

# Vital Bodies

A Visual Sociology of Health and Illness in Everyday Life

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## *Declaration*

I certify that the thesis I have presented is my own work  
other than where I have duly acknowledged that it is the work of others.

## *Abstract*

This thesis addresses theoretical and methodological concerns to embody sociology. It offers an account of the body, health and illness in everyday life that uses a sensorially attentive research practice to take the body seriously and make it audibly, visibly and viscerally present. The thesis is based on empirical research conducted over a year using a multi-method approach to unlock everyday bodily experiences. Thirteen participants aged between twenty-three and forty-three were interviewed about their experiences of living with a long-term physical or mental health condition (asthma, bi-polar disorder, chronic pain, depression, type 1 diabetes, epilepsy, joint hypermobility syndrome, muscular dystrophy, and rheumatoid arthritis) and asked to make a video diary and/or keep a journal to show and tell about their body and their condition. In addition Polaroids and hand-drawn questionnaires were used to add dimensionality. The accounts that were made are presented in this written thesis and in the film that accompanies this text, with the aim of conveying a sociological analysis of illness that keeps the vitality of bodies alive. In doing so, the thesis offers an account of illness that is not based on anguish, isolation and powerlessness but on the embodied activity of living.

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## *Introduction: Revitalising the Sociological Body*

In writing this thesis I have sought to revitalise the sociological understanding of the body, so that we might see how bodies matter in new ways. With the title *Vital Bodies* I intended to affirm the vitality of the body, but I also wanted to suggest that this thesis is as much about living as it is about bodies. The work of listening to and writing about the vital organs, processes, signs, capacities, and sensations of bodies has demanded a particular mode of attention, and here again the idea of vitalism has proved useful, not as a method or a theory, but as an imperative and an ethical system: an attitude that affirms the originality of life (Greco 2009: 27). The bodies in this thesis are vital not in the classical sense, which asserts that life cannot be explained by the principles of mechanism (Fraser, Kembler and Lury 2005: 1), but by the fact that they are essential, indispensable, pressing, compelling, a matter of life and death. They are also lively, active, vibrant, and hearty: they are alive.

Holding onto this vitality within the confines of academic scholarship has involved making a series of leaps and jumps through theoretical and conceptual debates, as well as a generous amount of methodological inventiveness. As Blackman states, the task at hand is to inject an aliveness and vitality into a body that for many years has only been an absent presence in social and cultural theory (Blackman 2008: 13). The disconnection between theoretical bodies, which are silent, subservient, and sterile, and real life bodies, which are noisy, troublesome, and messy, is one that I argue needs addressing. My own solution has been to embrace materiality, from the flesh and blood materiality of the body to the specific material qualities of the

research methods and devices that I have used. Turning to materiality has introduced a sensuous dimension to this project, creating a mode of scholarship that viscerally and vibrantly resonates with the living body.

Les Back has written (in our student handbook) that, “Visual sociology to me not only offers the promise of expanding our repertoire beyond words and figures but also the opportunity to make sociological ideas and arguments more vivid, vital and beautiful”. I have tried to keep this promise, and to explain the body without explaining it away or wringing the life out of it. Thinking creatively about how to do research has led me to ask different questions and to find other ways of showing and telling. In the following thesis, I present an account of the body that was created with the help of thirteen people: Anna, Anwen, Ben, Imogen, Jeffrey, Kaldon, Kim, Matt, Martin, Meghan, Nell, Sophie, and Xan. Their contributions came in the form of spoken words and written thoughts, as well as drawings, photos, and videos. Much of this data has been written into these pages, and I have used their own words wherever possible – both in quotations and in my own writing. Selected photos and drawings are included in chapter 2 as records of these research encounters. By holding onto the details of the project my intention is to bring the reader closer to the research process, creating a sense of proximity with the life of the thesis. Some of the video diaries are also presented separately in the film that accompanies this text. Following the thematic framework of the thesis, I edited the video diaries into a sequence of split-screen compositions that make use of fragmentation, body parts and boundaries. This piece of the thesis invites a different, more embodied, engagement with the ideas I present and offers a live encounter with bodies. Drawing both the eye and the ear to the body, the film allows the viewer to see the significance

of bodies and experience ways of listening to and caring for them more directly than this text alone can offer. It also plays with the difficulties of data production and highlights the practical craft involved in producing new forms of sociological representation.

To develop an analysis of the body I decided to focus on illness. The people in this project all have mental or physical long-term conditions, from arthritis, depression, diabetes, and epilepsy, to muscular dystrophy, joint-hypermobility syndrome, and bi-polar disorder. This means that their bodies are anything but quiet or unremarkable. Their accounts reveal the overlap between medically distinct conditions and between mental and physical illness, and they emphasise the value of the body, its possibilities and constraints, its strengths and vulnerabilities, and ultimately its mortality, showing once again that bodies are vital. They also offer a portrayal of illness that is not based on anguish, isolation and powerlessness but on the activity of living – as Carel (2008) writes, it is possible to find health, and happiness, within illness. This is true for people who are forced to live with illness but it is also true for researchers working on the topic, and it highlights the need to think about illness differently and to ask different questions.

Throughout the thesis I draw on personal experiences of illness that are carefully focused on the body, so that the body itself becomes another way of telling about human lives. In doing so I hope to overcome the tension that currently exists between subject-based accounts that tend to be disembodied, and accounts of the body that tend to lack a subject. Putting subject-based experiences back in their bodies, I offer an account of health and illness in everyday life that has the personal body at its heart. Here I draw on Smart's (2007) conception of personal life, which

gives recognition to areas of life that used to be “slightly below the sociological radar” (Smart 2007: 29). Smart writes that the personal designates: “an area of life which impacts closely on people and means much to them, but which does not presume that there is an autonomous individual who makes free choices and exercises unfettered agency” (Smart 2007: 28). For Smart, individuals are not entirely free because the personal is embedded in the social. I add to this the suggestion that the personal is also embedded in, and so constrained by, the body. Attending to the personal body therefore offers the possibility of bringing the social, the personal, and the body together in equal measure. Smart also writes of the tension between small-scale detailed empirical research and generalised theoretical statements (Smart 2007: 8), which all too often fail to connect with one another. In this thesis, I have aimed to present empirically grounded research that has an impact on what Smart describes as sociological Thought with a capital T (Smart 2007: 8), and to make sense of sociological theory through understanding the ways in which people live and experience health and illness within and without their bodies.

The thesis itself is presented in four chapters, each of which is summarised below. In chapter 1, *The Vital Matter of Bodies*, I survey the body’s history as a sociological concept and consider what might be missing from the landscape. I posit that our ideas about bodies are formulated in response to a series of misunderstandings about the nature and role of matter, and that in order to take the body seriously we need to re-think what the body is. Using the themes of dualism, fragments and skin, I present the possibility of a non-reductionist material understanding of the body. Positioning the material body at the centre allows us to recognise that, in reality, bodies often shape, control and regulate us, and that their

voices whisper, scream and shout for our attention: a conclusion that opens up new possibilities for presentations of the body within sociology. In the first section of the chapter, *Dualism*, I argue that Cartesian mind body dualism, often blamed for sociology's neck up approach to the body, should not be rejected outright. The section thinks through the ways in which dualism is a lived concept that continues to exist in everyday life and explores the qualities of dualism that might usefully be held onto. Then, in *Fragments*, I consider how viewing the body as a collection of parts can be used to explore the meaning and purpose of the material body from a sociological perspective, so that each fragment of the body might speak of sociological things. Breaking the body down into its constituent parts is typically perceived to be negative, objectivist and inherently medical. Here, instead of reducing people to their bodies, fragmenting the body is introduced as a way of bringing the body to life, revealing its hidden aspects and providing solid anchor points from which to develop an understanding of the body's relationship to the social world. The final section, *Skin*, explores the physical marker of the body's limits. The boundedness of the body is subject to historical, cultural and sociological interpretation, and drawing on this status I suggest that the notion of skin can be gainfully employed to dissolve the opposition between process and substance; skin both holds the body together as a dynamic unity and it is permeable, it establishes the body as a material object, reveals the ways in which we inhabit our bodies, and is a site wherein the material and the social converge.

In chapter 2, *Methods for Mapping Bodies*, I present an imaginative approach to researching the body. Through each of the chapter sections, touching, sensing, mapping, talking, writing, and filming are explored as ways of encountering and

presenting bodies. Each thematic cluster is linked to one or more of the research devices and methods that were used in the project, highlighting and unravelling the significance of method within the context of this project. Questionnaires and Polaroids helped to develop research relationships that disrupted expected ways of telling. The questionnaires, hand drawn with a black marker pen on A3 sheets of paper, touched on themes of mind body dualism and body parts. Participants were invited to divide their body and mind into percentages and to draw a part of their body and tell a story about it. Polaroids were made together with participants, based on themes that arose from interviews. More than simply illustrative of those themes, they often led to new insights. The tactility and immediacy of both of these methods added a sensuous dimension to data collection. Journals and video diaries enabled participants to become observers of their own lives, and proved to be novel methods of encounter. In the journals, routines, thoughts and social scenarios were recorded, drawings were made and images stuck in. As an audiovisual medium, video diaries were able to make the body both audible and visible. They captured the affective qualities of illness and the vital signs of bodies, located everyday realities and practices, and made illness less anonymous. Moving beyond the constraints of traditional sociological practice and using different methods, devices, forms of articulation, and modes of analytic attention, it became possible to open up spaces within which bodies could be seen, heard, felt and sensed, transforming the body from elusive to sensorial and making it knowable in the flesh.

In chapters 3 and 4 I present my original empirical research, locating the body in space, in time, and in the sociological imagination. Chapter 3, *Bodyrhythms*, shows how in illness the basic needs and drives of our bodies to eat, exercise and sleep affect

and redefine our everyday routines. Using rhythm analysis, this chapter shows how illness brings these rhythms to our attention so that they become important to us, impacting on our social worlds, altering our relationships with our bodies, and creating new rhythms of life. Through three sections, *Eat*, *Exercise* and *Sleep*, we follow body rhythms that are used in the everyday management of illness and the maintenance of stability and explore notions of care, control, responsibility, and mortality. *Eat* focuses on the importance of diet, showing how the basic need to eat can become a defining feature of our lives, whether we are calculating carbohydrates, seeking the nutrition that our bodies need, or controlling their shape and size. Meghan, for example, has rheumatoid arthritis. In her search for a magic bullet to cure her of her daily aches and pains, she has consulted nutritionists, bought supplements, subscribed to diet and nutrition email lists, and read countless magazines, books and websites. Disciplined eating forms part of Meghan's strategy for health, and routines structured around food provide a sense of security and control, revealing significant dedication to caring for the body. *Exercise* considers the rhythm of our bodies in motion and the complicated relationships between exercise and illness. Exercise is both a necessity and a joy, and for Anna, who has depression, it has become a form of self-medication. Running and cycling regularly make her feel less depressed, so she tries to be physically active at least four times a week. Disruption to this routine can cause her mood to plummet quickly, showing the dependence that she has on her body. *Sleep* looks at how the demands of our working and social lives can conflict with the demands of our body, and at how illness redefines our lives through the need to sleep. Kaldon has rheumatoid arthritis and rest is a better cure than any drug, but with a modern life in London it is the hardest

thing to come by. Sometimes his body screams for sleep to rest and rejuvenate, evidencing the conflict between how Kaldon wants to live and what his body needs. Together, these three sections highlight the temporal and rhythmic changes that affect bodies in illness. Through this chapter the importance of each of these rhythms and of listening to the body is made clear.

Chapter 4, *Bodyscapes*, ventures into the internal worlds of our bodies, the external environments they inhabit, and the spaces and places that they long for in order to show how physical bodies and social worlds are entangled in space. Each section presents different fragments of the body starting with *Genes and Organs*, then *Feet and Legs*, before finally ending with *Hands and Hearts*. *Genes and Organs* examines how the interiors of our bodies structure and influence our exterior surfaces and identities and shape our daily lives, and how the inner workings of our bodies, the circulations of blood and the flows of air, affect and betray us. This section traces the transmission of conditions from their interior origins within the body to the outside world of everyday life and considers how the inner landscapes of the body are both visible and significant. Nell, for example, has asthma. She has learnt the warning signals of an asthma attack, from the wheezing sound originating from her chest, to the tight feeling in her shoulders, and the sudden pain in her teeth. She knows when to take her inhaler, and she also knows when to reach for the phone and call the emergency services. In moments like these illness is transported from the safe and invisible interior of the body to the outside world. Moving from the interior to the exterior, the chapter continues with *Feet and Legs*, body parts that, as our connection to the earth and our way of navigating through the world, are perhaps our most direct link to the external landscapes in which we live. How do our feet and

legs, as well as the shoes and canes that accompany them, connect us to, negotiate us through, and redefine how we know the built environment? How do our bodies redefine the topography of our worlds? This section considers the importance of these seemingly simple body parts and the influence that they have on the ways in which we move, dress and travel. Anwen has muscular dystrophy and has lost most of the muscles in both of her legs. But by finding new ways of using her body and by learning her environment in detail, she has held onto her ability to walk and her independence. The final section of the chapter, *Hands and Hearts*, considers the emotional connections between bodies, minds and landscapes, and touches on themes of finding a home and belonging in the world. Anna, who has depression, does not have any of the same doubts about her hands that she does about her mind and its thoughts. She never thinks twice about their ability to do things, and they don't seem to suffer from the same anxiety and self-hatred that she does. Anna's acute mind-body split illustrates how she belongs in the world through her body and at the same time feels distant from it. Through this chapter we see how bodies find their own routes through the spaces of everyday life, and how, just as illness refuses to be contained within bodies, bodies refuse to be confined by illness.

The thesis ends by returning to the idea of listening and to the ways in which listening to the body reformulates the craft of sociology and presents challenges to existing ideas about the nature of the body and its place in society within the context of this project.

## CHAPTER 1

### *The Vital Matter of Bodies*

Our bodies have been kept silent too long. They have been like children told to be seen but not heard at the dining table, or trophy objects polished to perfection and placed on display, or books that on occasion might be dusted off and quietly read. It has been presumed that bodies do not have a voice of their own; that they have nothing to speak of. Their silent history as discursive texts and socially constructed things has made them seem like ‘the finest consumer object’ (Baudrillard 1998); *we* read, interpret, shape, control and regulate *them*. If sociology is a listener’s art (Back 2007), then how might we listen to our bodies, listen with our ears and with our eyes? Bodies are our self-expression; we economically and psychically invest in them through exercise and diet, dress and design, so that we can see ourselves in exterior. We discipline them, and society disciplines us through them. Shilling’s (1993) notion of physical capital, developed from Bourdieu’s notion of embodied cultural capital, states the facts of our modern society. Giddens (1991) writes of the body as being open to colonization and reconstitution. These tenets of sociology’s social constructionist attitude to the body show the importance it has to us as social agents and as consumers; these are the ways in which our bodies have come to matter to us. The central aim of this thesis is to revitalise the sociological understanding of the body, so that we might see how bodies matter in new ways.

In this chapter, the theoretical legacy of the body and its future are put into question. I argue that rather than being silenced or controlled, bodies need to be

listened and attended to, and that in order to hear them we need to begin from a theoretical position that recognises their value and ability to speak. We need to listen to our bodies because they are vital to us. They are the conditions of our existence and are essential for being alive; their vital organs and their vital signs ensure that we pulsate and breathe life. Charting the contemporary bodily turn I show that while the body is becoming ever more present in sociological thinking, it continues to lack real substance or agency. As such it remains in many ways silent, unheard and in danger of slipping out of sight. In order to re-think the vital matter of bodies I begin by taking a closer look at the reasons why the body has been absent and at why it has remained silent for so long, starting with the sociology of health and illness.

