to challenge her memories. However, while this approach worked for some participants, including Sue, not all people want to have deep engagement with research, as suggested in Chapter 3. Further, while it was the role of my research not to determine particular social or cultural identities or categories, it could be argued that there is a certain research culture surrounding participatory and feminist methodologies, which do not suit all people. Davidson (2008) describes how feminist methodologies were inappropriate for autistic people in her research, who didn't want to be given the option to be involved in decision-making.

While participatory studies of disability are relatively rare (Kitchin, 2000, McFarlane and Hansen, 2007) they have great potential and produce rich data, as shown in this research. All of the ideas, explanations and questions in this research were shaped by interactions with the participants and data, as methodological techniques enabled empirical themes to emerge.

#### **12.4 Future becomings**

In this final section I outline the potential for future becomings, which emanate from the theoretical, methodological and empirical temporalities explored in this thesis. Firstly, I discuss the challenges and opportunities that PAR with disabled people presents in the context of the methodological becomings explored in this research. The emotional temporalities associated with embodying and (re)negotiating disabilities, health conditions and illnesses, show that as disabled people feel changes to their body/ies this may impact on their feelings of participation i.e. during periods of relapse. The challenge of 'accepting' non-participation sits along side 'researchers' own feelings as levels

of participation often fluctuate over the course of the research. However, this acceptance also reflects the ethical commitment and values of PAR, by opening up to and understanding disabled people's needs. While these experiences might lead to (re)engagement with participants at a later date, significantly it is the temporal relations that matter to future becomings of PAR.

By taking time to engage with slow geographies (kinpaisby, 2008) there is more time for the temporalities of PAR to develop, such as the time taken to 'do' PAR, to build relations of trust, and to incorporate the temporal capacities of fluctuating energies in disabled people's lives. However, the challenge of slow geographies remained fixed within the 'timeframe' of research projects and external funding (See Pratt and Alliance, 2007 for a discussion of the longevity of PAR), specifically in relation PAR PhDs, which are predominantly single, authored<sup>71</sup> (Klocker, 2012). This leads to my next point as I discuss the types of disability politics that might be enabled by a focus on disabled temporalities.

Secondly, it is through the process of conducting a participatory project and revealing the temporalities of becoming disabled that scope for a specific disability politics has unfolded. My concept of gentle geographies draws on the use of less intrusive ways to 'get at' the temporalities that affect disabled people's every 'day', every 'night' and lifelong experiences, ensuring a more subtle temporary politics of disability. Shildrick and Price (1999) discuss the demoralising practices of self-surveillance, which have been used in the past to understand the frequencies of disabled people's health and social care needs. However, on the other hand, gentle geographies have the potential to respect disabled people's lives and to provide insights into the temporalities that matter in order to produce appropriate change or 'action'.

While 'action' and 'activism(s)' comes in different shapes and sizes (Horton and Kraftl, 2009), a gentle geographies approach is particularly emblematic of the 'quiet politics' discussed by Askins (forthcoming). Askins

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<sup>71</sup> While PAR is frequently conducted with multiple participants, the commitment to reaching the final submission deadline by producing a completed PhD thesis, which is usually text based and written by 'one' author, is the responsibility of the PhD 'researcher'.

demonstrates that while small scale relationships of care matter they are equally as mundane and banal as the (re)presentation of everyday life. Therefore a (re)engagement with a specific disability politics through the lens of gentle geographies would potentially avoid feelings of marginalisation, which are often (re)produced as disabled people endure demoralising and bureaucratic testing, in order to receive financial and health care assistance.

Thirdly, I suggest the potential for future becomings based on the temporalities discussed in this thesis. By defining disability in its own terms, research could expose the way that definitions vary according to specific disabilities, health conditions and illnesses. We could learn more from disabled people, including the complexities and relationality of disabled people's lived, both in cultural and geographical contexts. For example, future research could explore the emotional temporalities of chronic illnesses across the life course by capturing a range of ages, including children, youth and particularly those adults between the ages of 18-40, an area that remains uncovered by the empirical findings in this research. Future becomings may explore (re)openings and (re)beginnings in relation to juvenile arthritis, and cycles of time across different types of multiple sclerosis, including progressive MS, as well as examining the way that the longevity of different chronic illnesses affects everyday and lifelong temporalities.

By exploring the *embodied temporalities* of disabilities, health conditions and illnesses, future becomings might do more work to examine the historiographies and temporalities of medical practices, including the rhythms of and relations between hospitals, 'patients', 'professionals' and other people both 'now' and in the past. This would explore the role of power relations and the performance of emotional and gendered temporalities in the hospital. In addition, this might explore the bio-ethics of medical 'accidents', responsibilities of care and the significance of these histories to disabled people's emotional recoveries.

Finally, future becomings might engage with the affective temporalities of neurological differences, aiming to understand the way that bodily and temporal rhythms of the every 'day and 'night' time are shaped by varying intensities of pain. Future becomings might explore the challenge of addressing the (non)representational complexities of painful identities, developing creative and engaging methodologies that are appropriate for the varying energies of participants with chronic pain. One way to bring participants together in order to explore the relationality of affect would be to access participants at 'home' using online methods so that participants can share their experiences with others, uploading photographs and videos of their everyday routines.

## Appendices

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### Appendix 6.1.1: Chronic pain advert



Department of  
Geography

#### Recovery and chronic pain

You are invited to take part in a research project run by a researcher from Durham University, where you can talk about living with chronic pain. Following initial discussions with the Chronic Pain Support Group in Durham in November 2010, conversations in a relaxed environment uncovered the topic of recovery and pain over time.

In these face-to-face encounters recovery and pain were discussed in terms of: alternative therapies and medical appointments; organising daily routines; as well as feelings associated with recovery and living with pain. This research project is also interested in talking to members who do not attend the Chronic Pain Support Group meetings, but use the telephone support service.

You can get involved with the project from the comfort of your own home – please **telephone** or **email**; or come along to the next Chronic Pain meeting on 22<sup>nd</sup> March 2011, where we will talk about ‘daily pain’ and ‘pain in the past’. We will be using talking, writing, drawing and/or diagramming techniques to explore the processes and practices of recovery used in chronic pain that are relevant to you.

If you would like to speak to me before this time, please contact me as follows:

**Jayne Sellick**    Tel: [mobile]    Email: [j.m.sellick\[at\]durham.ac.uk](mailto:j.m.sellick@durham.ac.uk)

## Appendix 6.2.1: Photovoice Instruction Sheet

**Contact:** Jayne Sellick **Tel:** [number] **Email:** j.m.sellick@durham.ac.uk

The purpose of this task is to consider the processes and practices you use as part of recovery on a daily basis; as well as pain and recovery in the past

### The task:

1. Using a camera try to capture significant places, people, objects, moments, items, rooms, etc that represent, show or illustrate what pain is like
  - a. On a day-to-day basis
  - b. In the 'past'
2. The aim is to use all of the film, firstly taking photos of daily pain and how you experience recovery. Secondly, thinking about pain in the past

### Tips for taking photographs and completing the blank table, to show what you were thinking when you took them.

- a. **What?** Objects, items,
  - b. **Where?** Places
  - c. **When?** Time of day
  - d. **Who?** People
  - e. **Why?** Objects, items
  - f. **Time?** Moments, periods of time, length or duration of pain or recovery
- It could be **related to a task** you are carrying out;
  - How you **feel** at the time (this could be related to your pain threshold i.e. worst pain you have experienced so far);
  - **Where the pain is happening** (either in your body or the place where pain happens – at home; in a particular room or place; who is involved with your experience of pain – family; friends; other professionals
  - Or you could take a photo of particular task that causes pain or how you complete that task in relation to your pain
    - g. These may represent different times of day, duration of pain

**Finally, please post your camera in the envelope provided with your completed table; or send digital photos from own camera.**

**Return By:**

**Photograph**

**When**

**Where**

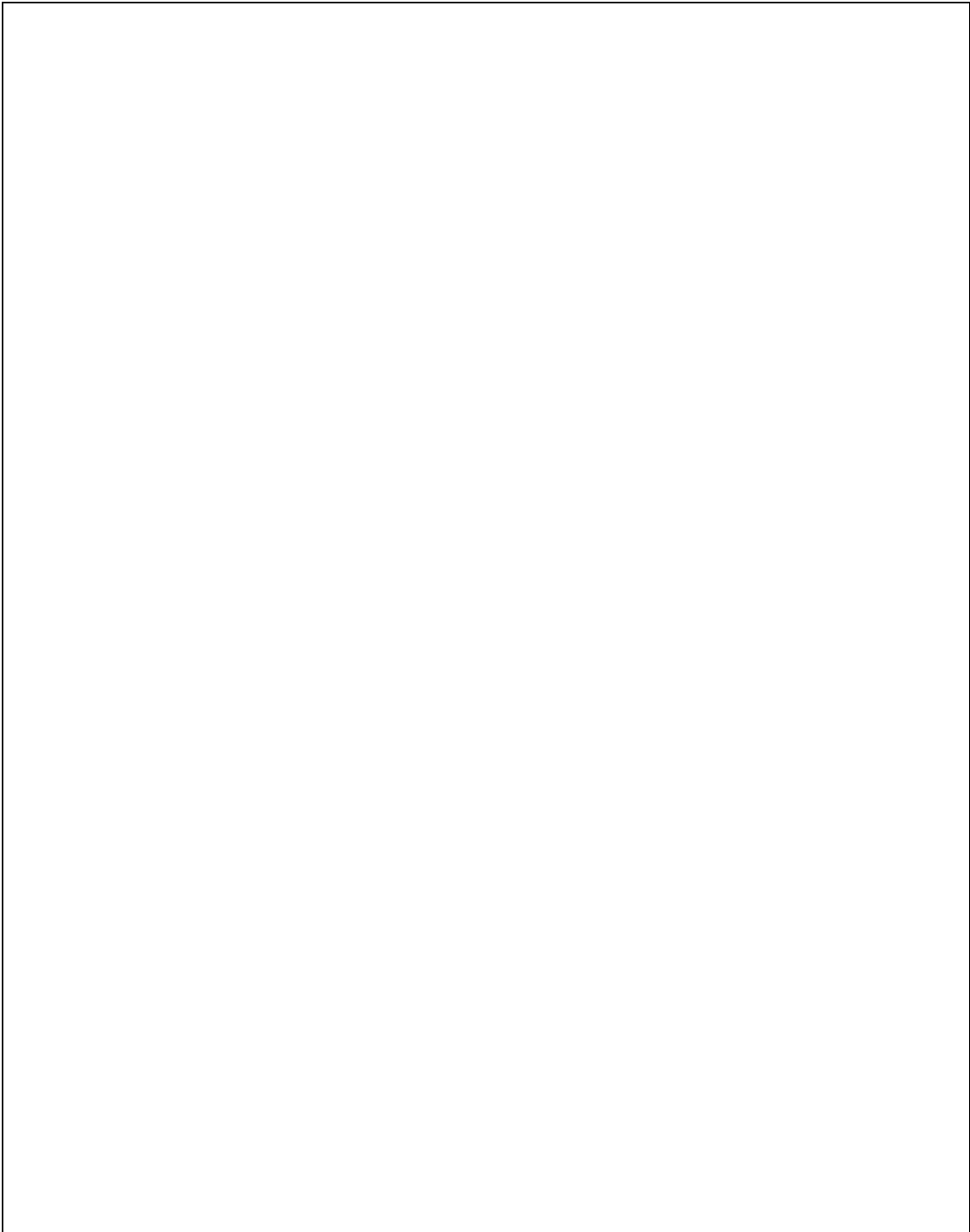
**Why**

**Relevance to time**

**Change over time**

**'Present' or 'past' pain**





## Appendix 10.1.2 Diary Entry: Childhood memories

### Diary 1 from Sue, April 2011

With very little memory of my younger days I wonder now how much of what I will tell you about are actual memories or imports of perception that I have engraved from what others have told me, by looking at photos, by listening to others perception of how they thought I managed. Mother has always been reticent to talk about these early years in great detail and now when she will, if I ask question, I only get small bits of information at a time and you know instinctively that to persist would not be a good thing to. But never the less what comes next is a sequence of events that came back to me when forced to remember 'what my first memories were' when taking an O' level English Evening Class. So brutal was the recall that once I had written the essay I could not read it or go back to reconstruct it how the teacher had taught me. So since this class in 1987 I have wondered about my memories and really whose they were?

Having spent some years in [*name of*] Hospital for crippled children in [*north east England*], I was now about to go home. I was around 5 years old and until that time home to me was a very long wooden ward, with a fire stove in the middle, where all the activities I had ever known I had watch happen from a metal cot, where through the bars I saw the only world I had any connection to.

Having been born with little of my hip formed and a very small jagged femur head I had been secured to a metal frame by being wrapped in a plaster cast, this would allow further growth that hopefully would mean I could walk without falling down as soon as I put feet to the floor.

This trip 'home' I remember being very excited about, as going out in the cold was not usually allowed for children with my condition. Carried to an ambulance with a coat on – another first – I would not lie down but wanted to see out the window during the journey. Not usually allowed, and anyway the glass in the main part of the windows was so black it made it difficult to see out of then. So I remember being supported enough by the ambulance man to allow me to see out of the little window above the black one.

Everything was white and although I had seen snow, I had not seen so much and anyway I had not left the hospital grounds (which were small) and therefore I had no conception of this amount of space; empty space with no nurses, doctors or other children in; big empty space.