The body's historical absence is attributed primarily to the legacy of Descartes: mind body dualism (Shilling (1993), Kelly and Field (1996), Lawton (2003), Bury and Gabe (2004), Fraser and Greco (2005)). By positing that 'I' am principally my mind, dualism has paved the way for sociology to focus on the mind as the defining aspect of the individual and to ignore the more material aspects of the body. The tenets of dualism (a hierarchical and ontological split between mind as non-physical substance and body as inert matter) are quite literally interpreted by social constructionism, and the individual as social agent is aligned solely with the (disembodied) mind or self. The absence of the body is also legitimised as an important disciplinary boundary, one that historically has established sociology as autonomous and distinct from medicine and biology, which are considered the proper disciplines of the body. This disciplinary boundary sets up a second division between the concepts of illness and disease that reinforces the irrelevance of the body for a sociological understanding of illness: disease belongs to the medical body; illness is located in the

social world (a fact that is reinforced through the everyday language that we use to talk about illness, which is not a language of the body (Herzlich 1973)).

These divisions cordon the body off from sociological discourse and legitimate its absence, but bringing the body back is not simply a matter of drawing the lines differently. The body is put even further out of reach because it is theorised as lying beneath our everyday perception, non-conscious and therefore mute. Leder's (1990) theory of illness as a 'dysappearance' of the body tells us that in everyday life it is the world around our bodies, not our bodies themselves, that we perceive. Only when our bodies dysfunction in some way do we begin to notice them, because then they are brought to the forefront of our perception. And, because a healthy body is a silent body, when the 'silence of the organs' (Fraser and Greco 2005: 20) is disrupted and the body is made present, our aim is to return the body to its silence as quickly as possible so as to restore health.

Constrained by these fundamental underpinnings, the sociology of health and illness has struggled to get a grip on the matter of bodies. Instead of being listened to, the body has been forced to live in a no man's land, existing only as a vague and slippery concept and characterized primarily by its 'absent presence' (Shilling 1993). Take, for example, Williams' (1996) application of Leder's theory. Williams describes the chronic illness trajectory as involving a shift from an initial state of embodiment to an oscillation between states of dys-embodiment and attempts and re-embodiment, "the latter involving considerable biographical work on the part of the individual." (Williams 1996: 23). Although Leder's theory works to describe the position of the *body* in illness: "Instead of just acting *from* the body, I act *toward* it in

the hope of finding relief” (Leder 1990 in Williams 1996: 27), it is the role of the *self* that Williams highlights in his use of ‘dysappearance’.

This focus on the biographical work that is undertaken in order to ‘re-embodiment’ ourselves, and, ergo, to push our bodies back into perceptual absence, illustrates how the body has been subsumed by the self, and has shaped the sociology of health and illness as a field. Bury (1982, 2001), Williams (1984, 1996), Kleinman (1988), Charmaz (1983, 1991), and Frank’s (1995) accounts of biographical disruption and narrative reconstruction have contributed to a picture of illness in which the war being waged is not biological but biographical, and in which the narrative processes of adaptation, coping and loss must be mobilized in order to adjust to the new conditions of our lives. Illness has become equated with suffering, with exhaustion, isolation, alienation, struggle, fear, stigma and shame. This narrative conceptualisation extends across a range of chronic illnesses and has been applied to mental as well as physical conditions (Karp 1994, Schreiber 1996), reinvoking the moral discourse set up by Parsons (1951) and Goffman (1963), and making illness into a wholly moral project.

While narrative places the onus of illness on the self, it does also do some work to give the ill body a voice. According to Frank, ill bodies are not so much mute as inarticulate (Frank 1995: 2), and by telling stories we can make the body familiar and reclaim illness experience from the grips of medicine. Frank’s work plays an important role in turning the dominant conception of illness as passive experience in which the ill body belongs to medicine into an active, possessive and personal one, but his concerns are to re-engage with the body as personal and social moral testimony and witness to suffering. This means that the ill body must subscribe to a

specific discourse and can only be spoken *through* by the self; ultimately illness stories, although grounded in the body, are stories of and for the self. It must be concluded that the sociology of health and illness is primarily a sociology of the self, with little space for the ill body.

But, “illness and disability can make visible how bodies have lives of their own” (Latimer 2009: 4);

...arteries fur up, blood clots, bones disintegrate, tumors grow, viruses and bacteria colonize, genes mutate. At times, then, it seems that bodies (or their parts) can get it wrong. And bodies, to put it simply, despite our best efforts, seem to get out of line: they do not just hurt, scream, giggle, leak, cramp, faint, get numb, they also at times seem to conceal, rebel, falsify and distort. (Latimer 2009: 4)

For Latimer, bodies are known and unknown, and they are also knowing and unknowing. As such, they offer the possibility of revealing the agency of the body and of understanding illness as other than suffering. While the dominant discourse of medicine constructs sick and diseased bodies as simply unknowing (Latimer 2009: 10) and therefore easy to ignore, the fact that bodies ‘conceal, rebel, falsify and distort’ points to something more. After all, “life is more than just an objectively assessed function of the body” (Latimer 2009: 11). To understand the ill body we need to examine the significance of its materiality, and begin to think of it not simply as a presence in everyday life but as an affective agent.

Outside of the sociology of health and illness the body has been receiving increased attention, with attempts being made to reintroduce it to number of sociological contexts. The philosophy of Merleau-Ponty has been fundamental to this shift. Merleau-Ponty’s (1962) phenomenological concept of ‘the lived body’, which

emphasises the integral nature of the body to our being in the world, dissolves the separation between self and world and overcomes Cartesian mind body dualism. Now, the body, our 'vehicle of being in the world', is indispensable: we *are* our bodies, and all our experiences are mediated through them. Present and meaningful, the lived body allows us to incorporate the ways in which our bodies physically and culturally inhabit the world into our accounts of the social world.

One notable area of work in the newly embodied sociology of the body focuses on body pedagogics; the ways in which we train our bodies to behave, to breathe like a soldier (Lande 2007) or to dance like a ballerina (Aalten 2007). These studies incorporate a direct relationship with the matter of our bodies and show how that matter is socially connected and culturally distinct. In Lande's study, army culture is shown to operate at the natural, organic level of the body via running and shooting, training situations in which a specific technique of breathing anchors the soldier's body in the military world. In distinct contrast, Aalten's work describes how the dancer must actively distance the body from awareness in order to overcome the hunger and the pain involved in attaining the ideal body of a professional ballet dancer. In both studies, the body is positioned as *active* matter.

Another new branch extends towards reengaging directly with biology. To do this, we must recognise that the body is a biological phenomenon and find a way of bringing the social and the biological together – processes which have traditionally been viewed as separate entities (Shilling 1993: 10) – without falling into a reductive or essentialist trap and negating the body as social. The in vogue solution to this problem is to position the body within a network of relations that are structured around a single state or condition, such as sleep (Williams 2005), alcoholic liver

disease (Law 2004), hypoglycaemia (Mol and Law 2004) or arteriosclerosis (Mol 2002). The sleeping body is at the intersection of biological, social, cultural, psychological and economic processes. As a 'between state', it is both embodied and embedded within a network of social roles and relations (Williams 2005: 97), which range from personal habits to public concerns. Alcoholic liver disease combines the medical and the social in one condition that has to do with the body but also reaches into social life, so that it is located both within and beyond the body (Law 2004: 76). And hypoglycaemia and arteriosclerosis are performed in a multiplicity of practices both within the body and across different sites (Mol and Law 2004: 123), so that these conditions of the body 'hang together' via the relational connections of multiple objects and enactments (Mol 2002: 125).

To reiterate: each of these examples takes a state or condition as an object of study, and in doing so is able to indirectly approach the body in a range of social and biological situations. The result is a lavish network of enactments and performances involving a number of *things*, one of which is the body. Take Mol's case of performing identity:

A lot of *things* are involved. Black ties and yellow dresses. Bags and sunglasses. Shoes and desks and chairs and razors. And among the state props is the physical body. (Mol 2002: 38)

The network becomes a decentralising concept that both downplays and extends the body; because the object of study (sleep, alcoholic liver disease, hypoglycaemia, arteriosclerosis) is embodied but not restricted to the body, what is in the body itself becomes ex-corporated: the body is dispersed, one thing multiplied among many.

This move beautifully dissolves the hard distinction between social and biological, shifts attention from what the body is to what it can do, and presents to us a picture of the body released from the constraints of its skin. Unbounded, our bodies:

...extend and connect to other bodies, human and non-human, to practices, techniques, technologies and objects which produce different kinds of bodies and different ways of enacting what it means to be human. (Blackman 2008: 1)

Decentering the body, its flesh becomes symmetrical with other material forms (Latimer 2009: 7). The distinction between what is inside and what is outside the body is suddenly put into question, redefining our body's matter in such a way as to negate the very matter of matter. We have fulfilled the sociological ambition set out by Rose:

We need to abandon the belief that we are 'in our very nature' discrete, bounded, self-identical creatures, inhabited and animated by an inner world whose laws and processes psychology has begun to reveal to us. On the contrary, we are 'assembled' selves, in which all the 'private' effects of psychological interiority are constituted by our linkages into 'public' languages, practices, techniques and artifacts. (Rose 1996: 250)

But when we talk about a multiplicity of bodies across sites and practices, or say that it is sometimes difficult to determine where bodies begin and end, do we really mean that the material body has broken out of itself, divided and merged with the world? Immaterial conceptions of the body risk producing grand ideas that are more science fiction fantasy than everyday reality, so we might be led to believe that, "Ageing,

disease and death no longer appear to be immutable facts about the human condition” (Turner 2006: 223).

Along the same lines, one might posit that: “Mind is a leaky organ, forever escaping its ‘natural’ confines and mingling shamelessly with body and with world” (Clark 1997: 53). Clark’s ‘Extended Mind Thesis’ parallels the body as assemblage paradigm by suggesting that when parts of the environment or social world are coupled with the brain, they become parts of the mind. What this means is that Otto’s notebook is a ‘part of his mind’, a claim that mixes up literal and figurative meanings and in doing so neglects the ontological difference between Otto’s mind and his notebook. Unless you wish to dissolve the distinction between mind-body and world the claim makes no sense (Fodor 2009). Applied to bodies it is even more damaging, because it denies the importance and uniqueness of the body’s ontological materiality. As the possibilities for extending the conceptual body into the future and into the immaterial expand, we must not forget that our bodies are the essential conditions of our lives, and that they cannot be taken for granted. While the body may exist in multiple ways, its materiality is, in one sense at least, definitively singular.

So it must be recognised that the body is not “an infinitely malleable phenomenon” (Shilling 2005: 762); the desire to keep bodies indeterminate and unstable, to resist making them into something too fixed or too material (Nast and Pile 1998: 4) brings us dangerously close to rendering the material body obsolete. While we have found new ways in which to incorporate the body into sociology and to engage with biology, the techniques by which we have achieved those aims have in some ways negated the original problem posed by the body. As an object dispersed

across multiple sites is the body now any less elusive, illusory, distant, absent or silent than it previously was? We are in a situation in which the body is in danger of existing more outside of itself than within itself. Suspended in becoming, the body is connected to the immaterial social world but in some sense disconnected from itself. In fact, when studies include the body as one thing among many, are they actually about the body at all? Finally, it is the operator, the state or condition, as opposed to the body, which can be said to exist across the network and which has the spotlight.

Admittedly, body pedagogics has a tighter grip on the individual matter of bodies, but by its own definition is oriented to taught and acquired practices; it is concerned with disciplinary regimes, that is, with the practice of physical capital: once again with what *we* do to *it*. Can we ever know the body *itself*? Merleau-Ponty's phenomenological framework, which dictated that all experience is mediated through the body, supplied a way of guaranteeing the inclusion of bodies; as we can only know the world through our bodies a disembodied viewpoint becomes impossible to attain. But like Leder's 'dys-appearing body', the 'lived body' is characterised by its silence; always in the background, it is taken-for-granted, intuitive and non-conscious. Merleau-Ponty's philosophy is also inherently oriented *from* the body *to* the world, and this has limited our perspective. Always looking outwards we are led to conclude:

The problems one is faced with are not conditions of the body. They pertain to one's body, but they are situated elsewhere: in one's life. (Mol 2002: 127)

This orientation de-emphasises the body, making it difficult to grasp hold of. Instead, we need to "move beyond Merleau-Ponty's emphasis on the body merely as a *medium* for having a world" and "recognize the body as more than just a means or a

conduit”. To foreground the “substantive, living body as conditioned possibilities for both *being* in the world and for *shifting* worlds” (Latimer 2009: 9), we need to reorient ourselves *to* the body.

To know the body we need to recover what has been lost: the matter of the body as *a dynamic unity*. Matter is what makes the body’s physical presence real and tangible. Matter is what can make the body visible, so that it might speak as a singular *object with agency*. To recover the matter of bodies we need to return to what the body *is*: we need to return to ontology. This question, ‘what is the body?’ lies at the heart of studies of the body and embodiment (Shilling 1993: 6), but our failure to satisfactorily address it has left us with bodies that are difficult to grasp hold of:

Bodies, in other words, become elusive, de-materialized, incorporeal entities through a postmodern bracketing of ontological questions. (Williams and Bendelow 1998: 125)

The contemporary focus on process as *opposed* to substance has led us to define the body by what it can do alone, enabling the incorporation of the biological body into a social network while negating the question of substance. The problem with this move is that what a body can do is intrinsically related to what it is, and unless we examine the question of substance we will be unable to see how the body does. To return to ontology we need to look at what is wrong with our ideas about matter. And to do this we need to re-examine some assumptions, in particular the revolt against dualism.

In summary, I have argued that the body has been silenced over and over again by the many different ways in which we have conceptualised it. It seems clear that abiding to conceptual and disciplinary boundaries leads to disembodied accounts: as we struggle to understand the social as embodied and to rejoin the social with the

biological, it is necessary to re-think a space for the body. Attempts to reintroduce the body to sociology have made some headway by breaking down the overriding belief in a social constructivist model of the body and creating a new space, in which our embodiment is recognised and bodies are entitled to be connected to social worlds in multiple ways. But they have also proliferated the body to the extent that its very matter is lost within the vast expanse of ideas:

The body is at once the most solid, the most elusive, illusory, concrete, metaphorical, ever present and ever distant thing – a site, an instrument, an environment, a singularity and a multiplicity. (Turner 1984: 8)

With so many forms but no solid material presence the body remains conceptually weak and lacking in agency. The overemphasis on a narrative approach within the sociology of health and illness continues to subsume the body within the self, while network approaches leave the body understated, one thing among many. Reviewing the reasons why the body remains silent even as it rises has brought to the forefront a series of problems, from our orientation to the body to our ideas about matter, disclosing the fact that bodies are not out of bounds because of disciplinary divides, but rather because of the ideas upon which our concepts of the body are founded. In order to develop the body further so that it might speak for itself, we need to revise our conceptual foundations. As Latimer writes, “it seems too precipitate to dispose of more common notions of flesh and blood altogether” (Latimer 2009: 9). Instead, we need to stop thinking about the materiality of bodies as *mere* flesh and blood. Combining the strengths of both narrative and network positions and underpinning them with revised understandings of the ideas and concepts that bodies consist of we

can hold on to the subject while giving greater agency to the body and re-engage with the body as a significant sociological topic.

Central to this move is the assumption that dualism should be overcome. Strangely, it is an assumption that puts the conceptual world and the experiential one at odds:

In short, while, at an analytical level, the study of illness, pain and suffering may demand a transcendence of dualistic thinking, at the phenomenological or experiential level they may perpetuate these very dualisms. (Williams 1996: 27)

This rift evidences the claim that current thinking about dualism is unsatisfactory. Conceptual theories are supposed to support our experiences, and we cannot continue to simply dismiss dualism if it means that our theoretical and experiential accounts do not fit together. Any attempt to re-think the body and illness will, sooner or later, need to confront this problem. In the next section of this chapter I attempt to reimagine the idea of dualism. My intention is not to resurrect this troublesome concept but to open it up, so that we might reclaim from it the building blocks for a material understanding of the body that can support the many different ways in which we experience our minds and our bodies. This alternative framework is then developed through the notions of fragments and skin, bodily organising principles which help to redefine the biological body as malleable – a quality which up until now has been reserved for the cultural body alone, and which provide a framework with which to look at bodies directly. Bringing these three sections together, it becomes possible to reconfigure the body as a starting point for sociological research, adding substance to our ideas about embodiment. These three ways of thinking the body are brought to life with methods in chapter 2 and put to work through original

empirical research in chapters 3 and 4, evidencing the resonance of these theoretical ideas with the corporeality of everyday life.

## *Dualism*

Mind body dualism has become an outmoded philosophical formulation. Contemporary debates are instead working to collapse, transcend, and silence this troublesome philosophy that has become embedded in Western thinking, shaping sociological theories and influencing disciplinary divides. Yet Leder's theory of dys-appearance, which describes the body as alienated from the self, continues to shape sociology's approach to illness, and more widely, dualistic imagery still persists in Western thought:

Within this scheme of imagery, dominant themes have included the body as alien, the body as confinement and limitation, the body as prison of the soul, the body as enemy, the body as the locus of all that threatens our attempts at control, and the body as machine (Bordo, 1993; Synnott, 1993). (Williams 1996: 23)

Perhaps then, it is a mistake to relegate dualism "to the trash heap of history" (Dennett 1996: 24). Perhaps dualism can provide some important insights into the concept of body, and perhaps it continues to exist in everyday life despite being dismissed by philosophers and sociologists. If this is true, then perhaps we can re-engage with dualistic thinking in a novel way.

Dualism is classically defined as a split between mind and body. This split denotes a hierarchy in which functions and processes of the mind are both superior to and different from functions of the body. The mind is the non-physical seat of consciousness, the house of will; its functions are the ability to rationally think and reason. In contrast, the body is physical substance, inert mass; its functions are those

of a machine governed by involuntary laws, for instance respiration and digestion. As such, dualism presents a view of the mind as a disembodied soul and the body as a machine. This view creates two fundamental gaps: one ontological and the other epistemological. The ontological gap exists between mind and body, which are dichotomous in terms of both the matter that they consist of and the qualities that they possess. The epistemological gap lies between the formal and the material, with ideas and rationality conceived as abstract and transcendent, disembodied from the physical, mechanistic and sensory world.

Dualism has left traces on both philosophy and sociology since being introduced in these terms by Descartes in 1641. Lying at the heart of the philosophical problem is the question of how mind and matter converge, and the problem of mapping human thought or mental states to the workings of the mechanical body or physical states continues to occupy philosophers of mind (Davidson [1970] 2001, Dennett 1996, Fodor 1978). Modern thought on this matter tends towards a reductionist solution, with philosophers like Dennett dismissing dualism on the grounds that consciousness and free will are the result of physical processes. This move locates the mind in the brain, closing the ontological gap between mind and body. But it is the concepts of mind and body themselves, rather than the ontological relationship between them, that have most influenced sociology and that continue to be problematic.

By positing that 'I' am principally my mind, dualism has paved the way for sociology to focus on the mind as the defining aspect of the individual and to ignore the more material aspects of the body. The tenets of dualism are quite literally interpreted by social constructionism, in which the individual in society is a social

and cultural construction that is independent from and uninteresting in terms of its physical body. Implicit is the assumption that, because dualism has lead sociology to ignore the body, we necessarily need to overcome it in order to bring the body back. Crossley (2001) has pushed the argument further by focusing on the problems that the dualistic mind, as opposed to the dualistic body, presents to sociology. He claims that because the Cartesian mind is disembodied, it must also be private and non-social, thereby undermining the very notion of a social world. If this is true, then “No sociologist can afford to be a dualist” (Crossley 2001: 20). In terms of both body and mind, it seems that most sociologists would like dualism left where Dennett puts it, on the trash heap.

I want to explore the suggestion that dualism still has something to offer a sociology of the body. Regardless of its ontological validity, the tension between mind and body definitive of dualism is a real experience; it is a socially and culturally enforced idea that we employ in our everyday lives, and as such, it presents some interesting and useful scenarios in relation to the body and illness that are worth pursuing from a theoretical stance. And, the dualistic body has the very qualities that evade most sociological accounts: the vital processes and functions, the flesh and the blood. The dualistic body may be subservient, undervalued and mechanistic, but its necessity is implicit, it is unquestionably material and it can never be absent. Only when we have a body can we begin to legitimately question the divide and seriously consider the ways in which mind and body interrelate, conjoin and separate. Together, these arguments raise a different set of questions about dualism; stretching from the idea that dualism represents a refusal of the bodily nature of the self to the extension of both mind and body into the social world and the consequences of

putting the mind back into the body. These are epistemological questions that have important repercussions for concepts of the body and which continue to have an existence beyond any ontological claims, but they will also help to redefine an ontology of the body.

The relationship between mind and body is constructed in various ways in everyday life:

As we may oscillate between the desires for intimacy and solitude, so too we construct a relation with our bodies that is a fundamental part of our everyday existence.  
(Bauman and May 2001: 93)

Dualism offers us a range of ways to relate to the body based on the refusal of the body, an idea that has been attributed to Descartes' own fragile state of health (both Johnstone (1992) and Porter (2003) suggest that Descartes' philosophical views were based on a fantasy that he could overcome his ill body). Imagine that dualism acts on us in different ways in sickness and in health: when we are healthy it is easy to forget or disregard our physicality and to view the self as disembodied – to be dualist; in contrast, when we are sick we become acutely aware of the body, its failure makes it impossible for us to take it for granted and we are forced to define our relationship to it, which we can do in a number of telling ways.

One relationship we might adopt is commonly expressed by the adage 'mind over matter'. Here, the relationship between mind and body echoes that of traditional dualism, wherein the mind is our primary essence of being. This relationship allows us power over the body, so that we might act despite our physical limitations. It carries an imperative; "our bodies won't let us down so long as we maintain the right state of mind" (Scott and Morgan 1993: 8), and it is employed both in daily life, when

the demands or constraints of the body interfere with our goals, and in numerous accounts of illness and of ageing, when the body lets us down, or when body and mind are experienced in disunity.

Examples from the works of writer Hanif Kureishi and autobiographical and philosophical essayist Jean Améry help to illustrate the significance of this mind-body relationship. In the short fictional story *The Body*, the leading man, Adam, is in his mid-sixties, and his body will not stop reminding him of his ailing existence (Kureishi 2002). His knees and back give him a lot of pain, he has haemorrhoids, an ulcer and cataracts. He finds it hard to eat and to hear, and he is self-confessedly grumpy, disengaged from the world, and preparing for his own death. When, at a party, a stranger offers him the chance to have a body transplant, Adam does not take long to make his decision. The next day, he visits a secret hospital, picks out a young, fit, attractive body, undergoes the operation, and starts a new life. Kureishi's Adam feels trapped inside his aging body, and jumps at the chance to transplant his mind into a newer model, thereby overcoming the limitations of his body. Similarly, Améry describes how as we age the body shifts from being our mediator in the world to our prison:

This body, which is no longer the mediator between the world and us, but cuts us off from world and space with its heavy breathing, painful legs, and the arthritically plagued articulation of our bones, is becoming our prison, but also our last shelter. It is becoming what remains, a shell. (Améry 1994: 35)

These descriptions bring to life Ryle's (1949) phrase 'the ghost in the machine'. They describe people as contained souls existing within mechanistic bodies, making the science fiction idea of body transplantation seem for a moment like a possible reality.

While Ryle objected to this conception of mind and body and derided dualism for creating such a view, 'the ghost in the machine' version of dualism aptly reflects one way in which we live. A second example provided by Améry shows how the mind and the body battle for control over agency and life:

Then, in the search for words to constitute the feeling of alienation, the aging may well think that the *res extensa* is gaining power over them and may side with the *res cogitans* rebelling against it. In other words, they think perhaps that the 'mental ego,' as their true ego, resists the assumption of power by the *physis* and is supposed to resist it. One of them, for example, takes a provocative stance and proclaims in high spirits, 'I still will not let my asthma forbid me life.' Then he stands - but who is this 'he' anyway? - against this asthma, repudiates the *res extensa*, and does not accept his body. (Améry 1994: 44-45)

While, as Ryle argues, the dualistic separation of body and mind may well be a category mistake, the point is that they are, in some circumstances, experienced as living separate lives, as through two conflicting entities have been forced to share one existence.

Both Kureishi's and Améry's examples describe the difficulty of having to come to terms with an aging body, and the desire to live on in spite of our natural limits. In these situations, dualistic thinking allows us to dream the unobtainable and makes it harder to come to terms with reality, so that we might fool ourselves into thinking we are immortal beings, unconstrained by our physical bodies. However in illness the ability to separate mind from body can be useful:

The one-sided insistence on the need to avoid dualisms underestimates the subjective appeal of the mind-body dualism for women in their everyday interactions with their

bodies. Living with chronic illness, for example, would be impossible without a certain amount of splitting. The suffering that bodily vulnerability entails means that a certain amount of transcendence (i.e. mind over matter) can be welcome and, indeed, necessary for an individual's well-being. (Davis 2007: 55)

Here, the power of the mind over the body allows us to live with, or despite, our physical constraints by separating ourselves from our bodies. But just as putting mind over matter can be powerful it can also be destructive, as Bordo's (1993) study of eating disorders shows. When the mind is the seat of our consciousness and the body is no more than a machine we inhabit, the self-regulation of consumption can become a triumph of the will over the body. Here, the conception of the body implied by dualism is taken to an extreme, and the body becomes completely alien. And dualism does not end there:

Unfortunately...the individual's contact with and experience of modern medicine may serve to further reinforce and perpetuate this split... through their contact with medicine and the use of their prescribed medical regimens, the chronically sick may come to view and describe their bodies through highly technical medical language and vocabulary. In other words, the body and disease may become reified (Taussig, 1980) as a product of biomedicine's 'clinical gaze' (Foucault, 1973). (Williams 1996: 29)

Under the auspices of treatment, the body becomes 'thing-like', alien, machine:

For example, the daily injections of the diabetic may result in a 'biochemical body' for the diabetic while the bi- or tri- weekly dialysis sessions for the renal insufficiency suggest a 'body-as-machine' for the dialysis patient (Herzlich and Pierret, 1987). In this sense the boundaries between fleshy corporeal body and the body as machine may

become blurred; a situation in which the machine has, in effect, become a symbolic extension of the body and the self. (Williams 1996: 29-30)

All of these enactments show that dualism is much more than a philosophical argument; it is alive in the ways that we deny our mortality, manage our physical constraints, and punish our bodies. Dualism:

...is a *practical* metaphysics that has been deployed and socially embodied in medicine, law, literary and artistic representations, the popular construction of self, interpersonal relationships, popular culture and adverts. (Bordo 1993: 13)

From a sociological perspective, it is these epistemologies of mind and body rather than their ontological validity that hold interest. As such, dualism is an idea that should be worked with rather than overcome. It is not 'rigid' and 'unhelpful' (Crossley 2001: 54) but rather a tool for imaginatively exploring the multiple ways in which people negotiate their bodies. While the dualistic picture of the body may be flawed, its necessity and its pure physicality offer a powerful counterbalance to sociological accounts in which the body is absent, providing a useful framework with which to explore the materiality of the body and reconsider the ontology and significance of bodily matter. Like the new body theories with their emphasis on doing, the dualistic body also has the power to act, it is a body that does, but unlike the new theories it acts with its organs. This is what makes it so significant for an account of the body in illness; a body which is affected by its own physicality and which influences the structure of lives through its organs and material parts.

It is a misnomer that the body as a closed system, a biological organism, is of no sociological interest. Rather, material bodies are the basis of our lives and the

route by which our affective capacities are shaped and enacted. We act, attend, feel, and feel alive because of our physicality. What can a Cartesian mechanistic body have to offer in and of itself and what questions might it raise? Johnson provides the following medical perspective of the body as a machine:

The body consists of distinct, though interconnected parts. It is a functioning unity or assembly serving various purposes. It requires an energy source or force to get it operating. Breakdown consists in the malfunctioning of parts. Breakdowns occur at specific points or junctures in the mechanism. Diagnosis requires that we locate these malfunctioning units. Treatment directs itself to specific faulty units or connections. Repair (treatment) may involve replacement, mending, alteration of parts, and so forth. Since parts causally interact, we must be alert for failures in causal connections. The parts of the functioning unity are not themselves self-adapting. (Johnson 1987: 130)

This picture is tied to a theory of disease that modern medicine no longer completely agrees with, and which is inadequate for understanding and treating illness. However the points within it still retain some value. Re-written as sociological research questions, the mechanistic body offers an attention to detail that is much needed. It values the individual parts of the body, their functions, status, and relations to the assemblage that makes up the whole body, it acknowledges the importance of consumption and diet, and it breaks treatment down into its specific effects. These are important aspects of everyday life and are especially significant for people who live with illness. As such, it is precisely the power of the dualistic conception to posit an external perspective on the body and to break it down into its constituent parts that is of value.

Because it is physical, the dualistic body opens up a possibility to think about the body in terms of its parts, boundaries and surfaces, as an object that has an inside and an outside, and as both constitutive and other. Hacking suggests that this view of the body as a Cartesian machine has already taken hold of society through the commodification of body parts. Hip replacements, skin grafts, corneal implants, stents, organ transplants, and pacemakers are now commonplace (Hacking 2006: 13). We replace a defective part by a sound one just as we do with other repairable machines (Hacking 2006: 14), and our acceptance of this bodily engineering speaks of a comfortable alienation (Hacking 2006: 15). In contrast, the body parts in this project cannot be replaced; their status requires recognition and speaks instead of an uncomfortable alienation.

There is one more thing that dualism has to offer, and that is doubt. Descartes original problem was to refute skepticism by finding something certain on which to base knowledge. He achieved his goal by asserting that the one thing we can know without doubt is that we exist as thinking beings. Descartes trusted his mind over his body, believing that his body was mediated by unreliable senses. His doubt and his mistrust of his senses are valuable for an understanding of the body. It *is* questionable how much we can trust our senses and our bodies, whether they are truthful or if they hide secrets from us, and from society, and how much we really know about them. In some cases, we will see that people trust their bodies despite their failures, inadequacies and unreliability, some show that what they fear most is their own bodies, some people possess a detailed knowledge of their bodies, while other bodies remain unknowable. In her autobiographical study of cancer, Stacey questions the

truth-telling capacities of the body and its power to deceive. Her questions reveal how our relationships with our bodies shift and change in illness:

Is it no longer to be trusted? Why has it withheld such crucial evidence? Whose side is it on anyway? (Stacey 1997: 5)

To conclude this section, we need not reject dualism outright but rather use it as a tool to think through the complex and multiple relationships that we have with our bodies. Dualism is a reminder of the physicality of the body, and it justifies the validity of its material details. Too often, accounts of the body and illness float free from the physical constraints that define them, losing sight of the body and considering the consequences of illness for self and identity with-out the body. Our experiences of bodily containment are important, and the grounding of ideas in the defined spaces and places of the body must not be overlooked in favour of expanding notions of mind and body beyond individuals and into the social world. My aim is not to deny the claim that the body extends beyond its own materiality or that the mind is embodied; the interconnectedness of bodily, mental and social life is key. But mind body dualism is not the enemy. As with all oppositions, dualism creates a problematic hierarchy and it can legitimately be accused of disembodiment and reducing the body to a machine, but it also has much to offer when engaged with in a novel way. As such it is better viewed not as a theory to be resolved but as a mandate for research. Engaging with philosophy and using dualism as a starting point for researching mind *and* body, the reasons why we characterise the body in the ways that we do became a feature of the accounts I collected during this project.

## *Fragments*

Re-engaging with dualism has opened up another way in which to re-imagine the ontology of bodies: by focusing on the individual fragments that together constitute the body as a whole. Breaking the body down into its constituent parts allows us to attend to the material body at a microsociological level, to take the body seriously and to get close to it. In doing so, we become able to grasp the physicality of the body and to appreciate its complex existence within the social world, because each piece, fragment or site is saturated with co-dependent biological and social meanings and significance; when listened to the biological body might speak of sociological things. Throughout the project fragments were used as focus points through which bodies showed and told their own micro-epistemologies.