The journey was long and once I arrived I was taken into a house that looked big but upon entering it got smaller and narrower. As the walls closed in on me I got more scared and upon been passed to a person who I occasionally saw at hospital I saw the ambulance man turn to go. This was the last straw and I cried – loudly. To pacify me I was shown round the house in the arms still of this woman; them all trying to make more of the room I was to sleep in. In this room was a wooden cot, where as my other bed was a metal cot, but somehow it

seemed not only smaller but not as inviting. No matter what they showed me nothing stopped me from crying and eventually it was agreed that I would be given back to the ambulance man and taken back – I presume to the hospital...because from here my memory stops so I do not remember what happened next. I presume that I went back to [*hospital*] – but is that correct, I could never be a 100% sure.

I cannot say for sure if this memory shaped any of my future – but what it did do is make me understand why I did some of the things I did later in life; like not be able to go into a cupboard without someone holding the door open – this coming out of the length of time I spent in such long wards, not just in [*hospital*] but others, making me almost claustrophobic.

This outcome took years to combat and still comes back if I am not in control of the situation I am in.

It had an effect on how I brought up our children.

I was fanatical about being around all the time – or if not me making sure that my husband was and when both of our sons went into hospital during their early years I went with them, stayed with them in hospital and even if this was not allowed I am sure that I would have fought tooth and nail any authority to do so.

This need to ensure that their mother was with them while in hospital never even allowed me to include their father – it never dawned on me to ask if he wanted to take them into hospital or be with them – it was my job and even he was not going to be given the opportunity to do this.

It was therefore fortunate that I had a husband who understood why I needed to do this and did not feel as though he was not considered or part of the family. Looking back I think he understood me better than I did myself.

Having been taken – there is no other word for it – from my parents at 14months (this happening at [*name of town*] Bus station of all places!) and handed over to a nurse who then took me to [...] Hospital (how we got there I have never found out - was it by bus or ambulance and if it was ambulance why not got to my home then?) for a significant length of time.

I lived the rest of my life until I myself became a mother thinking that it was because of the way I was born that my parents did not love me the same way as they did my older sister and then later when [*my younger sister*] was born 7 years after me, it showed to me even more how much they loved her more than me. I never had a jealous thought against either of my sisters or my mother because I thought I was the problem.

I am absolutely sure that my mother did not/does not think that she loved me less than her other two daughters.

Although she did tell a good friend of hers that she did not feel she had a second daughter because of the little time she saw of her.

But rather than get angry about this when I was told, I only understood why she would feel like that and why I would feel as though I had never been loved the same way as my 2 sisters. Knowing this though did not stop me feeling an outsider of a family I should be an integral part of then and now. But as time went by, as I got older, I became angry at what I had lost and never experienced – the childhood with my siblings, the family inclusion, the love that came with all that and the ability to feel safe within that family and the ability to rely on them, be with them, be included by them, be considered as part of the family.

Along with the loss of learning the ability to socialise with others, whether they were other adults or children (that were not in the hospital).

They say that time heals – but for me it only demonstrated more and more what I never had, missed, lost and never experienced and what is worse with no one to blame.

You feel as though you want to aim this anger at something – but there is no one, nothing and so this anger has no direction but yourself.

Ensuring that this does not make me bitter is a full time job and often very difficult to control as the older you get the more your memories are important. But what if you have so few?

My children say they never felt smothered; but always knew that I was there if they wanted or needed me. They say that I gave them a secure childhood and added the understanding of disability within a family and it made them considerate to others and their needs – a better rounded person one of them said.

But in the other direction – mother and sister – my independence has given them the opportunity to not feel responsible for me once I was married and without realising this (I like to think) alienate me and not include me in what they do as much as I know other siblings of families are. Because I managed so many operations and the consequence of them I could manage the rest of my life in such a singular way – almost saying that you can manage without us, you have shown us that...but not realising that really I should not.

### **Appendix 10.1.3 Summary of childhood memories**

#### **Diary 1: Childhood memories, Feedback, May 2011**

The notes that follow are a mixture of my thoughts and additional areas that we could potentially discuss.

This first extract outlines an account of your 'first' childhood memory, one that you produced as an adult in an English class. As this research is interested in change over time, including how emotions may change over time, the relevance to this particular account lies in the way you thought about this memory at the time you first wrote it (in class) and how you think about it now.

I would like to explore some of the emotions you outline here in further detail at a later stage, including how you were 'very excited' about certain parts of the memory; how you were experiencing some things for the first time; and how you think about some of these memories now.

Space is also important in this account as you discuss the shrinking of space as you enter your parents' home, as well as the relationships you encountered once you were inside this space. Further on in the extract you discuss the feeling of living in lots of space in the hospital and how in the future you felt less comfortable in smaller spaces. We can discuss the significance of these spaces to you and how they may have shaped your experiences at the time, as well as in the future.

Your discussion of the way past relationships shaped those with your future family is interesting, and equally how according to your sons, it shaped both of their childhoods. I think that the section referring to your personal feelings associated with "the way I was born" and the relationship(s) with other members of your family is also important to the way you formed relationships with others particularly your husband and children.

Near the end of the extract you make reference to how your emotions, particularly those of anger and bitterness that have become more apparent over time; suggesting that, "the older you get the more your memories are important". There are also the memories associated with how once you were married, how other members of your family became less responsible for you. Again, I feel that this is something we can discuss in further detail.

### Appendix 10.2.1 Guidelines on recovery and time

Write about the process of recovery following a hip replacement operation. You could focus on your first hip replacement and include:

The processes involved in recovering from the operation including how you felt at the time (considering this was something new to you at this stage).

These feelings could be associated with the actual operational procedure, the outcome (or intended outcome); those feelings before, during and after.

What is the role of others in this memory:

- i. Doctors; physio; other medical professionals?
2. Family; friends; others?

What were the expectations of these above?

Can you discuss references to time i.e. time to recover, time to complete exercises etc

Can you describe daily tasks or routines involved in this process of recovery?

In terms of the practices or processes you were asked to go through in the recovery process, could you talk about who determined and chose the practices? i.e. the physio's schedule v. your schedule

Was there anything in particular that influenced your choice to do more than they suggested; or the things they told you not to do? i.e. something in the past?

Could you talk about the feelings associated with what this hip replacement could/would do for you?

In your timeline you suggested how it allowed you to have children

Secondly, do you think you could compare how the replacement that you found psychologically difficult involved a different process of recovery or different feeling(s) than those experienced in the above example? This could include emotions as well.