Ontologising the body in fragments reasserts the material body as a site of importance, but it should not be confused or equated with a medical perspective. Medicine works to reduce bodily experiences to symptoms of illness, a form of objectification that denies the body its affectivity and positions people as medical objects. It controls the patient and objectifies the body not only through the 'clinical gaze' (Foucault 1973), but also through acts of listening. In his study of repeated acts of stethoscopic listening to heart sounds or 'murmurs', Rice (2008) shows how repeated medical practices of listening can reify and isolate aspects of the body, turning them into objectified clinical cases. Nor does this perspective equate to a dissection of the body. Medicine pries open the body in order to inspect it anatomically, but it is already a corpse, dissociated from the life it has lived it can

express nothing. Live bodies, in contrast, engage with the world through their parts and can communicate with them; a fact that makes them harder to capture than their dead counterparts, but which also means that they can speak to us, if we learn how to listen. Now, Rose's (2007) molar body, the body composed of tissues, bones, limbs, blood and hormones, becomes an important aspect of a sociology of the body.

Starting from the body allows us to locate the material anchors of affect and to create objects with agency. Attending to fragments reveals the significance of place within the body in an alternative light, turning the materiality of the body into a sociological concern and providing a counterbalance to sociology's tendency to reduce the body to process. As such, the problem of objectification does not arise from regarding the body as a collection of parts, but from what kinds of accounts those parts are allowed to tell: the same body part can be highly personal or entirely depersonalised according to how we allow it to speak. One situation in which the various parts of our bodies come to prominence, in which those who are affected can hear them clearly, is illness. Because then we are forced to pay attention:

We notice our body when the sudden or progressive impairment of one of its functions interferes with our daily activities, disturbing the order we take for granted. A leg that will no longer walk, an eye that will no longer see, a heart that strains to run a familiar stretch, impose themselves on our attention as they transform our customary relation to the world. (Fraser and Greco 2005: 20)

Each part suddenly becomes significant in itself, contradicting Merleau-Ponty's claim that, "nails, ears and lungs taken separately have no existence" (Merleau-Ponty 1962: 501). Fragments of the body tell us what our bodies are and what they can do, and they define us in new ways. Each fragment of the flesh contains the origins of our

fears and can make our concerns real. This micro perspective of the body is a stance against the social constructionist tradition in which the body is neither seen nor heard, and it is a way of holding onto the body in an account of illness, a way of making it viscerally present. Returning to Leder's theory of 'dysappearance', we are now in a position to re-focus our attention on the ways in which our bodies call for our attention, and the ways in which we tend to them. This is a significant shift: the primary interest is no longer dictated by the self, and the goal is no longer to push the body out of conscious awareness. Instead, we are open to understanding a variety of different relationships between body, self and illness, as well as to seeing a multitude of connections between bodies and social worlds.

The micro allows us to get a sense, "of how bodies might protest, speak back or simply refuse to participate in the workings of disciplinary power" (Blackman 2008: 28), and gives us a tighter fit, a solid link, between the social and the physical aspects of the body. It also begins to open up a way of understanding how biology is not fixed, but rather how we become and un-become through the changes in our material bodies, and introduces the body as a way of knowing and of telling. All these things are important for an understanding of the body in illness, because each aspect of the body affects interaction in the social world differently and, when attended to, will reveal a complex relation between bodily and social life.

## *Skin*

Having disassembled the body it is now time to consider its role and qualities as a whole; a unitary object bound by the skin. Skin is a site with multiple meanings, and as such it holds the potential to bring together contradictory ideas in a single material place. Embracing 'both/and' instead of 'either/or', the skin performs a number of physiological tasks, supporting, containing and protecting the body so that it is bounded from the world, and simultaneously interconnecting the sense organs, transmitting sensory experiences of cold, heat, pain, and pleasure, communicating with other bodies, and opening the body up to the world. It acts as a material boundary between internal and external, private and public, and reality and appearance, holding the body together as a dynamic unity, and it is permeable, bringing these distinctions into direct contact with each other, so that they converge, become entangled, and ultimately undermine each other.

Where precisely the physical lines between private and public, invisible and visible, reality and appearance are marked on this material site is open to historical, cultural and sociological interpretation. If the body is viewed as social capital then, "it is the exterior territories, or surfaces, of the body that symbolise the self at a time when unprecedented value is placed on the youthful, trim and sensual body" (Shilling 1993: 3). In modernity, the body is a temple of worship, the public presentation of the private self, ours to manipulate and control. But sometimes those exterior surfaces themselves hint at the vulnerability of our embodiment, as illustrated in Burnett and Holmes' (2001) conception of the body as a heritage site, a

site of visible interpretation and re-presentation. Scars are anchor points that can be meaningfully interpreted, revealing accounts of misfortune, stupidity and bravery and providing glimpses into personal lives. Marks, lines and disfigurements leave visible reminders of our duty to take care of and preserve our bodies, and they reveal our failure to do so (Burnett and Holmes 2001: 22).

At other times, the body's vulnerability is far less obvious or visible on the exterior, making the ill body impossible to see without intruding into the inner recesses with medical instruments. In this case, x-rays, scans, and stethoscopes give us access to the interior body, making it both visible and audible. If the body's skin is the boundary between private and public, the boundary between what we can see, hear and feel, and what we cannot, then we might be led to believe that it is a boundary that can only be crossed by medicine, which has the power to examine the body from the inside through processes of biological objectification and abstraction that make the invisible, private body both visible and public.

This view of medicine as the conqueror of the internal body emerges in historical parallel with our views of body management, individualization and social capital, described by Elias (1994) as the 'civilizing process' in his book of the same name. They also emerge in response to changes in medical practices, which themselves reshaped the body:

The fundamental restructuring of medical diagnosis and treatment to deal directly with the inside, without applying treatments on and in the skin, could not fail to influence the collective body image. A conception of the skin as closure and a necessary boundary layer could arise only after these multifarious practices of drawing off substances through the skin and opening the epidermis were dismissed as

prescientific and replaced by intracorporeal medication or surgical intervention (which opened the body but afterward neatly closed it up again). (Benthien 2002: 41-42)

Together, these views solidified the body's boundaries, which were previously more leaky and permeable, making the skin a static and impermeable boundary between the self and the world. They also go some way to explaining why it is that sociology has been unable to penetrate the body in the way that medicine does, so that it has clung to the notion that the body should be understood as nothing more than a 'plastic resource' (Sweetman 1999: 68) for the self.

Yet as Benson's (2000) study of tattooing reveals, skin and our practices on it bring into sharp focus the fantastical nature of Western ideas about body and self. None of what Benson sees in the practices of body modification,

...looks much like the flexible, mutable personhood celebrated in so many post-modern texts: on the contrary what seems to be central is fear of fragmentation, anxiety about boundaries and about the relationship between will and self; the body is the battleground in which such anxieties are played out. (Benson 2000: 252)

When we begin to probe at the shiny surfaces of self-presentation it becomes clear that while we are bound by the 'epidermal frontier', a frontier that has enforced our individualism and personhood as existing in and defined by our mortal, modern bodies (Cohen 2009), that frontier is not a safe or dependable one. The body is not under our control as we might wish, our boundaries require maintenance, and they are site of contention, open to attack and to redefinition. Just as repeated acts of listening can objectify the body (Rice 2008), the force of noise can transgress bodily

boundaries. As Gunaratnam's (2009) study of 'noisy mourning' in a multicultural hospice ward shows,

...sound is a complicated sensual, psychic and metaphoric medium for delineating bodily surfaces, within a field of forces, through which we come to feel and solidify relationships between inside and outside, me and you. It is in the midst of such corporeal sensations and co-motion that bodies and worlds are formed, producing the effect of boundaries and surfaces (Ahmed, 2004). And every once in a while such insurgent movements can entail a significant rupturing of boundaries and a rupturing of what it is known. (Gunaratnam 2009: 5)

Perhaps the skin is not so much a boundary as a meeting point, a site of slippage and seepage wherein the corporeal and the social resound. Skin simultaneously reveals and conceals both the physical and the social, and it shows us that bodies are *active* matter, in control of us as much as we are of them. Changing perspective from the outside in to the inside out, we can begin to listen to our bodies and to let them show us how the physical and social aspects of our existence are entwined. We can take Burnett and Holmes' scars and connect them to memories, we can be told the stories behind Benson's tattoos, and we can add to these visible markers other bodily and sensory ways of knowing and remembering; "the stylized movements of dance, the melodic contours of music, the fragrant odors of perfume, or, perhaps, the rhapsody of song" (Stoller 1997: 47).

The skin becomes knowable as an organ of perception and the flesh is recognised for incorporating visible and invisible knowledge through its senses, such that our bodies are entangled with the practices of everyday life in virtue of their flesh. While "Different ways of doing the body are not simply written upon the molar

body but are inscribed into and upon the different practices of everyday life through which bodies are made and remade” (Law 2004: 126), those practices are themselves experienced and remembered by the body. These are the ways in which we exist as bodies and as people; in which the skin is “a *pars pro toto* of the entire human being” (Benthien 2002: 13), in which it acts out biological distinctions between exterior and interior and blends them with the social and the personal, and through which we experience the world directly.

But the skin is also other than the self; it is an “enclosure, prison, or mask” (Benthien 2002: 13). We are taken back to the etymology of the English terms ‘body’ and ‘embodiment’, which stem from the old Saxon *bodig* meaning ‘vessel’ (Fraser and Greco 2005: 23) and returned to mind body dualism. As a container, a hollow, inhabitable space, the skin can be characterised as a dress or as a house. Both analogies have a long tradition, and both describe the ways in which we imagine and treat the matter of our bodies as bounded objects (Benthien 2002). As a dress, the body is a visible and performative surface that can be modified and updated. As a house, the body is immovable and static, protecting us from the outside world. Both analogies are taken to reflect our ideals of social capital and control and both deny the body agency. But if we extend those analogies and begin to think of objects themselves as having agency, then they can become a useful way in which to understand the boundaries and limitations of the felt, sensing body that is otherwise in danger of losing its own substance.

Extending the analogy of the house and borrowing from bioscience the idea that bodies need to defend themselves (Cohen 2009), the body can be reimagined as a home, a fortress or a prison. It can protect us from the world and it can isolate us

from it, it can hold us captive, and its walls can crumble around us. Inhabited, the body asserts its spatial properties, countering the medical body with an alternative physical presence and offering a language with which we can talk about physical 'lived' bodies in meaningful ways. Honkasalo, for example, uses the idea of experience as being housed by the body, or space as inhabited, to suggest that people with chronic pain are *homeless*; "Is not this the core of their suffering? Their homes are spaces which allow them neither peace, nor shelter, nor stability" (Honkasalo 1998: 48), while Bauman and May describe the body as a fortress which may come under assault at any moment; "You need to surround the fortress with moats, turrets and drawbridges and it must fall under our gaze twenty-four hours a day. Some of the infiltrators 'settle in' and pretend to be part of the body, while in fact they are not – they remain the aliens 'inside'" (Bauman and May 2001: 98).

These imagined bodies and borders are explored in chapter 4, illustrating the need for solid boundaries between the body and the world and at the same time highlighting the role of those boundaries in disconnecting us from the world. Finally, the significance of skin is made apparent through the emotional connections that it produces and the centrality of touch to our relationship with the world. Touch is not restricted to the fingertips, but involves the entire bodily surface (Ratcliffe 2008: 314), and, as Ratcliffe writes,

What characterizes rootedness in a familiar situation, belonging to a context, is the extension and diffusion of boundaries, a blurring of the self-world distinction. Perception of the body as a discrete object with clear boundaries is, at the same time, a failure to perceive and engage with the world, a loss of connectedness. Suppose that one's whole body were experienced as a bounded object, ending at the skin. What

would experience be like? Many phenomenologically minded psychiatrists have pointed out that this kind of predicament is characteristic of experiential pathologies such as schizophrenia (see, for example, Stanghellini, 2004), where diminished bodily affect is, at the same time, an object-like conspicuousness of the body. In conjunction with this, there is a lack of relatedness to the world, a failure of the body as a ‘feeling’ rather than ‘felt’ entity and a consequent sense of unreality, estrangement and lack of practical belonging that pervades all experience. (Ratcliffe 2008: 317)

To conclude this section, the notion of skin can be gainfully employed to overcome the opposition between process and substance. Skin both holds the body together as a dynamic unity *and* it is permeable; it establishes the body as a material object – as a heritage site, a dress, a fortress, a prison, or a home – revealing the ways in which we inhabit our bodies and the wars that they wage, and as an object with agency it acts on us, defining the conditions of our existence and our belonging in the world. As a site wherein biological and social processes resound and become entangled, the boundaries of the body are not fixed but they are significant. Skin becomes a way in which to know the body as a grounded and spatial whole. Through it we can begin to appreciate our being in the world: the boundaries between the biological body and the social body are dispelled.

## *Conclusion*

Once taken for granted, the body has received increasing analytical interest in recent years, proliferating the ways in which we know it. It has journeyed through assorted incarnations and its meaning and significance have been fervently disputed, but all the while it has remained elusively silent. This history can be roughly divided into two parts. To summarise: the first part is dominated by social constructionism, which gave the body its political and social significance, value, and power as text and lifeless object; the second part is characterized by notions of assemblage and multiplicity, dispersing what was once a singular body across untold relationalities and realities so that we have come to appreciate its processes and practices within different social contexts. Each historical part has contributed to the ways in which we know bodies and has revealed new aspects of their existence in the world, and each has had its accompanying problems. On the one hand, the body has been reduced to a means of doing, while on the other it has been reduced to its relationship with whatever other aspects of the assemblage it is defined in relation to. This double reduction has served to infuse the body with elusiveness; either its matter is insignificant or else it is defined by concepts that are themselves constantly in flux. It is no wonder then, that the body cannot be heard.

Turning to ontology has brought to life the matter of bodies, and the question now becomes,

...how does recognizing, indeed even foregrounding the body as organic, animate, vital, processual, generating and degenerating, affect how we incorporate

understandings of the body, and being (un)bodied, into social science? (Latimer 2009: 4)

Real, tangible and audible, bodies act on us and speak to us in ways that redefine our ideas about what the body is and, as a consequence, our ideas about what it can do. Through encounters with dualism, fragments and skin, the notion and practice of physical capital has been reversed; the question is no longer what we can do to our bodies but what they can do to us:

For in truth we do not own our bodies, they own us, and the only thing that is certain about our bodies is that they will let us down, that in the end they cannot be mastered or bent to our will. (Benson 2000: 253)

In reconsidering the concept of dualism it became clear that the troublesome distinction between mind and body is alive in multiple permutations. As such it is impossible to dismiss. Instead of ignoring this fact and revolting against dualism, we can re-work the notion so that it becomes a useful one. Instead of overcoming dualist reductionisms we can mobilise dualism itself in order to overcome *body reductionisms*, using it to remind ourselves that bodies are natural matter and that they are important. Shifting from a view of the body as a taken-for-granted aspect of life to one that sees it as an explicit object means that we can begin to take seriously the physicality of living and lived bodies.

No longer simply a bridge between self and world, the mechanism and matter of bodies becomes infused with life. Instead of being passive or acted on, the material body is an object to be feared but also to be listened to. Orienting ourselves to the body and grounding our transactions in it through its fragments and its skin, we can

turn the notion of matter on its head; bodies do not remain fixed or static because matter is neither fixed nor static. Boundaries exist so that they can be traversed and substances deteriorate; matter can no longer be equated with permanence or stand in opposition to process. But rather than leading us full circle and returning the body to the assemblage paradigm, this discovery highlights an important distinction that brings us closer to the body and allows matter and process to be incorporated into a single account without undermining each other. This is because the attention to matter – to the body itself – illustrates the difference between the material body and the body’s presence beyond its corporeal form, a distinction that can too easily be conflated by the assemblage paradigm.

Performing a ‘reconstellation of concepts’ (Massumi 2002), we are now able to situate the body at the centre; the orienting point is no longer a condition, situation or practice, but the body itself. No longer ethereal and ghostly, the body has a life of its own, and it is one that is both biological and social. Two important claims follow: bodies are social in their materiality, and they are productive in their own right. Saldanha propounds the argument for a materialist ontology that shows bodies to be productive in their own right in his discussion of race: “Bodies need to be appreciated as productive in their own right, just like words or money or architecture” (2006: 12). This alternative reconceptualisation provides a systematic approach with which to analyse the body as both *structure* and *agency*. Escaping the confinement of a single ontology, it becomes possible to explore how multiple ontologies are epistemologically alive, to push social analysis towards the corporeality of life, and to move the fundamental basis of illness from the self to the body, making illness an embodied concept rather than an abstract state. Now we can truly practice the art of

sociology, and listen to the body as it whispers, shouts and screams in illness. We can add to the accounts already offered a fresh angle, a new way of working in the sociology of health and illness that blends biological and social and that starts with the matter at heart; the matter of bodies.

This reconceptualisation forms the foundation of this project, and each of the points made is central to the following thesis. The three ways of thinking the body presented here, dualism, fragments, and skin, are brought together under different frameworks in chapters 3 and 4. In *Bodyrhythms* rhythmanalysis is used to view the body in motion. Locating the body in time it becomes possible to see how dualism, fragments and skin are animated and affected by the temporal rhythms of life; rhythms of eating, exercising and sleeping that are restructured by illness. In *Bodyscapes* the body is located in space and the same elements, dualism, fragments and skin, are used as starting points from which to explore the internal worlds of our bodies, the external environments they inhabit, and the spaces and places they long for. Together, these chapters evidence the resonance of these theoretical ideas through original empirical research and work to locate the body in space, in time, and in the sociological imagination.

## CHAPTER 2

### *Methods for Mapping Bodies*

In this chapter I argue for an inventive approach to researching bodies and describe how I approached the methodological problem of researching ill bodies from a sociological standpoint. In order to capture the body's presence and retain its vitality, I learnt imaginative ways of listening; I listened with my ears and with my eyes. Visual methods and tangible forms of data collection were used by participants to show and to tell about their illness experiences in ways that gave a visceral sense of what they were like and which were rooted in their bodies. This approach had at its heart a desire to take the material body seriously, to explain the body without explaining it away or wringing the life out of it, to introduce a sociological body that has a beating heart. From the context of the fieldwork to the methods that were used, each aspect of the project aimed to engage bodies so that they might speak for themselves.

Thirteen participants aged between twenty-three and forty-three were interviewed about their experiences of living with a long-term physical or mental health condition (asthma, bi-polar disorder, chronic pain, depression, type 1 diabetes, epilepsy, joint hypermobility syndrome, muscular dystrophy, and rheumatoid arthritis), before being asked to make a video diary and/or keep a journal about their everyday bodily experiences. The project was conducted in London and the sample included a gender mix, some social class diversity and people at various life stages, however it should be noted that participants were predominantly white,

middle class, university educated and aged between twenty-five and thirty-five. The project also included one person who is intersex, a general term used to describe conditions in which a person is born with a reproductive or sexual anatomy that does not seem to fit the typical definitions of female or male. Xan's inclusion within the project is not based on the classification of her condition as an illness, but on the relevance of her experiences of embodiment and her own desire to explore her condition within the context of the project.

Like all the participants, Xan was not selected for the project but actively chose to take part by responding to a call for public participation. The project was advertised on a dedicated project website and Gumtree (a free classified ads website), and details were circulated through the Arts Admin email list, several university email lists, and via personal contacts who were asked to forward the project details to their contacts. Participation was open to anyone in London aged between eighteen and fifty with a long-term physical or mental health condition. These parameters were set to avoid any logistical issues that might be involved in working outside of London and to exclude issues specific to childhood and aging. This method of recruitment and the resulting sample made it likely that participants were in some sense already primed to tell their stories, and, while it is always hard to ascertain what motivates people to participate in research, my own feeling was that something in the project details had resonated with the people who contacted me.

The project was conducted over a year, during which time I met each participant two or three times. After an initial meeting to discuss the project participants were interviewed and asked to complete a hand-drawn questionnaire. They then made a video diary and/or kept a journal. Around a month later we met

again so that I could collect the video camera and journal, discuss any issues that had cropped up and re-confirm consent to use the interview, video and journal data. During these meetings I sometimes asked if I could make some Polaroids with the participants, a process which often led to further conversations and new insights. After copying and scanning the data that had been made I returned the original journals and DVD copies of the unedited video footage by post to each participant. Over the year I met with every person who contacted me, eventually closing the project when I felt that the sample consisted of an adequate gender mix (five men and eight women) and range of conditions.

My intention was to disorient our usual ways of looking at what we think of as illness and by doing so to enable people affected by long-term conditions to speak about their specific, local and corporeal everyday lives. As Frank writes, the dominant cultural conception aligns illness with passivity, making us see “the ill person as ‘victim of’ disease and then recipient of care” (1995: xi). Like Frank, I wanted to shift my perspective from passivity towards activity, thereby creating a space within which the agency of the body could be seen. As an illness group, long-term conditions share a number of features. They can occur for many different reasons, have different physical effects, and can be more or less difficult to live with, but they hold in common the fact that once they happen they become a permanent feature of our bodies; they are conditions for which there is no cure. Unlike acute illnesses, which start suddenly and are quickly recovered from, and unlike terminal illnesses, which loom with an absolute certainty of death, long-term conditions are neither transient nor final, but become a part of our life, affecting our bodies and our lives on a daily basis. They are also less known by medicine; sometimes they take

years to detect and often they defy medical management. As such, medicine has no privileged access to these bodies; instead self-management is crucial.

Given this background it made sense to look at these particular ill bodies at home and in terms of everyday life, while also taking specific contact points with doctors, hospitals and medical regimes into account. Focusing on the often invisible and the taken for granted, the endotic as opposed to the exotic, meant bringing to attention what was largely already habitual and evident for the participants in the project. Together, we worked to reveal what are the *remarkable* practices of their everyday lives: the ways through which they negotiate their bodies in order to maintain normal lives. Sontag (1978) once wrote that health and illness are like two different countries. Most of us are passport holders of both domains, dwelling for the most part in the land of health but occasionally forced to enter the land of illness. Advances in living conditions and medical knowledge mean that while many illnesses still cannot be cured, it is now possible to continue living with conditions that would once have been terminal. This phenomenon of contemporary society means that instead of travelling between polar states, a growing number of people now inhabit a no man's land between health and disease (Frank 1995). In fact, at least 60% of adults living in England have one or more long-term condition (Department of Health 2004), a statistic that challenges the very idea that health is our normal or default country of residence. As such, this project called into question the legitimacy of imagined borders between health and illness.

Unbounded from medical categories it was possible to look at long-term conditions as a collective and to identify some of the overlaps and similarities, instead of the differences, between bodies. From this perspective diagnoses, along with sex,

gender, race, skin, and blood, were “indeterminate and unstable signifiers of the differences and similarities between bodies” (Nast and Pile 1998: 4). Instead, the things that bound these bodies together were their strategies and styles of living, their challenges and their insights. This understanding of embodied difference means that rather than being opposites, people might be considered ‘neighbours’, with many things in common (Grosz 1998). By the same token it became possible to see that mental illnesses can be just as dependent on, influenced by and managed through the body as physical conditions are. These commonalities between conditions bind physical and mental long-term conditions together as a phenomenon that makes visible the reality of the human condition, reminding us of the significance of our bodies.

In order to encounter the body in the flesh an imaginative engagement with methods was needed. While theoretical work on the body has recently proliferated and bodies have emerged as a new site of analysis (Stoller 1997: xiii), the issue of methodology in relation to the body remains largely under-explored (Shilling 2005: 764). Reformulating the body requires both theoretical *and* methodological work in order to prevent the details of corporeal life falling out of accounts and back into abstraction, and to hold on to the body and communicate an understanding of these details and affective qualities different forms of description were needed. One way to bring the body back into sociology was to stop relying on aural and text-based methods alone and to move towards more imaginative and evolving methodologies. Our first thought tends to associate social research with what we can read (text and statistics) or hear (interviews and conversations) (Silverman 2006: 242). But as Back writes, “If we stop listening only to ‘voices’ then we can reanimate the idea of

description and attention” (Back 2010: 17). This is especially important for the task of researching bodies because, as Stoller writes, “...articulating the body in a disembodied and ‘bloodless language’ weakens the impact of embodied studies by reducing bodies to lifeless texts” (Stoller 1997: xiv-xv).

Visual and tangible forms of data collection including hand-drawn questionnaires, Polaroids, journals, and video diaries were used to represent embodied moments without flattening them, empirically grounding the theoretical body and creating audio-visual research data that, like bodies, is tangible and active. The materiality of these visual methods made it possible to shift engagement away from a dependence on narrative and instead to connect with the materiality of bodies. Unbounded from discourse, participants were released from dominant narrative ways of telling about illness and new routes of exploration became possible, routes on which the body could be encountered. Instead of distancing the body through “language, technique and the sociological gaze” (Scott and Morgan 1993: 19), or stripping it of its “smells, tastes, textures, and pains” (Stoller 1997: xiv) these methods offered novel opportunities to attend to embodied experience. We rely on our bodies and our senses to tell us about the world on a daily basis, to tell us how we are feeling, what our body wants and needs, and what it can or can’t do on any particular day. Attending to the body gave access to this corporeal knowledge, making it possible to learn the histories, rhythms, pains, needs, and desires of bodies, and to get a sense of what it was like to live particular embodied lives.

It should be noted that visual methods are not new to the sociology of health and illness. A number of researchers have used techniques including video diaries, photo-voice, auto-photography, draw and write, and photo-elicitation to explore

conceptions of health, the lives of children with asthma, deaf people's worlds, and the hospital ward (see review by Harrison 2002). But while these techniques have enabled researchers to access experiences of illness in new ways they have not filled the absent presence, distinguishing the use of visual methods in sociology from a sociological representation of the body. Putting the body back in sociology is not simply a matter of documenting the physical presence of illness: medical photography with its encumbering notions of the real and focus on the biological is of little help to the sociology of the body. Medical images serve the useful purpose of illustration, assisting with the process of classifying and cataloguing medical conditions, but this objectification of bodies does not communicate the experience of those bodies that a sociological understanding seeks. In this project, visual methods were combined with the ways of thinking the body outlined in chapter 1, making the body fundamental to illness and bringing it to attention in new ways.

In the following sections of this chapter, touching, sensing, mapping, talking, writing, and filming are explored as ways of encountering and presenting bodies. Each thematic cluster is linked to one or more of the research methods and devices that were used in the project, and each method and device created a different sort of research encounter and has its own story to tell. In *Touching Bodies* Polaroids and drawings are introduced as tactile methods that connect touch with vision and create a close encounter with the body. *Sensing Bodies* expands the connection between touch and sight by incorporating and reimagining all of the senses. By taking a multisensual approach it becomes possible to redefine what it means to look, opening up new ways of attending to bodies. In *Mapping Bodies* the body is connected to its environment through emplacement and the qualities of maps are introduced as an

analogy for the project. *Talking Bodies* describes how in interviews the practice of talking was reformulated as together we learnt to talk about bodies, and *Writing Bodies* extends talking to writing through the journals that participants made. The final section, *Filming Bodies*, addresses the practice of making and editing video diaries and questions sociological ideals of observation, authenticity and ethics.

These sections highlight the particular qualities of each method and show how each device brought the body to attention in its own way. While they are addressed individually in this chapter, the data that was produced for the project was integrated during analysis. In order to organise the data interviews, journals and video diaries were transcribed and then analysed thematically using *HyperResearch*, a data analysis software package. By identifying categories and concepts across the different types of data I was able to consider each piece of data within a broader context. I then developed the emerging themes by returning to the original sources so that I could re-incorporate the more-than-textual elements of the data into my analysis.





## *Touching Bodies*

The most direct way to connect to the materiality of bodies is through touch. Appealing to the connection between seeing and touching, visual and tactile methods were used to touch the body. The title of Pallasmaa's classic architectural essay, *The Eyes of the Skin*, links sight and touch with tactility, expressing the significance of the tactile sense for our experience and understanding of the world and creating a conceptual short circuit between the two sense modalities (Pallasmaa 2005: 10). As an extension of the sense of touch, vision is a specialisation of the skin and the eye's gaze "implies an unconscious touch, bodily mimesis and identification" (Pallasmaa 2005: 42). By linking sight with touch we can imagine that, "The hands want to see, the eyes want to caress" (Johann Wolfgang von Goethe in Pallasmaa 2005: 14).

Pink describes research materials as sensory texts and material objects with their own biographies (2009: 122). As objects that possess their own materiality, sensuousness and intentionality, Polaroids and drawings invite a tangible relationship and resonate with the qualities of bodies. Polaroids are instant, tactile and unique; they are objects that link sight with touch and intimate the qualities of the sensory and sensuous body. Using Polaroids as a research device, I was able to keep close to the body. Each print captured a fragment or body part, for example hands, feet or legs. The prints solidified the moment of the encounter and were based on themes that arose from the interviews. More than simply illustrative of those themes, the process of making them together often led to new conversations and discoveries.

Take, as an example, Meghan's hands. Meghan, a participant in the project, is 32 years old and has rheumatoid arthritis. An autoimmune disease in the same family as MS and lupus, rheumatoid arthritis is a condition in which the immune system is over productive, meaning that Meghan's body is essentially attacking itself. The condition affects women two or three times more than men, and differs from person to person, so no one can ever say what will happen; it is entirely possible to have a mild form all of your life, or it might take a turn for the worse. The arthritis makes Meghan feel swollen and tired, manifesting itself in her fingers, hands and feet, and sometimes in her knees. But hidden beneath the surface the condition is invisible to the eye, affording some protection from the otherwise public consumption of her body. During one of our meetings I asked Meghan if I could photograph her hands. She positioned them on the table in front of me, nails neatly polished in a femme fatale dark red, fingers spread. We chatted as I prepared the camera, the Polaroid instamatic that I had specifically chosen because of its ability to re-produce fragments of the flesh in an immediate and tactile format.

During the two or three minutes while I photographed, Meghan rearranged her hands several times. Together with the frustrations of painful fingers that lack the dexterity they once possessed comes a careful attention and care, from her choice of rings – she is very careful about the way in which she calls attention to her hands, and anything that makes her fingers look big or swollen will be rejected – to the match between her skin tone and the colour of her nail varnish. These hands, which she thinks about a lot, are both a site of illness and of normality, a delicate balance between femininity and betrayal. And while they moved on the table in front of me, they always returned to the original position: palms down, fingers spread. Because

this is how Meghan's hands are normally inspected: by the x-ray machine, which monitors the progression of the arthritis within her joints.