## Appendix 10.2.2 Recovery and Time

### Diary Entry 2: Recovery and time

**Write about the process of recovery following a hip replacement operation. You could focus on your first hip replacement and include:**

**The processes involved in recovering from the operation including how you felt at the time (considering this was something new to you at this stage).**

*It might have been something new but I was not aware of it at the time.*

*All I was bothered about was stopping the embarrassing way I use to nearly hit the floor after each 3<sup>rd</sup> or 4<sup>th</sup> step – making it look like I was drunk and unable to walk properly – I had no aids then.*

*The striking pain I experienced was debilitating too.*

*The pain came and went so quickly that that really was not the main problem but it was the not knowing when it would occur that made you live your life on the edge wonder ‘when next’? But the actual recovery process was long and frustrating.*

*Because I was on a Balcome beam – like a large macarino set around the bed – I was there for the time a broken bone needs to heal; around 8 weeks.*

*I was incapacitated in such a way as to stop as much as possible the movement in the hip and especially the knee – therefore the hip.*

*For the first week at least I was not allowed to sit up or move; then I was slowly cushioned up to a sit up position which, whether I should have or not, allowed me to move sideways in the bed.*

*To ensure that I would not move the knee and therefore the hip, I had a steel rod positioned through me leg below the knee – not through the bone.*

*This automatically stopped me from bending the knee at any time – the steel bar came out of the leg each side and was the only aspect that I constantly remained concerned about in case people touch it or knocked it.*

*I also had weights attached, by a wrap of elastoplasts round my leg, (this later had to be ripped off as I became allergic to it and caused at least 2 weeks longer in bed and hospital as the skin that came off with the elastoplasts healed) attached to me to ensure that the femur would mend away from the socket and keep the liquid that allowed the movement of bone running between the hip socket and femur bone head, from rubbing together.*

*Because of the amount of time in bed and lack of movement before the hip was pronounced stable, I was too weak to get from the horizontal to the vertical in physio without fainting and being sick – this took a full week to achieve.*

*I was taken to physio every day from the ward and placed on a bed that would move another section towards being vertical for a certain amount of time that was extended each time and then lay back down again!!*

*The following week I was given exercises to move the legs to get the strength back into them; I was already doing basic exercises in the ward – moving your ankles, turning them in circles bending a stretching my right leg, tightening muscles in both and letting go were some that I remember.*

*I found this hard as the scar under the left knee caused more problems than it solved then and during my life and in my usual 'wanting to get on quick' mode I was constantly watched to ensure that I did not over do it.*

*Mind you blacking out on a regular basis also stopped me from doing that! When you have been laid down for so long and you stand up for a little time your whole body feels so heavy...like getting out of the water in the swimming baths...therefore everything seems to take even more effort than normal and drains you so quickly from doing anything else afterwards is nigh on impossible.*

*I was so tired after these visits to physio that all I wanted to do was sleep, but usually when I returned it was lunch time and until I got strength back I remember feeling sick after each visit.*

*When the me, the main time in hospital is around going to physio and if you do not work at it takes longer to get out.*

*So as time progressed I would wheel myself down to the physio and do my exercises going earlier and earlier so no one noticed and do more time until someone did notice and then back to the ward.*

*The Physio department made a film of the way I walked and did this as a teaching aid for Doctors and physios too.*

*The time between the parallel bars walking toward a mirror, with large dots on my hip bones trying to keep these dots level as I walk towards the mirror are ingrained in my mind and probably gives reason to why I do not like to look at myself walking toward a mirror in any way!!*

*The [hospital] had a Hydrotherapy pool then and I was in that every other day doing exercises I was not able to achieve in the gym room, I loved those times and later when I went home I use to go to physio at [town name] hydro pool which was bigger and swim in it when no one else was in it.*

*When eventually I was allowed home – at least 6-9months later – I was walking with crutches and walking well, no pain, but plenty of frustration and tiredness after short bursts of doing anything....but progressing.*



*I would be going to physio at hospital for the next year and seeing my surgeon on a 3 monthly basis.*

*I was unable to go out on my own, or possibly more to the point of not being allowed to and this was so so frustrating after having the freedom before I went in of being my own person.*

*I did not fully recover before I was in for further surgery – the shortening of my right femur about 4” to stop the deterioration of my back and to enable me to walk straight and not have the waddle I had associated with the condition, but as they say that is another story.*

**These feelings could be associated with the actual operational procedure, the outcome (or intended outcome); those feelings before, during and after. I think I have told you about most of these as I have done each section except the following -**

*This was the only time that I found that there are people who take an instant dislike to you and want to make you not only feel small but not worthy of compassion or consideration and for some reason want to punish you for what you are and who have the power to do so.*

*You are very venerable when depending on others you do not know and this was the first time that I had been in an adult ward.*

*Then there were auxiliary nurses – they did the changing of beds, meals, getting bedpans, washing – anything none medical.*

*But they are also the people who saw you the most and so should pass on any concerns from the patient or they find them selves.*

*I constantly told this particular one that the Elastoplasts was driving me crazy because of the itching.*

*She never passed it on and it was nearly a week later when my surgeon Mr. [...]came round and upon seeing the swelling and irritation when taking the covers off me (the few I had on!!) that something was done.*

*He was very angry – he usually was but like this I had never seen him and when he asked me how long it had been going on for he had to leave the ward to talk to the Sister before he came back and apologised to me.*

*He asked me to explain what happened and so I told him and also that I had told the auxiliaries who I presumed would let the nurse know even if it was just at report back time at the change of shifts.*

*So the only way to maintain the tension was to have crape bandages round my leg to secure the rope that held the weights to me.*

*Of course no auxiliary nurse was ever present at ward rounds, but somehow she presumed I had fingered her and with a guilty consions, felt as though upon the dressing down the Auxiliaries got that it was mainly intended for her – I know this because she told me when she could get me on my own.*

*Consequently the bandages had to be redone often and if this woman was on I was castigated remorsefully as she did the procedure again and again; so much so that if she was on I would bend pass the 80degrees that I should to pull the ropes myself and try to secure them.*

*I often got caught doing this and got told off.*

*I had a special relationship with one nurse who I told and although she never said she had not I presumed she had not reported it as nothing was done.*

*This went on for months and eventually I told my mother.  
Now it had to be bad to tell her.*

*She spoke to the Sister, Sister spoke to me; I was moved nearer the Sister office to be watched and eventually she was moved to another ward!!*

*For quite a while, when I eventually came to live [here] 3 years later, I use to see her often; each time I felt physically sick, but she never recognised me.*

*You see she use to do other things like leave the meals just out of reach, take longer to wash me so that I got cold, leave my bed cloths wet, when I tipped a bed pan or washing myself I spilt some water, making me wait for a bed pan and again to come and collect it saying she forgot because she got called to do something else .*

*I was just 20 and had never experienced this before.....and as I was brought up to believe from [hospital] that I was the person who was bad and therefore was born like this I took it all on the shoulder thinking this was my punishment - until I could take no more and told my mother.*

### **What is the role of others in this memory:**

#### **i. Doctors; physio; other medical professionals?**

*Already mentioned in other section.*

*There were no Occupational Health people to assess your home; so nothing was ever done there and no Community nurse ever suggested anything like that to mother.*

*My mother only found out too late that I, she, could have had financial help with shoes and clothing when I was 18, then it had just come in that 18 you were an adult so she could claim nothing when she did find out!*

*Benefits for children might have been available and even if mam wanted to dad would not have let her – no one was to give him charity!*

*Yet he paid National Insurance and took Sick Pay from the Union.....but that was the way he and others were brought up.*

*Whenever I needed new shoes they had to be built up and Mr. [...] would do this.*

*It meant that shoes had to be bought at least a month before they were needed as they took 2-3 weeks to get built up.*

*They had to be up to the ankle and with shoe laces as wood was used then and this type of shoe was the only one that would secure it to your foot.*

*Later cork was used but the type of shoe bought for me never changed until I was 16.*

**Family; friends; others?**

*I had no friends up North – they were all down south where I was last working – they remained friends for life – but distance and money stopped us from meeting very often but letters were our main stay of communication.*

*Though I thought I had a real friend that I had met from my swimming days that I went around with for about 4 years – but really she was a friend only if you did the running around after her and then when she emigrated to South Africa, while [partners name] and I were still dating, she never bothered to write back. She only once came to see me in hospital ever, and only because my then boyfriend brought her with him.*

*The friends from School were never friends, as looking back I do not think they knew how to be friends with someone like me and because I did all my home work in the break times (the teachers were scared in case I would get hurt so they did not allow me to go out to ‘play’ until I was a teenager – and then it was too late!)– because I had no one to talk to/befriend with, I was eventually called names for always having my home work done in the time asked for.*

*My boyfriend at the time came to see me often – but due to finding him in bed with someone else at a party we were going through a difficult time at the time I went into [hospital] for the operation we are talking about.*

*My mother hated him, no exaggeration, so getting time together was always difficult and meant lying often.*

*When I was well on the way to recovery I met my husband and that meant a lot of visits as he lived in [name of town].*

*As for my parents they came when they could; even though it was mam who learnt to drive first, they rarely came during the week and my sister [...] got an aversion to coming to see me when I had anything medical showing on me.*

*She was not initially allowed to visit me when I was younger –hospital regulations –but later mother kept her away on purpose and so I think she developed this aversion from that.*

*Even now, because of my independence – which was forced on me by the circumstance of my life – they do not visit; mother or [sister’s name].*

*I have many acquaintances and people do pop in – but in hospital they disappear and then, of the time I am writing about, were nonexistent.*

*I know the role of visitors – but I am not sure that my parents did the supporting I needed then, before or now. I learnt very early to suppress my feeling in front of my mother as they only meant that she went home feeling bad.*

*So I became the 'strong girl', 'family hero' and worse of all 'family brave girl' who just got on with it without moaning or complaining.*

*What was the reasoning behind that?*

*I still had to do it, put up with it, and endure it – not them and the quicker I did the quicker it was all over.*

*They also never thought that I had no choice but to do these things and that each op was the last and it is as though they were telling themselves that so they could cope!*

*The washing of clothes and bedclothes was mainly done by my mother and along with replenishes in things to do and sometimes some 'goodies'.  
But because of the irregular times they use to come I often would have my clothes washed in the hospital and later taken home by one of the nurses – which was not allowed really.*

*I cannot truly say that my parents did not support me – it might sound like it, but that is not true.*

*Although they were often afraid of what I would do next they never stopped me from trying new things and although the rules at home for a 20 year old were old fashioned and therefore unbearable to live with, I know they did their best with what they had and the information they were given and with the old fashioned ideas that were instilled into them as they grew up.*

*[My partner] was a different matter –and another story!*

### **What were the expectations of these above?**

*For some of them a full recovery and even when they were told about what this operation did and that it was not a cure for some reason that is how they saw it and so treat me as though it was such.*

*In that I mean that they expected that this was it I would now be completely OK.*

*It was something that on this occasion I never thought about at all.  
Going through it, experiencing it, recovering from it was all that I thought about.*

*What my parents thought of I do not know.*

*For something that was a big part of their and my life it was one area that we never talked about at all.*

*It was all said in front of the surgeon and then apart from relying that to dad, who very rarely came to the appointments due to them being during the week and him being at work, nothing in front of me was ever discussed.*

*From what I now know this was normal, not only in those days but certainly between my parents who had the attitude that if you do not talk about it, it is not there and you can pretend that it never existed – mam still does this.*

*OK when you are the child and you are not always under discussion – but later in life it meant that I often had to decide things on my own knowing that my parents did not want to discuss it through – discussion made meant you had to acknowledge that it was a problem and make a discussion so why not leave it till you need to talk about it?*

**Can you discuss references to time i.e. time to recover, time to complete exercises etc**

*Already included above I believe.*

**Can you describe daily tasks or routines involved in this process of recovery?**

Getting dresses is simple to most people.

But when you are not allowed to bend at all, cannot lift your legs and have little energy – it can be the most laborious job to start the day off and the most embracing.

In hospital you have your wash...but how is this achieved when you cannot sit up on your own to use 2 hands, when you are laid flat and cannot get to the flannel in the water and are scared of tipping the bowl over therefore instigating a complete change of the bed - which is painful to do when having had surgery or a place on the side of your hips that is still very tender with sutches in?

So what did I do.....I lied often about having had a wash.....I would wet my face to dry it – it has a different feel to it when it had been wet and the nursed use to check!

Then I would leave the soap in the water – thus giving it the cloudy look of use. Why did they not assist me?..... because with only 6 nurses – working in pairs for all the ward of up to 24 beds, of which they had to get this all done before 8.30am , always, they had so many to do and it quickly became know that I would try to help myself .

I quickly say I was rarely asked - it was just assumed that I would not need them. 'Oh [Sue] can manage! '

(Of course this was well after the op – before that they would have to have dealt with me too – on those occasions I hated them washing me. Why? Because when you wash someone else you are never as quick with the washing off of the soap and by the time they get back to you with the wet cloth the soap has dried on you!!

And you get so cold so quickly with no covers as well – the there is the embracement of it all)

Only at bed-bath times did I get the ‘full treatment’.

While on my back meal times were no better, trying to eat on your back with a foot up in the air of bottom of the bed on your own is hard.

You have to chew more as swallowing is harder to achieve at the wrong angle. But trying to fork your meal, bring it to your mouth without it dropping on your bed...makes meal times very interesting and longer.

**In terms of the practices or processes you were asked to go through in the recovery process, could you talk about who determined and chose the practices? i.e. the physio’s schedule v. your schedule**

It would be the surgeon who would inform the Head Physio what the outcome of what he wanted for me.

I suppose in my case it would have been to get me back on my feet and walking again.

Then he would want to see me on a regular basis to assess what stage I was at and with the physio input come up with future ways to continue to build up my strength and power.

The problem with me is that in the past operation had cut through muscles to get to the bone; where now they have realised that the muscle is elastic and therefore they leaver them out and pin them to the cover sheet/frame until the bone job is done and then slowly let them go back.

Consequently I had little muscle power to use to lift my left leg up and bring it through and then take the weight of the right leg while it was brought through for the next step.

I therefore had to build up the power in the parts of muscles I had and get those that are weak due to long stay in bed, to develop.