Encounters such as this offered methods based translations of the theoretical idea of fragments, making it possible to trace the processes through which concepts take material form in bodies. Each print captured and framed an individual body part, abstracting and chopping up the body into novel units of analysis to be unraveled. The partiality of the prints allowed for different connections to be made, and for different ways of finding bodies. Often fuzzy and out of focus, they appeal to Pallasmaa's notion of unfocused vision, offering a sense, rather than a direct sight, of the body parts under investigation and drawing the viewer close:

The very essence of the lived experience is moulded by hapticity and peripheral unfocused vision. Focused vision confronts us with the world whereas peripheral vision envelopes us in the flesh of the world. (Pallasmaa 2005: 10)

Drawing became another tactile method through which to encounter body parts. Drawing methods are most often used with children, or in cross cultural research when participants could find it difficult to express themselves verbally (Bagnoli 2009: 548). However, the potential of drawing as a research method applies more widely. With people of all ages,

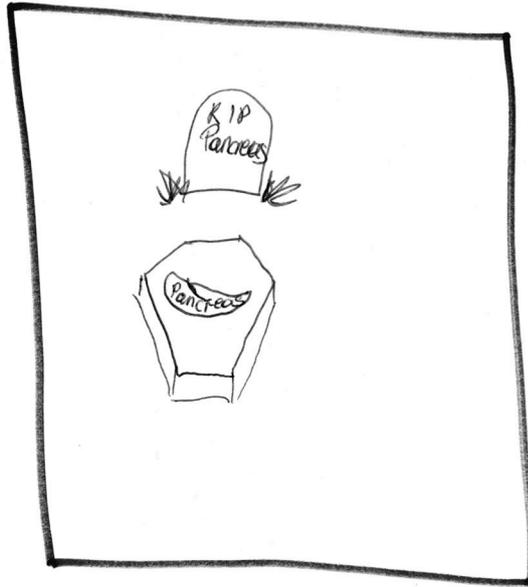
...the introduction of a simple visual task within the context of an interview may be very helpful for elicitation purposes. Focusing on the visual level allows people to go beyond a verbal mode of thinking, and this may help include wider dimensions of experience, which one would perhaps neglect otherwise. A creative task may encourage thinking in non-standard ways, avoiding the clichés and 'ready-made' answers which could be easily applied. (Bagnoli 2009: 565-566)

Thinking in 'non-standard ways' about my own methods I included a drawing box as one aspect of the questionnaires, which were hand drawn with a black marker pen on A3 sheets of paper and used during interviews. The questionnaires touched on the themes of mind body dualism and body parts, with participants being asked to divide their body and mind into percentages, write three words to describe their body, draw a part of their body and tell a story about it. Although some of the participants were initially hesitant about drawing, they quickly became involved in the task and were able to make concrete connections to their bodies through it. The tactility and immediacy of the questionnaires helped to add a sensuous dimension to data collection and to tease out some of the more hidden aspects of the body, its futures and relations. Anwen's body part drawing, which is of her walking stick, powerfully illustrates the significance of the stick as an extension of her body. The image tells of both the limitations of Anwen's body and of its continuing independence with the aid of the elegant stick, which keeps her from needing a wheelchair. Imogen's drawing, a gravestone marked RIP with her pancreas beneath it, locates the source of her diabetes within the body and differentiates this malfunctioning part from her body as a whole, indicating the different connections and relations she has to her body. It also lays bare the foreboding reality of living with diabetes.

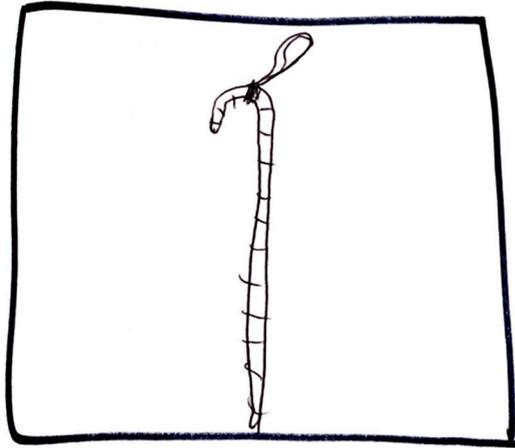
As images, the Polaroids and drawings also possess their own agency, demanding relationships with the viewer just as bodies do. The relationship we have to each other is like the one we have to images, and they to us, because images, like people, are social; they possess their own agency and exist in reciprocal relationships with the viewer. As Mitchell (2005) writes, it is this relationality and orientation of the image to the beholder that creates a field of desire between the two. According to

Mitchell, this field of desire gives an image wants, demands, desire and needs, and entices the voyeur to respond to those wants, to appropriate the image, to take it in and be taken in by it. As quasi-agents, images are multi-sensory, they are things to be kissed, digested, breathed in and spat out. Like bodies images are vitalistic, and their processes look “suspiciously like those of living things” (Mitchell 2005: 2). Shifting the question of how to interpret the visual from what pictures do to what they want, from power to desire, moves us away from reading images to entering into a dialogue with them – not with the creator of the image or even the figure that might be in the image, but with the image itself (Mitchell 2005: 46).

Together, these tactile methods helped to get up close to the texture and surface of the body and to place it centrally in the frame. Their materiality, sensuousness and intentionality captured and recreated fragments of the body and allowed them to speak, making the focus of the project and the value of the material body evident from the beginning. Developed specifically in response to the theoretical arguments of chapter 1, these tactile methods became innovative techniques with which to capture fragments of the sociologically elusive body and provided new ways of making a research encounter.



one day my pancreas  
decided to give up. Ever  
since I'm not allowed to



This is my stick. I  
use it quite a bit. I'm  
glad this isn't a picture of a wheelchair.  
No offence to wheelchair users.

## *Sensing Bodies*

Expanding the connection between touch and sight, visual methods were used to incorporate the body in a multiplicity of multi-sensory and mixed up ways. Appealing to the qualities of the methods themselves as ways of researching corporeal experience, it became possible to redesign how we pay attention to bodies and through bodies. As Pink writes:

Most existing discussion of questions relating (audio)visual media to sensory experience in ethnographic practice to date has focused on the use of media to represent sensory experience, rather than to research it. (Pink 2009: 99)

As a research tool and an embodied practice, multisensory imagining provided a visceral connection to the body and led to a reinterpretation of the acts of listening and looking. It became apparent that listening is not simply the domain of words or looking the domain of images, nor is listening only performed by the ears or looking by the eyes. Just as sight and touch mix up eyes and hands, it might be possible for ears to look and eyes to listen. Re-imagining the connections between body parts and senses, mixing up feeling, listening, and looking, hands, ears, and eyes, meant expanding the sociological repertoire and paying attention in new ways through these unusual pairings.

Cross-talk between the senses overturns the “modular conception of the sensorium” (Howes 2006: 381) so that each sense is no longer confined to a specific sphere. Instead, attending becomes a multi-sensory act in which the senses themselves are interconnected and non-hierarchical. Nor, in this collaboration of all

the senses, is there necessarily any direct correlation between specific media and sensory modalities:

...categories of visual experience might be effectively explored through audio-recorded interviews, tactile experience through photography and olfactory experience through video. (Pink 2009: 58)

Developing a multi-sensory approach to visual methods required not simply destabilising the visual in relation to the other senses, but also challenging notions of what it means to look. In the craft of social research, it is not simply what we look at that is important but also how we look, and while visual methods are currently gaining popularity in the social science arena, the act of looking often remains unquestioned. In our ocularcentric society, the sense of sight is privileged over the other senses and looking is perceived as an act of spectacle and surveillance that turns observers into spectators. It is “the site of desire, pleasure, and objectification” (Fraser and Greco 2005: 27), “cool and distant” (Pallasmaa 2005: 31), and removed from the body. But, as Pallasmaa writes, “Alongside the critique of the hegemony of vision, we need to reconsider the very essence of sight itself” (Pallasmaa 2005: 10). One way to adjust our eyes is to unfocus our vision. While focused vision pushes us out of space making us mere spectators, unfocused peripheral vision integrates us with space (Pallasmaa 2005: 13). Putting our eyes back in our bodies, we can reunite them with our other senses so that they are no longer isolated, detached or alienated (Pallasmaa 2005: 39). Moved from exteriority to interiority, looking becomes a collaborative act involving the whole body and the distant objectifying gaze gives way to a participatory and empathic one (Pallasmaa 2005: 36).

Following this theoretical mode of looking, visual media were used not as observational or objectifying tools but as routes to embodied ways of knowing (Pink 2009: 99). In order to avoid voyeurism and the possibility of fetishizing the body in practice, research encounters were designed to be intimate, taking place at home or in familiar public places. Sometimes they acted to reveal, perform and simultaneously appropriate a medical, objectifying gaze. Making Polaroids with Anwen resulted in a series of three prints that gave a 360-degree perspective of her legs: front, side, and back. While I had asked Anwen if I might photograph her legs, it was Anwen who suggested the prints be taken from each angle. Looking at the resulting images together, she told me that they were exactly like the ones on her medical chart. While I was initially taken aback by what my methods might be recreating, Anwen explained that the objective knowledge of her body held within the chart was comforting to her – who and what those images were for was concrete and reassuring. Without having made the prints together, I would not have had this insight into the way in which Anwen, her body, and medicine interrelate. In her interview we had only spoken about the frustrations, anxiety and fear that have defined her experiences in hospitals and with the medical profession. Here was an instance that highlighted both the comfort of medical knowledge and Anwen's ability to hold onto her own body in medical settings. The encounter turned notions of the medical gaze on its head. Anwen's appropriation of the medical imaging of her body and the prints we made together question the ways in which health and illness are represented and show how photographs (even medical ones) can become infused with personal experience and meaning.

The “materiality of establishing intimacy” (Fraser and Puwar 2008: 8) was also created by focusing on the everyday; on the mundane acts that we all perform in our daily lives. Within this context accounts could be made without the risk of becoming spectacular to the viewer, because instead of regarding the body from afar everyday acts offer points of connection. In her video diary Meghan recorded her morning ritual, which includes preparing a glass of water with freshly squeezed lemon. The drink forms part of a complex relationship that Meghan has with her rheumatoid arthritis, but the recognition that takes place within the performance of this everyday material process produces a situation of intimacy. Steedman describes how she gets close to Hamilton’s kitchen and pantry in just this way:

...the charm of recognition, the extraordinary materiality of processes and procedures stretching back over 200 years or more that entrances me. I chop an onion, scrape a nutmeg on a grater, in the same way. And it is a very great pleasure to contemplate what is in this kind of sensate physical activity. Like words, physical activity carries the past and something of everyone who has sliced a lemon in half for squeezing. (Steedman 2008: 27)

Using her body as a point of connection, Steedman brings the past to life through her own corporeality:

Within the movement of the body in the act of cooking at home, across the shared cookery textbooks, as well as the aroma and texture of the lemon, embodied recognition occurs. The body can have a memory across time, a memory which is distributed across the spaces of everyday life. (Fraser and Puwar 2008: 7-8)

At other times, it was important to let the body slip away. The interplay between proximity and distance is apparent throughout the video diaries, which offer glimpses of bodies as they slip in and out of frame. Within the video diaries bodies are perceptible and imperceptible, visible, audible, and hidden. Not always shown in their entirety, the traces of bodies are present in other ways: parts of bodies are shown to camera, shadows are trailed on pavements, and reflections are captured in windows and objects. Sometimes bodies are heard speaking, but they are also present in the sounds of breathing and footsteps, and sometimes they are silent. In these ways bodies are not directly seen or heard but remain sensed or felt, leaving space for the imagination:

Deep shadows and darkness are essential, because they dim the sharpness of vision, make depth and distance ambiguous, and invite unconscious peripheral vision and tactile fantasy. (Pallasmaa 2005: 46)

For Meghan, keeping a journal began to draw too much attention to her body, and she chose to stop making entries. Kim decided to withdraw from the project soon after we met. At the time of writing she was five months seizure free. For the first time in 17 years, since her first seizure at the age of 11, her body had become silent. This was something that was quite amazing for Kim and which she wanted to think about as a success. Remaining in the project would have meant questioning that success, so instead she withdrew, taking the opportunity to simply take her medication and forget about her condition.

Throughout the project, participants and bodies had the choice to engage and to look away, a choice which prevented the project from becoming clinical or sterile. Perhaps, as Blackman suggests:

These aspects of experience suggest something else about bodies: not materiality, but perhaps an immateriality that is felt and registered but cannot easily be seen, known or understood. (Blackman 2008: 132)

These aspects also suggest something about sensory methods. As well as helping to make bodies present through their own sensory materiality, sensory methods became a way of evoking some of the intangible aspects of corporeal experience, showing that “sensory intangibility” is vital to the practice of sensory methodology (Mason and Davies 2009: 587). As Mason and Davies argue, “it is important to avoid a literal or wholly tangible interpretation of the sensory, or of embodiment” (Mason and Davies 2009: 601). Instead, the senses are ways of exploring “sensory entanglements” (Mason and Davies 2009: 600), encompassing the tangible, the intangible, and what resides in-between.

To summarise, bodies were allowed to slip and to seep through the multiple combinations of senses, methods and devices used, remaining on the register all the while without being pinned down. Moving through the micro accounts created using Polaroids and drawings to the larger places and spaces of the body, issues of intimacy, proximity and distance became central to the practice of seeing and highlighted the importance of using visual methods not to objectify but to understand the body. Appealing to the senses it became possible to develop methods that could meet the demands of the theoretical foundations of the project and bring to life the conceptual body described in chapter 1; a body that is productive and material but also divided, fragmented, and entangled within and without its own skin.





## *Mapping Bodies*

Opening up the body and allowing it space to shift around without melting away or vanishing completely was supported by working with ideas of emplacement and cartography. Emplacement extends the notion of embodiment by connecting the body to its environment:

While the paradigm of 'embodiment' implies an integration of mind and body, the emergent paradigm of emplacement suggests the sensuous interrelationship of body-mind-environment. (Howes 2004: 7)

This turn to space was a strategy for maintaining material thinking (Thrift 2006), grounding the project in the physical world. Working with emplacement meant that the boundaries of the project were extended from the individual bodies of participants to the local environments that they inhabited, giving bodies space to move and breathe while at the same time keeping hold of their materiality through their physical interactions with the world. In her video diary and journal Xan focused on movement and belonging, defining her own identity geographically in relation to the places she has lived – specific boroughs of London, America, and India. This tactic helped to reveal how Xan's body fits into the world and how different environments impact on it.

As a geographical platform for the project, London offered a diverse space within which it was possible to draw out different bodily connections and discover how different lives come together. The transportation system, for example, highlighted how people experience and negotiate the city differently because of their

bodies. Anwen has muscular dystrophy and never uses the tube – it would be too difficult. Kaldon has rheumatoid arthritis and uses it daily to travel to work, but the overcrowded journey carries the risk of putting strain on his body and hurting him, and Anna, who has depression, avoids tubes and trains at all costs. She prefers to travel by bicycle, and the experience of whizzing down a steep hill on her bike is a guaranteed mood enhancing moment.

Researching the body in situ through emplacement provided the necessary context for understanding how through their movements bodies are in constant interaction with the environment, how society shapes and claims our bodies, how private and public locations and practices are connected with notions of stigma and body ownership, and how world and body inform and redefine each other. Sometimes, the methods themselves became responsible for instigating situations in which these dilemmas were acted out, as Imogen captured in her video diary:

They wouldn't let us film in hospital because I hadn't asked permission, which I find weird because it's all about data protection, and you know that they're allowing CCTV cameras to record you, which is somehow different, than when you want to record your own body, but they said if I'd asked permission there wouldn't be a problem, so what can I do - I can do it at home, or like this, or at the side of the hospital. It's strange, the negotiation you have to play with your own body, what can be filmed, what can't be filmed about yourself, purely because you're in a hospital, and who owns your actions or whatever. (Imogen Video Diary)

Imogen's encounter illustrates how different environments take possession of our bodies, and points to an important distinction between the hospital surveillance and her own observations through the video camera.

Beyond the specifics of emplacement, cartographic thinking helped to make the body visible, so that it could be seen and talked about. Cartography, the study and practice of making representations of the surface of the world on flat pieces of paper, combines science and aesthetics to create readable maps with which to explore multiple territories. The secret of a good map is that it represents the mountainous, watery, trodden, and un-trodden parts of the world in two dimensions without flattening it. Anna's map of her very messy brain, which she drew in her journal, brings this point to life. A personal geography and a voyage through her mind, the map marks unknown regions, rain clouds, mountains, volcanoes, springs, danger, and a veritable horde of monsters.