I was 20 when this operation was done and at that time they dealt with the hip replacement as a broken bone and at that time they disabled the bone for 16 weeks. So I was incapacitated for 16 weeks in bed, unable to sit up for 3-4 of the first weeks; with the end of the bed up on blocks by a foot.

My left leg was attached with Elastoplasts to weights to ensure this was keep up at a certainly angle and incapacitated.

On top of this there was a ‘pin’ through my leg, below the knee, that missed the shin bone to ensure that I did not bend my knee thus moving the ball in my hip.

The following weeks I was able to sit up and move, as long as I was not rotating the left hip – I assure you this is achievable...just.

Because of the amount of time I was in bed my muscles had deteriorated considerably and it took the physio a whole week to get me from being flat to being vertical without passing out.

Then a further month to get me walking at all and the following year to build up my muscles to walk on my own- even then still with aids.

I needed a built up shoe on my left hip – it was nearly 6” at the beginning but on this occasion it came down to 4 and half and that had to be done before I could start to walk.

Which meant a Mr [...] came in to measure me in Physio and brought it back for a fit.

The build up was then, in wood!

I use to be placed on a bed in the physio department and have a sling place on the knee and thigh which was then attached to spring whose coils were tensioned in different degrees to make your muscles work as you moved the leg in these slings.

This system – still well used now – could be adapted to develop all muscles in your leg, hips and pelvis area.

You started with only 10 minutes a day, and then proceeded onto 30 minutes. Eventually though, due to my persistence I was there most of the day, with Hydrotherapy (exercises in water) in the afternoon. There was no ‘my schedule’ and only the desire to get as fit as I could to get away from home and be able to contribute to the relationship that [partner’s name] and I had by then.

Until I met him in hospital I had thought of going abroad to be a Nanny.

I had not told my parents about this as I know they would have stopped me; but meeting [my partner] meant that I had a decision to make and that could not be made until I had got as physically fit as I could and the surgeon had signed me off. The decision was made 2 and half years later.

**Was there anything in particular that influenced your choice to do more than they suggested; or the things they told you not to do? i.e. something in the past?**

I was in the [...] Hospital as a child and made friends with a boy who was very ill; further surgery was needed and although I did not know then it was of such magnitude that his life was in danger during it, but just as much if he did not have the surgery.

Looking back now I think he knew; he seemed to have an aura about him that enabled him to be a child but one who sometimes talked like an adult but with a child’s voice.



We use to sit for ages in the communal room at the bottom of the ward and play – but I mainly remember the talks.

I was also very friendly with 3 other girls of my age in the ward – but yet they never ‘ribbed’ me about him but just left us alone and they never seemed jealous either.

Somehow we got talking about what we would do after we got out – well at least I did but he never would say and I knew never to push him after trying only once and getting no were.

I have always had sensitivity about people like this and have experienced many events in this area – out of body experiences and out of body pain control being 2 of them.

So the way he talked never concerned me or scared me. I talked of wanting to do things I was incapable of doing then or ever – impractical things like being a ballerina.

But he use to lovingly chastise me for such unachievable dreams and only consider talking about the possible ones.

The day before he left the ward (I cannot remember if this was the day of the op or not) we spoke again about the future and he asked me to do something for him.

I thought it was pinch some of the sweets that Sister kept for us!! (the parents were not allowed to bring anything into the ward that was food, it was kept communally to be given out to all children in the ward at a certain time of the day - something as I child I can remember being very disgusted about) after his op when he was able to eat.

But no, he was to ask me to take lives opportunities when they were offered and live my life to the full.

I made a promise – which he did not ask for – but I felt that he needed to hear from me at that time.

The thing was that I took this to heart and tried my best to live by it all my life. Yes, partly in his place but also to ensure that I had a life that was as much outside the disability as it could be.

He never came back; no one told us why not, but implied that he had either gone on to another hospital or home, without actually saying, but somehow I knew and later through inference I found out he had died.

With the comings and goings being so regular and the amount of wards I had experienced over the years, even at that age, I was use to making friends and

finding they had disappeared the next day; sometimes not even been able to say goodbye – the parents often hurrying the child and been given no time to say goodbyes (I was told by a parent later that this was because they saw all the experience in the ward as being of a negative value and wanting the child out of that experience as quick as possible back at home to replace it with the positive family values! Impossible and of course wrong).

But I have never been able to forget this boy and the promise I made him. Therefore I have always filled my life with as much as possible – taking every available opportunity I possibly could and living it; so much so that when I got married I would not sit in front of the TV or when talking to visitors without a craft in my hands to do.

This caused some problems between us – years later I am not so bad now – but in all truthfulness this is only because my hands are now affected with Fibromyalgia and I cannot sustain work continually with my hands as they are now.

But would this have happened anyway – because I know I have a personality that includes the inability not to give in?

Therefore if you do not give in you must be a fighter and that is what I did – fought as much as it was possible to do, for each step of improvement. But I was never satisfied with it coming at the rate others would have me believe. I wanted it now – so I worked harder at home.

Going for bike rides, swimming more often, roller skating, walking places instead of bus or tram, running in burst the way my father taught me, which was running to one lamp post and then walking slow to the next, a bit faster to the next and running to the next and so on.

I was told by physio, to do 10 of each of the many exercises they gave me to do at home – I would do 50 (I still do this now!)

Waiting was not something that I did well if I had control of it and I had control of my own ability and so I always did more than I was told. (I hasten to add I knew when this would not affect the surgery or me to such an extent I would do damage and I always asked for updates of my progress from the Physio's to ensure I would not hinder progress if more was done out of their eye sight!).

So would this desire have been there anyway without my friends words or has it added that extra zing to my personality? I will never know.

[*My partner*] wants me to add that I am not good at being told no....to me no means try and see if you can.

So I tried everything I could, skating, scooter, horse riding, high diving, going on fairs, climbing hills, long walks, dancing, ball room dancing, jazz dancing, tap dancing, and so on.

It goes well past wanting to prove that I am just as capable as others to be able to do these things but there seems to be an in bread need to see if I can do it and if so how well?

**Could you talk about the feelings associated with what this hip replacement could/would do for you?**

I am not sure that I can – because this replacement was a necessity to stop me collapsing every couple of step and just one of those things that I had accepted needed to be done.

*The 'plate' had worn to such a degree that it was not doing any job at all in allowing me to walk.*

***I HAD NO CHOICE** but to go through with this operation and so no thought to what I would do with it any more than walk without showing myself up in the street when I collapsed or in company in a pub etc would be a bonus.*

All I wanted to do was have the pain taken away, the embarrassment and the ability to get on with my life.

When you have a disability like this you do not usually look further than the recovery of the operation.

Mind you unknown to me it did mean that later in life I would be able to have children – but this was unknown to me then.

**In your timeline you suggested how it allowed you to have children**

I was told when I was 16 that it was very unlikely that I would be able to have children.

The reason being that the pelvis area was not big enough for me to go full term and in those days there was no thought that you would automatically put them in an incubator as this happened rarely I could suppose that they did not have the knowledge they have now about early births.