As an orienting theme for investigating the human terrain, cartography provides a number of qualities that are useful for thinking about the practice of research (Becker 2007). Maps are not impartial reference objects but instruments of communication that express particular points of view; they construct rather than reproduce worlds. Every map is shaped by political, cultural and social conditions, maps can be personalised or disorienting, and they can make the past and the future present. Maps give us a solid sense of things:

As if he were reading a map, he ran his hand over every part of the stone, memorising every bump and cranny, getting a solid sense of it. (Murakami 2005: 323)

They offer a means of describing intangible states of mind, and they remind us that any attempt to represent the world results in some amount of distortion:

It can't be done. You can't turn a sphere into a flat surface without distortion. The price of having a map at all is distortion the user learns to live with. (Becker 2007: 94)

These cartographic qualities were useful tools with which to address “the challenges of reimagining method in light of new concepts for thinking bodies” (Blackman 2008: 123), and provided an orienting point that pulled together the different fragments of data so that the map became an analogy for the project itself; a world in which different elements, influences and viewpoints sit layer upon layer together, and an exercise that questions rather than asserts the world, giving people their own ways of viewing their lives and allowing them to create their own atmospheres. These qualities guided the development of the methods that were used, turning the notion of mapping into a way of researching embodied life.

I'M NOT SURE IF THE INCESSANT WORRIED VOICES ARE PART OF A DEPRESSIVE MINDSET, MAYBE OTHER PEOPLE ARE LIKE THAT WHO HAVE NEVER EXPERIENCED A SEVERE DEPRESSION. THERE'S SOMETHING NIBBLING AWAY AT ME AT THE MOMENT, A LITTLE RAT, NOT THE SHARP ATTACK OF A SIGNIFICANT DEPRESSION. IT JUST MEANS THERE'S A LITTLE SOMETHING MAKING ME FEEL 'WRONG', OR BAD ABOUT MYSELF, A REMINDER I'M NOT GOOD ENOUGH. I'M TRYING TO REMIND MYSELF THAT THOSE ARE JUST INVADING THOUGHTS, STORIES & HABITS. I SHOULD PROBABLY MEDITATE, BUT AM TOO LAZY AND PREFER TO WATCH SHIT ON TV. BUT MEDITATION CAN REALLY HELP WITH THIS MADDENING BABBLE. I'M NERVOUS ABOUT WORKING TOMORROW. BY THE EVENING I'LL BE FINE I'M SURE. <sup>THOSE</sup> IT'S A PATTERN I'VE GOT INTO. I'LL HAVE INSOMNIA TONIGHT AND THE THOUGHTS OF HOW BREAD-FULL EVERYTHING IS GOING TO BE WILL GO ROUND & ROUND. THEN IT WILL BE MEDITATION TO OF X I'LL GO HOME WONDERING WHY ON EARTH I LET THINGS GET TO ME SO BADLY. (UNLESS EVERYTHING DOES GO TERRIBLY WRONG OF COURSE). IT'S SO PREDICTABLE, WHY THINK I SHOULD JUST BE ABLE TO GET A GRIP AND STOP.

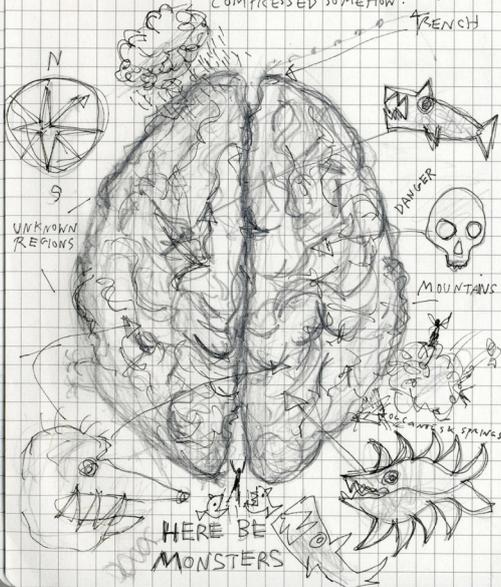
# WHIZZ

WHIZZING DOWN STEEP HILLS ON A BICYCLE IS THE ONE ABSOLUTELY GUARANTEED MOOD ENHANCING TREATMENT... CAN LAST UP TO FIVE OR MORE SECONDS IF THE HILL IS STEEP ENOUGH. I DO THIS ABOUT 9 TIMES A WEEK ON MY JOURNEYS ROUND SOUTH LONDON.



25/03/09

YES, A VERY MESSY BRAIN TODAY,  
AND LOTS OF RAIN INSIDE IT. MY  
BODY FEELS UNCOMFORTABLE, SQUASHED,  
COMPRESSED SOMEHOW.



RAN ON MY TREADMILL FOR THIRTY MINUTES (AS MUCH AS I COULD STAND OF THE NOISE). THE WEATHER IS A BIT RAINY ON AND OFF WHICH IS MY EXCUSE FOR STAYING INDOORS. BUT I JUST DON'T FEEL UP FOR IT TODAY. I DON'T FEEL LIKE SEEING ANYONE ELSE. I FEEL FRAGILE. SOMETIMES I'M VERY CONFIDENT AND COMFORTABLE WITH OTHERS BUT OTHER TIMES I CAN'T EVEN LOOK AT THEM. IT'S ALMOST AS IF I FEEL INFERIOR TO OR JUDGED BY OTHERS. TODAY SEEMS LIKE ONE OF THOSE DAYS (THOUGH I HAVEN'T SEEN ANYONE ELSE TO ACTUALLY TEST THIS OUT). IT MIGHT BE A BIT OF A LOOP, BECAUSE THE LONGER I HIDE MYSELF AWAY THE HARDER IT GETS TO FACE PEOPLE, BUT I REALLY HAVE GOT GOOD AT 'FORCING' MYSELF OUT. I'M LUCKY MY MODE OF WORKING SUPPORTS THESE PHASES (I SUPPOSE OTHERS MIGHT THINK IT'S UNFORTUNATE THAT IT ISN'T A CHALLENGE) BUT I'VE PUT MYSELF INTO MUCH MORE CHALLENGING SITUATIONS OVER THE LAST COUPLE OF YEARS, FROM BEING IN A SITUATION WHERE I HARDLY EVER WENT OUT AROUND OTHER PEOPLE, I'M NOW DOING IT FOR WORK FOR REASONS ON A REGULAR BASIS. BUT TODAY IS NOT ONE OF THOSE DAYS!

WRITING THIS JOURNAL HAS HELPED ME TO RECOGNISE SOME OF THE WAYS IN WHICH I HAVE CHANGED. I DON'T THINK I'M DELUSING MYSELF BY SEEING THEM AS POSITIVE. THERE ARE LOTS OF AREAS FOR IMPROVEMENT STILL, I KNOW THAT! I'D LIKE TO FEEL:

- \* NOT LESS ANXIOUS
- \* MORE CONFIDENT ABOUT MY WORK
- \* LESS THREATENED BY OTHER PEOPLE

## *Talking Bodies*

Visual methods made it possible to experiment with sight, sound and sensation as sociological tools for rediscovering the bodies we live in on multiple registers of feeling. They provided material points of attachment through which access to bodies became possible, helping to focus attention on small details of socio-material significance that are otherwise easily overlooked. But they did not supersede the practice of talking. Instead, they reformulated it. ‘Creative interviews’ (Mason and Davies 2009: 590) formed the basis of the project and were used as a starting point for getting to know the project’s ethos before moving beyond the interview.

During these interviews, which were unstructured and conversational, biographical and medical histories were discussed, and together we learnt to talk about bodies. Many of the participants in the study had spent a great deal of time thinking about their bodies and conditions, about how they feel in them and how they feel about them, about how and why they are important and about what they need, but these thoughts were rarely if ever spoken aloud. Embodied everyday life is not a part of doctor-patient narratives or of medical histories, nor is it something that people typically choose to discuss with friends or family, either because the condition is kept private or because they do not want to complain about it to others. So talking about bodies was a new experience, and obtaining thick physical descriptions depended on orienting conversations towards the body. This was achieved with the aid of the hand-drawn questionnaires and drawing exercise, which helped to elicit details about bodies and descriptions of them.

## *Writing Bodies*

Extending from talking about bodies, at the end of the interview participants were given journals in which to write about bodies, which they were asked to keep for one month. This time period was flexible and some journals were kept for much longer. While structured diaries in which participants log health actions are relatively common within applied health research, open diaries are rarely used within applied qualitative research on any topic (Elliott 1997: 2.6). But diaries are noted for their value in recording everyday routines and processes, details that can be difficult to access retrospectively in an interview (Elliott 1997: 2.6), and as such they offered the perfect medium for recording the thoughts, encounters and everyday routines that were important to the project.

As physical objects, the journals added their own sensual materials to the project. The paper, ink and other made and found objects – postcards, drawings and tickets that were inserted between the pages, rooted the written words in the materiality of the journal. Each one had a brightly coloured hard cover and squared graph pages, providing a format that was not strictly linear. A5 in size, they were small enough to be kept close and carried around, and entries were made on buses tubes and trains, at home, at work, and on holiday. These qualities helped to differentiate the journals from the medical diaries that several of the participants also had to keep, or had kept in the past. Medical diaries are intended to record neutral facts, to score pain and to monitor diet, and the participants who had kept them reported finding the task frustrating to the point that their records were often

incomplete or abandoned. It was important that these journals invited a different kind of engagement. Each journal came with a short and simple set of instructions, providing a starting point for how to use the journal without being prescriptive:

Please keep your journal for one month, it is up to you how frequently you write/draw in it during this time. The idea is to make an inventory of the things that are important to you and the things that happen to you in relation to your body and your condition. As well as writing, I would like you to make lists and to count things. This might include a list of the medications that you use, a list of words that describe your body, or counting the number of times something related to your condition happens in a week. I would also like you to make a day survey - choose one day and write about it in detail.

For Imogen, keeping a medical diary was a task that needed to be completed but which she resisted. The fact that this activity was situated outside of a medical context, where there was a different motivation and a different reader or audience meant that keeping a journal was a task that could be fulfilled on more personal terms and which allowed her to make her own health intervention:

What I really need to do, and having a diary will be useful – especially a nice moleskine because the DAPHNE one, it's just not the same, it's NHS, it's a bit orange and a bit white and a bit wrong – but I need to write it down day-by-day precisely what I'm eating, precisely where my sugar levels are going, that would really help, I know that will help. (Imogen Interview)

And later:

Curiously (or maybe not really) in writing this journal, which is not just to be read by me, my levels seem to have been possibly the best they've been in years over this past month. Perhaps, because it is not for a doctor, but rather for research/public display I feel I have to show myself and my sugar levels at their best. So I've been measuring all my food out, eating salads for lunch so that way I don't have to worry about miscalculating carbs and generally keeping on top of it! (Imogen Journal)

The journals allowed participants to get a better sense of their own illness patterns:

It has been interesting writing this, though I've changed some of my conclusions over the course of writing it. It feels like I'm always going to be susceptible to feeling low, so I'll have to work with it for the rest of my life, instead of expecting some dramatic moment of complete transformation, I should have known that anyway! Maybe I did. I'm surprised how much my mood flits from one state to another, as I've never 'inventorized' it as such, & how much feeling physically low can get mixed up with being depressed, I know that but it seems really clear looking at a breakdown of it. (Anna Journal)

I'm generally quite aware of my A. and how it affects my body but since receiving this journal and not knowing what to write about, I've paid a little more attention to my joints. (Kaldon Journal)

And to set new goals for their futures:

Writing this journal has helped me to recognise some of the ways in which I have changed, I don't think I'm deluding myself by seeing them as positive. There are lots of areas for improvement still, I know that! I'd like to feel:

- \* A lot less anxious
- \* More confident about my work
- \* Less threatened by other people

\* Less dread

\* I'd like to look forward to things instead of thinking catastrophe is around every corner

(Anna Journal)

They provided longevity and space within which bodies could make themselves known and entries could be left and returned to, extending the duration of the project without making participation over-demanding. Entries were fragmented across different topics and across time. This flexibility was important, because body and illness moments are not constant but are themselves fragmented over daily and weekly routines. The journals were used to record daily observations, social encounters, patterns of behaviour, personal thoughts, and memories, offering small insights into everyday lives and highlighting otherwise taken for granted details. As Meghan wrote:

So maybe this journal will be a collection of not just my own feelings and thoughts about my own body, but about all of those random anecdotes I overhear and don't know what to do with. Because there is a societal idea of the body and one's very own idea of their own body. (Meghan Journal)

Unlike the interview situation, which requires an immediate response, the journals gave participants time to think and remember. At the same time they were a way of recording spontaneously as thoughts and events unfolded:

They are not given 'all of a piece' – such as a life history might be – but rather are written discontinuously, either daily or over longer intervals of time (Allport, 1943) and as such provide a record of an ever-changing present. (Elliott 1997: 2.4)

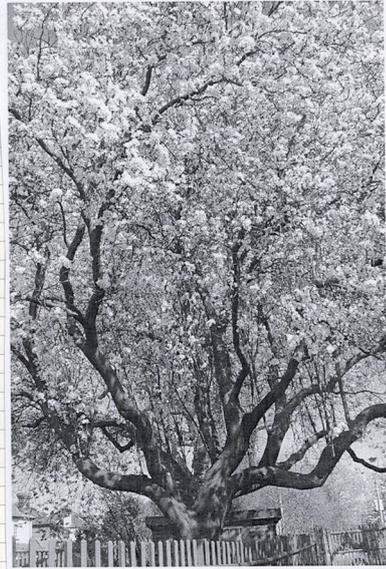
Together, reflection and spontaneity helped to create a sense of intimacy and participation in individual lives. More personal, private and secret than any other research medium, the journals became a place within which participants could write about childhood memories, future hopes, and sexual relationships. The act of writing proved less likely to make participants feel self-conscious (with the exception of concerns over correct spelling), but this did not mean that lives risked becoming over-exposed. The project dictated a frame of reference and entries were clearly made with this reference and an audience in mind, making the journals themselves a mix of three models of the diary:

Allport (1943) identifies 3 distinct models of diary familiar in everyday life: the intimate journal, in which private thoughts and opinions are recorded, uncensored; the memoir – an ‘impersonal’ diary, often written with an eye to publication; and the log, which is a kind of listing of events, with relatively little commentary. (Elliott 1997: 2.2)

As a non-intrusive point of access into the hard to observe phenomena of daily lives and private thoughts, these hybrid journals did not act as a substitute for my own observation in settings that I could not access, but were a way in which the participants could observe their own lives and make their own representations for inclusion in the project.



I RUN PAST THESE TREES  
SEVERAL TIMES A WEEK, IN THE  
LAST WEEK AND A HALF  
IT BECAME INTOXICATING,  
LOOKING AT THEM FEELS  
BENEFICIAL, IT'S A BOOST TO  
MY MIND BEING IN THEIR PRESENCE.  
I'VE BEEN PAINTING PHOTOGRAPHS  
THEM FOR NEARLY 25 YEARS.



THEY FEEL LIKE A REALLY POSITIVE  
PART OF MY LIFE & ROUTINES,  
WHEN THINGS AREN'T GOING VERY  
WELL OR I'M FEELING SPLIT ABOUT  
MYSELF. IT'S REALLY IMPORTANT/USEFUL  
TO ANCHOR MYSELF IN THINGS LIKE THESE  
TREES OR THE BLENDS OF THE LANDSCAPE A  
FEW HUNDRED YARDS FROM MY HOME.

I was to squeeze every day in each hand for several minutes. The good news is that it travelled all the way from NY with me. The bad news is that I had to dig it out of my closet yesterday. I may re-start that today. Though again, if I were to make a list of all the things I should do daily, I wouldn't have time for anything or anyone else. Things I should do daily:

- ① Sleep 8 hours
- ② Floss Teeth - R.A. can also cause inflammation of the gums
- ③ CARDIO - at least 20 minutes of activity which raises heart rate
- ④ Squeeze yellow putty for 6 minutes (increase grip strength)
- ⑤ Drink 8 glasses of water

- ⑥ Eat 5 servings of fruit + veg
- ⑦ Take B-12 supplement
- ⑧ Get Omega 3s either by nuts, seeds or oily fish (but not more than 2 servings per week)

I'm sure there's more!