On top of which I had a plate of steel, that with a 6” nail was doing the work of my hip and that was protruding into the area a child would develop.

Thus when [my partner] and I talked of marriage I told him about this.

It never came to me that due to the 2<sup>nd</sup> full hip replacement that things would change until later when I talked to the surgeon about the future and mentioned that [my partner] and I had accepted no children.

He quickly assured me that this is now possible – but that I would have to be monitored carefully to see the effects this would have on my hip. But as it happened everyone was very surprised that what it did do was develop the pelvic muscles, the back muscles and the pregnancy was basically as normal as I could have.

Mr. [...] was very pleased as it had developed my muscles and not done any damage to the hip.

He did suggest strongly that I might think that this was the only one we should have.

But that is not how it turned out.

**Secondly, do you think you could compare how the replacement that you found psychologically difficult involved a different process of recovery or different feeling(s) than those experienced in the above example?** This could include emotions as well.

As the years had progress I kept up to date with improvements in replacements and with other surgery in-between I easily got to know about the new recovery programme for hip replacements and why they got out of bed within 24 hours of surgery.

Laying in bed for 16 weeks is not good for the muscles and it was proved that little exercise means bone marrow does not replace as quick to stabilise the replacement's; this being one of the vital aspects of recovery; the hip would not get so stiff if I used as soon as possible – and earlier than 16 weeks!

The fact that you got out of bed no longer than 24 hours after your operation, when all you have heard is so sensible, does not help the mind to accept that everything would be OK and that if 60 year olds around about you could do it why can't you?

Even now I cannot understand the block, as usually I am so sensible about medical things but once the aesthetic had worn off, once the catheter was gone, once the pecas (patient regulated drug dispenser achieved by pressing a button and a allocated amount is delivered to the patient in a controlled way in small doses. You can press more than once – but it will not deliver more than the allocated dose allowed in 4 hours) was detached from the canola (a needle in a vein with the addition of a port hole that drugs can be administered without using a needle EVERY time – which having experienced both is a lot easier and less painful) I knew the following day I would be got up.

I had never thought about it earlier than this – this aspect of the recovery never entered my mind any more than it would occur and it was part of the process of recovery and even I find that strange.

*To say I was petrified would be an understatement and this was a new experience for me; because I know I have been frightened in the past but not like this.*

*I allowed them to get me out of bed and into a chair and that was traumatic enough **but when the physio's came round late morning I would not budge. I was very lucky in that my surgeon came round at that moment and I asked for a word on his own.** *Crying, I tried to**

*explain of my unreasonable fright in getting up to walk.*

I explained to him that I knew I had to do it sometime and I would but I just needed some time to adjust to what was about to happen.

Because of his age, I believe, and therefore his knowledge of what happened in the past (he had known about the method himself of being on a Balcome Beam and in the past had used this method for his patients) he understood and told the physio to just get me to stand and nothing else until I was ready.

I personally saw this as being at least 3 days or more – but unknown to me Mr [...] –the surgeon - had said to the physio it would only last 2 days before I got bored and wanted to get on with it all.....he was right.

Getting me to stand for a small period and extending it a minute each time got me itchy feet to want to see the rest of the ward.

It is strange but you get institutionalised in your own space round and in your bed and you usually ache to see more of the world than just the ward and the people in it – even if you are just exchanging it for another ward!!

Everything holds a crisper edge to it, you see the world that you slowly re enter a more exciting place to be and when you go outside for the first time – usually to go home – it is like re-seeing the world a new for the first time and everything is sharp, well defined, alive and exciting as you experience everything around you for, what seems, the first time.

In the time I was left to sit in the Chair I would try to analyse why this was happening, what was stopping me from walking and I knew that the longer I sat the stiffer I would get and the harder the walking would be to achieve but still I could not move. The following day I was in the Chair beside my bed and assisted in standing for a longer period. But the day after I was raring to go.

Overnight I had talked myself around to making the effort keeping telling myself that I was only making matters worse for myself if I did not get started. The only answer I have for what happened is that my mind could not equate this getting out of bed 24 hours after surgery with the return from theatre pinned to a balcome beam bed 20 years earlier. And that the memory of that occasion was so strong it would not comprehend this new idea.

Memories can be great; but sometimes they can hinder progress.

## Appendix 10.2.3 Summary Recovery and time

Email correspondence to Sue (1/07/2011)

Dear Sue,

Whilst I asked you to draw on a number of things from your memories of recovery associated with going for operations, it became apparent that throughout your account you discussed different *practices* related to:

the *hospital* i.e. issues of power, respect for patients, privacy;  
- the *physio* i.e. the role of the physio and the expectations placed on you;  
- other *professionals* i.e. the doctor who understood your emotional difficulties;  
- your own agency i.e. choosing to sneak down to physio early to get more exercise completed.

A lot of these were linked to your daily routine at the time and carried particular emotions with them. For example, the decision to 'look' washed. Some of these practices also shaped parts of your future i.e. not looking into mirrors when walking. One question I had related to your story about the physio dept using a video to record your walking, using it as a teaching method. It's not necessarily a question to answer now, but I wondered if you can remember how you felt about watching the video (did Sue get to see the video? Was she consulted about consent?) and whether it helped to shape your recovery?

The role of emotions came through at multiple points in your story and I was thinking about whether some of the practices and attitudes of staff influenced any of the *relationships* you built with other medical professionals as part of future operations? The future of relationships? There were the emotions linked to visitors and in particular the touching story that you told of your friend from the [name of hospital] and how that *encounter shaped* some of your future outlook/decisions.

Talking of *decisions*, you mentioned the way you made decisions without your parents input, as things were rarely discussed together. This made me think about the choice you might have made had you all been involved in the decision. I know these are not necessarily questions that can be answered; again these are just my thoughts. So, based on your independence (which you have spoken about on numerous occasions), do you think you would have agreed on decisions or do you think that your independence was influenced by these interactions?

I feel like I've said quite a lot already, but something that seems to stick out in your narrative is the focus on recovery taking place in the hospital (I know you spent a substantial time here following operations), so perhaps the role of your recovery at home is something we could move onto next. I know there are accounts from your parent's home; however, I wonder whether a focus on your partner's role in supporting you following subsequent operations could be something to think about? I suppose here I am thinking about your later operations - this would also include more detail on having children and how your experiences helped to shape the day-to-day role and future relationships with your children.

We have certainly touched on these topics before, but I feel there might

be more to say. If you can let me know your thoughts, then I can send you some questions to help focus your diary entry.

### **Appendix 10.3.1 Guidelines Timeline of achievements**

1. Give your timeline a name/title – you may want to change it once you've finished, if you find another title more fitting.
2. Use your 'first' timeline to frame or give context to your timeline of achievements - can you already highlight achievements from the first timeline? Complete a diary entry that might start by saying why you are 'doing' the timeline in the first place.
3. Can you describe this 'bad day of depression' that made you think about completing a timeline? Try and think about what an achievement means to you – does it sometimes involve others? What is the role of others in these specific achievements?
4. Try to write about the memories or feelings you revisit or encounter during certain points of the timeline. Have certain points helped you revisit particular memories – can you discuss those that are blurred and less clear memories; and those that are more distinct?
5. Can you think about the way past experiences have shaped the decisions you made throughout your life in relation to the 'achievements' you are talking about?
6. Include any other feelings or emotions that you think are relevant.
7. Finally, can you write about how you feel now the achievements timeline is 'complete'?



## Appendix 10.3.2 Timeline of achievements and diary entry

### Timeline of achievements, October 2011

Give you timeline a name/title – you may want to change it once you've finished, if you find another title more fitting.

Use your 'first' timeline to frame or give context to your timeline of achievements - can you already highlight achievements from the first timeline?

**I have never been good at doing a job more than once and this to me is one of those times.**

**I will need time to get the dates right in the time line I have started and I will get it done one day – having the list in my diary is already of benefit to me so I will not rush the next part.**

Complete a diary entry that might start by saying why you are 'doing' the timeline in the first place.

**I have made 6 pages in my diary of items that I have been involved in – therefore being able to achieve what I have.**

**In one of my down days when I did not think that I was doing enough to make a difference to any one – [my partner] pointed out to me a list of things that I had changed.**

**It got me wondering what I had achieved and if I had them on paper so that I could look at them anytime I could use these 'achievements' to lift me on these down days.**

**So I decided to make a list, trying to keep them in order, and realised how much I had done and how difficult it actually was to keep them in order – thinking to myself I will have to get the diaries out and put dates on them.**

**A job for an other day.**

Can you describe this 'bad day of depression' that made you think about completing a timeline?

**As quoted above**

Try and think about what an achievement means to you – does it sometimes involve others?

**They mean more than I care to admit.**

**To accomplish what I wanted I needed to be born at least 15 years on to what I was – as then disabled people were more involved within the community and I would have been the right age to have been more fully involved.**

**I earlier realised that living were I was would not get me in the right place (which is why I tried to stay around London when I was a teenager but health as usual stopped me) at the right time so I started making aims and objectives for myself; they were small and as I grew in confidence and knowledge and contacts they got bigger.**

**At the height of being involved in the thick of the changes of the disability movement I even considered becoming an MP – but time had caught up and so had my health and so since then I seem to have dropped back considerably and concentrated on Local issues and therefore aims**

**My achievements gives value to my life....a reason why I was born the way I was.**

**Yet without being born this way I know I would not achieved what I have and wonder if I would have achieved anything at all? A question that is impossible to answer.**

**These achievements mean that being alive the way I am and suffering the way I have means it was worth while when I look back and see what is there now because of me.**

**It is hard to acknowledge but I deeply feel that if I had not achieved anything I would have thought my life worthless.....dramatic, depressing, but true.**

**Why do I feel that life has to have an achievement to be a fulfilling life? I really do not know.**

**What is the role of others in these specific achievements?**

**I am not quite sure there was anyone until [my partner] and his mother.**

**Mother and father never quite believed I could achieve anything - yet when I do quickly tell everyone about it -strange!**

**So when I started to do things and want to tell them about it they were interested until they got disturbed and I can only remember that this seemed to happen all the time (there must have been other times; why can I not remember them?)**

**This even continues now to the point where once I got, as usual, upset about the lack of interest of our [sister's name] on what I do, having entered mums house in the middle of me explaining some event, mam quickly turned to talk to [sister's name] and that was that, She never asked later on for me to continue, [sister's name] never asked what we were talking about when she came in and she never asks, like mama, what I have done. SO on this particular night returning home I vowed to never tell them about anything unless they ask and only answer the question and not expand on it as I usually did.**

**That was over 5 years ago and only once has mam asked me what I had been doing and when I mentioned politics she declined to listen to anything else saying she was not interested in politics.**

**[My partner]'s mam on the other hand from when we first met, use to want to know everything. We first met when she visited me in hospital; as [my partner] had started to come regularly to see me, she wanted to know who he was visiting.**

**Just round the corner from where she lived, a half hour visit took in what craft I was doing and from then on she had never stopped being interested in anything I did.**

**[My partner] has been my rock and stabler.**

**When I am not sure if I am making a difference he is there to tell me I am and expound on that; he allows me to go off and do what I want knowing what benefits I get from this physically and mentally.**

**Obviously I have not been able to achieve some of the things I have without others assistance in many ways – but unlike [my partner] and his mother I really cannot say there is/has been anyone who is/has specifically helped me to achieve what I have.**

Try to write about the memories or feelings you revisit or encounter during certain points of the timeline.

Have certain points helped you revisit particular memories

**I have had a few occasions that have allowed me to recall some memories – but they have mostly been an expansion of what I already having my recall – which is disappointing really.**

– can you discuss those that are blurred and less clear memories;

**My experience in [...] hospital was not good, I feel it inside; yet I also know that I enjoyed certain aspects of it – the toy room in the corner of the ward – but on this occasion of hospitalisation and others I remember very little about the children I was with; about the family life that I had between these time at home (there are very few occasions, small in time and experience and always bringing with them a feeling of missing something, of being wanted, needed, loved for me, or being in the right place) about the junior times at school – this is defiantly where I can only remember about drinking 1/3<sup>rd</sup> bottles of milk and sleeping on camp beds...everything else...gone. I remember VERY little about my time at Secondary school.**

**It is as though I only started living when I went to College!**

**Nearing 60, this has nothing to do with age – it has always been like this. and those that are more distinct?**

**Most already done.**

Can you think about the way past experiences have shaped the decisions you made throughout your life in relation to the ‘achievements’ you are talking about?

**My health has always shaped the experiences I have achieved and NOT achieved through my life; without the way I was born I would not have had the experience and because of it I have not been able to take up some of what has been offered.**

Include any other feelings or emotions that you think are relevant.

**Envy of people who have real friends.**

**I have none.**

**An exaggeration – no.**

**Friends to me are people who you go out with, visit regular, want to meet some were and have coffee, go shopping with, discuss every day things, phone when you are down or happy, first persons you think about when you want to tell some good or bad news.**

**(I often think who will I phone who is nearby that will help me if anything happens to [my partner] – before the children get here. There is no one that comes to mind straight away. If I continue thinking I can recall a couple of people but they NEVER spring to mind straight away...this makes me feel very isolated.)**

**It is probably why never being asked to go with my sister when she organises going to the theatre, see Cliff or even attend an Uncles Golden Wedding Anniversary or a cousins birthday hurts so much.**

Finally, can you write about how you feel now the achievements timeline is 'complete'?

**I have not completed the timeline - but by actually starting it I can honestly say that I feel really good, pleased, amazed at what I have done and really proud of myself.**

**The benefits of writing this timeline have already proved worthwhile and I sorry that I never thought of it earlier.**

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