And then there's the not so positive list:

- ① AVOID (or in my case, don't overindulge in):
  - CAFFEINE
  - SUGAR
  - ALCOHOL
  - RED MEAT - not a problem for me
  - DAIRY - not a problem for me

There's also some question as to whether citrus fruits + vegetables in the nightshade family cause/aggravate inflammation

- ② Watch your saturated fat intake
- ③ And above all, don't get stressed!

## *Filming Bodies*

The final phase of the project involved making video diaries. The use of video is rapidly increasing, both in social research and in modern life, and there is now a significant amount of video-based research. Popular video methods include the testimony and witness of participatory video, typically used with marginalised and vulnerable communities as a tool for social change, and the analytic gaze of observational video, used to record naturally occurring activities and to analyse human interactions in detail. Easy access to video recording equipment and the development of technology means that people are now accustomed to using video cameras and to sharing their recordings, both with friends and in the public sphere:

People are increasingly accustomed to having their everyday lives recorded, often with the understanding that the footage may be viewed by numerous other people. To use video recordings in research is to harness this wider cultural aspect which in turn can reveal the complexities of everyday experiences and realities. (Forsyth et al. 2009: 214)

Despite the social popularity of video, however, participants in the project were often uncomfortable with the idea of filming in public places, being in front of the camera, and recording their own voices. Their discomfort points to the fact that while using video in research plays into the wider cultural popularity of video it also stands in sharp distinction to it, and what participants filmed played an important role in determining both how filming was approached and how comfortable they felt with the camera. In spite of these reservations, the video camera quickly became another

device with which participants could record their lives, and the format offered a novel way of engaging with the materiality of their bodies. As Pink writes:

...the use of a video camera encourages research participants to engage physically with their material and sensory environments to show the ethnographer their experiences corporeally. (Pink 2009: 105)

As an audio-visual encounter in the flesh, video offered an alternative medium to text or discourse, one that is perhaps, therefore, more appropriate for the task of researching bodies. It encouraged participants to focus on their own bodies, both directly and indirectly, and it allowed those bodies to be brought into the project in all their physicality. In order to make using the video camera less daunting, participants were encouraged to record short clips rather than to make a comprehensive or joined-up account. Along with some basic operating instructions, a simple brief was provided:

You will have one week with the handycam in which to make a video. You can also take photographs with the handycam. It is up to you whether you put yourself in the frame, but try to think about both the visual and audio components and how you can show and tell about your body and your condition. If you are happy to do so, I would also like you to take close-up photographs of parts of your body and to talk about them.

In the video diaries, participants were asked to show and to tell, and the body was allowed to be simultaneously social and biological. The technology provided much more than a simple medium for recording social behaviour (Shrum et al. 2005: 2). Both audio and visual, video diaries were able to make the body visible and audible.

They captured the affective qualities of illness and the vital signs of bodies, located everyday realities and practices, and made illness less anonymous. Making a video diary was not about telling a narrative story but about capturing examples and allowing them to play out on camera, and the short clip format meant that long monologues did not dominate the frame, allowing other sights and sounds to come into focus. The format also meant that no straightforward, complete or singular picture could be formed. Instead, the hints and traces of bodies helped to reveal the fact that video is not a simple or straightforward act of recording. Bodies were captured in different acts and contexts, in hospitals, at work and at home, exercising, gardening, eating, and sleeping. The partiality of these bodies means that they resist singular definitions, and multiple situated ways of knowing and combining the social, biological, material, and sensuous aspects of bodies became possible.

In this way, the production of video diaries made it possible to record bodies and to get a sense of being there with them without making claims to any objective or definitive reality. Regardless of the height or angle of the lens, we are always shown through the camera an eye level view, an embodied and situated response – not ‘le regard surplombant’, the look from above (Starobinski in Pallasmaa 2005: 29). The inherent creative potential of video recording enabled a novel sociological encounter and repositioned notions of authenticity and fabrication. Writing specifically about the use of video diaries in social research, Pini states that we need to let go of questions about authenticity and over-simplistic ideas about empowerment (Pini 2001). These concerns, she argues, are redundant. Rather than undermining its authenticity, the qualities of the video diary as captured and constructed reality, fact

and fiction, are precisely what enable the opening of new routes of exploration and evocation. Again, writing about the use of video in research, Brown states:

We must start by treating it less in terms of being an objective or factual record of what people do and more as a constructed audio-visual representation that may be used to *evoke* a sense of subjective positions and experiences. (Brown et al. 2008: 3)

Approaching the camera not as an objective recording device but instead as a productive means of representation serves a two-fold purpose. It warns against the dangers of adopting a naïve realism in sociological research and it allows bodies space to move, breathe and live in front of the camera, preventing them from becoming mere objects on the screen. Following Back:

I want to suggest an embrace of this productive/creative dimension – might help enable an encounter with ‘the real’ without a naïve realism slipping in through the back door. The recordings made by the [sound] device provide the illusion of ‘being there’. If we leave behind the simple idea that they ‘capture’ the real but instead produce a realist imaginative object then they may provide a different kind of possibility for social understanding or revelation. (Back 2010: 20)

The illusion of being there is also an illusion of the body being here. As Brown suggests, the camera is beautifully sensate, having the capacity to remind us of the body in all its physicality:

For us, a comparative methodological strength of headcam was that it created a vivid impression of the sheer physicality and visceral experience of recreational activities. The punctuation of experiences with persistent, rhythmical breathing was particularly striking, for example, the evocative sound of laboured inhalations and exhalations.

Although a far cry from the actual sensations of lungs burning and heart beating through the skull associated with strenuous breathing, the footage prompts greater or at least more immediate empathy for the experience than language alone could.

(Brown et al. 2008: 9)

In Brown's study a mounted headcam was used to capture the experience of mountain biking and walking. In my own study, video cameras were pointed at heaving, asthmatic lungs, and they were taken on walks and to the gym, carried on bicycles and held while running. The footage brings these physical experiences to the screen, reminding us of our embodiment. As MacDougall writes, the interconnectedness of seeing and touching that underlies film means that it is able to communicate sensory experiences using the entire perceptive field of the body. We:

...see with our whole bodies, and any image we make carries the imprint of our bodies; that is to say of our being as well as the meanings we intend to convey.

(MacDougall 2005: 3)

These recordings are not mere prompts to our physical memories; often they highlight the importance of strategies and styles of living, call into question the strength of bodies, and challenge our perceptions. And sometimes the representations are at odds with the feeling. Anna's footage of running, for example, sends the viewer lurching left and right at a heavy and heaving pace. Although her 'running with camera technique' improves as she goes on, the resulting footage is at odds with her own experience of running, which makes her feel light and free.

In the creation of video diaries participants decided what to film and how to film it, controlling the degree to which they are revealed to the camera and the perspective from which they are seen. Their active involvement renders concerns

about the potential impact of the camera on participants' behaviour, which is common to researcher-generated observational video, redundant. The camera's presence is undisguised and participants are not objects in front of the camera but active participants in their own investigations. Gibson (2005) suggests that how participants present themselves for the research camera is in itself data that can be analysed, and that their engagement with the camera is a process of identity construction. In this project, the difference between filming styles is clear to see, with each participant finding their own way of approaching the project and their own filmic language. However, while their decisions about how and what to present are important, the fragmented nature of the video diaries and their focus on bodies and illness, as opposed to self, mean that the diaries are less about capturing identity performances (Holliday 2004) or doing identity work (Gibson 2005), than they are exposés of the nature of bodies through unstaged but conscious performances of everyday bodily practices.

These facts do not make the camera's eye any less revealing. Writing against the naïve idea that video diaries are objective records, Gibson (2005) criticises Rich for describing the camera's gaze as "indiscriminate and uncompromising" (Rich et al. 2000: 162). I argue that the camera's gaze *is* direct, indiscriminate, and uncompromising, and at the same time indirect, carefully controlled and subjective. It is precisely this dual ability of the camera to show and to hide, to reveal and augment, which creates the *illusion* of being there. The audiovisual qualities of video recording mean that it can go beyond text to achieve the impression of a direct connection to experiential realities (Pink 2009: 134), and while the video diaries are not a direct reproduction of experience, they do provide a more direct connection

with the participants in the project because our connections with other people are made genuine and strong by being personally directed. Watching someone from afar the viewer is made spectator, but brought close and addressed directly the viewer becomes a captive audience, and even a friend. The indiscriminate and uncompromising moments are those in which we are forced to look when we would normally turn away. Imogen, for example, films as she injects her insulin, the camera closing in on the needle piercing the skin of her stomach. Captured on video, such moments force us to look, purposefully laying bare what can be the brutal reality of living with illness.

Like the journals, the specific format of the video camera invites a particular relationship, encouraging participants to take an ethnographic position and become observers of their own lives, so that “behaviour and observation occur in both directions – in front of and behind the camera” (Shrum et al. 2005: 1). The camera does not remove the observer from the picture, or provide a one-way lens. It would be a mistake to see the lens as only looking one way (Back 2004: 137). Instead these corporeal images are:

...not just the images of other bodies; they are also images of the body behind the camera and its relations with the world. (MacDougall 2005: 3)

As a third agent in the project, the camera offers a set of eyes and ears for the participant to address and for the audience to see and hear through, and as a physical object it leads the participant-observers on a journey through their own lives. This does not mean that camera and participant are alone on their journey. Gibson (2005) describes the researcher as an absent presence in the filming process, a figure not there but which the lens is oriented towards. One-way conversations and comments

like, “I thought I should show you this” (Imogen Video Diary), reaffirm the filming agenda and the presence of the audience in the process of filming (see also Worth 2009 on the presence of the audience in audio diaries).

As well as making bodies present the video diaries made people present. The presence of the participants on screen, often undisguised, strongly conflicts with the sociological ideal of anonymity in research. But this does not mean that visual methods are inappropriate for the task of doing social research – to reach that conclusion would be to overlook alternative possibilities, as Sweetman writes:

...not least the way in which images can contribute towards what might be referred to as an ethics of recognition rather than one of protection or concealment. Recognition, which, for Axel Honneth, involves a basic acknowledgement of the other as a person rather than a thing, can be seen as a precondition for any form of ethical engagement, and image making can be said to both allow for and encourage such forms of acknowledgement. (Sweetman 2009: 8)

An ethics of recognition was fundamental to the making of video diaries and to the project as a whole. This does not mean that participants were expected to make themselves known in the project, but that anonymity and recognition were discussed at each stage. Participants were given copies of transcripts and video data, and journals were returned to their rightful owners. In a process of ongoing consent, they maintained total editorial control of all the data that they made. Illness itself is an anonymous phenomenon, and public perception of what it means to be ill means that stigma always threatens. It was important that participation in the project did not reinforce these ideas by assuming anonymity and adding another layer of secrecy to illness. At the same time, it was also important to respect the fact that many of the

participants in the project choose not to reveal their conditions to the world on a daily basis, and that in some cases anonymity was important to preserve. By making anonymity and recognition features of participation that could be controlled to different levels, it became possible to make illness itself a little less anonymous, and to challenge the stigma that surrounds it. In a process of co-production and collaboration, interviews, Polaroids, journals, and video diaries were made with and by participants. Their involvement in the making is evident, ensuring that even when anonymity is maintained their contribution is recognised.

In order to make an anonymous video diary, Anna (a pseudonym) wrote notes to the camera. This ensured that her identity would not be revealed through the recognisable sound of her voice. Her notes were then placed as subtitles on the screen, separating her voice from the ambient sounds she recorded and putting text and image in the same space. The combination of words, sounds and images in her edited video diary is evidence of the ongoing interplay between written, audio and visual forms of representation in the project, which were used throughout the fieldwork and in writing this thesis to mutually support each other. In this case the absence of Anna's voice gives the images more space to breathe while the text anchors them. More broadly, the introduction of sound to the mix of methods helped to reanimate the visual in different ways. The audio captured on camera, which included voices, but also ambient sound, breathing, and footfall, situates the eye by reinforcing a particular sense of place and widens the aural beyond the voice. Acoustics have their own intimacy and they help us to see differently, working against the dominant way of looking and bringing the viewer in to the experience:

Sight isolates, whereas sound incorporates; vision is directional, whereas sound is omni-directional. The sense of sight implies exteriority, but sound creates an experience of interiority. I regard an object, but sound approaches me; the eye reaches, but the ear receives. (Pallasmaa 2005: 49)

When filming was completed, the video diary footage was used in two different ways. As research data each of the video diaries was transcribed into text, so that it could be thematically analysed together with the interview and journal data. Some of the footage was also edited as an independent form of dissemination, a filmic representation of the project findings. In discussing the collaboration with participants it was emphasised that the data they produced would be edited and shown to an audience – here again the short clip format was useful, freeing participants to film without needing to think how their own clips might fit together. Throughout the editing process I attempted to stay faithful to the original material, however a clear line was drawn between making data and producing it, and responsibility for authorship of the film that accompanies this thesis lies solely with me.

Following the thematic framework of the thesis, the video diary footage was edited into a sequence of split-screen compositions (showing either two or three frames simultaneously) that make use of fragmentation, body parts and boundaries. The logic of this configuration is intended to disrupt normative expectations of how film works, getting away from a linear narrative and bringing the viewer round to the principle of attending differently. Illness is a non-linear experience and this is reflected in the final format of the video diaries, which emphasises space and temporality without being bound to linearity. At times the split screen allows the

viewer to be in two different spaces at the same time, so that bodies become meaningfully and contextually layered. At others it allows the audience to view the same moment from multiple perspectives, giving a sense of dimensionality to the otherwise flat screen. The hazy edges and sometimes soft focus of the shots, which are indicative of the camera's auto-focus function struggling to adjust to fast hand-held movements, open up vision through their tactility and reinforce the presence of the bodies that made them. The spaces of film are "analogous to those we experience in everyday life" (MacDougall 2005: 25), again reinforcing the intimacy and normality of the encounter. Through the use of subtitles, talk mingles with vision, linking the visual with the aural. Each technique is designed to create stylistic unity and to increase the sense of being there with the participants, offering a sense of virtual intimacy and "enticing the body to travel through the illusory space" (Pallasmaa 2005: 35). Watching,

...we cannot halt the flow of images for analytic observation; instead we have to appreciate it as an enhanced haptic sensation, rather like a swimmer senses the flow of water against his/her skin. (Pallasmaa 2005: 36)

By moving beyond the surface of the page, moving images offer a form of sociological representation that reveal in more than words (Halford and Knowles 2005), creating sociological engagements that are "contextual, kinaesthetic and sensual: that live" (Halford and Knowles 2005: 1.2).

## *Conclusion*

In order to explore the sociological body in the flesh an imaginative engagement with method was needed. Moving beyond the constraints of traditional sociological practice and its reliance on the dominant narrative voice, different methods, devices, forms of articulation, and modes of analytic attention were used to open up spaces within which bodies could be seen, heard, felt, and sensed, transforming the body from elusive to sensorial and making it knowable. Looking and listening to and through the body's materiality, it was possible to engage bodies so that they might speak for themselves. Tactile, audio and visual methods combined to bring bodies to attention through their own sensory corporealities, resonating with the material, sensorial and affective dimensions of the body and offering novel opportunities to attend to embodied experience.

Key to this approach was the reformulation of what it means to look. No longer the organ of distance, separation and control, the eye was reincorporated with the other senses and with the body so that its gaze became 'aletheic' (Pallasmaa 2005: 36): multiple, contextual, intimate, and caring. Nor was looking limited to the eye, instead, a multisensory and non-modular mode of attention was developed in order to push at the boundaries of observation. Opening up attention through the idea of show and tell, the project developed into a collaborative ethnography in which the participants became observers of their own bodies and lives. Each method invited a different kind of participation in the project, pointing to how different media can encourage different forms of engagement and capture different features of corporeal

life. Their representations reveal the significance of the body in novel and exciting ways.

Each individual method allowed a specific mode of thinking, a sensory and embodied way of speaking to the body and making it visible without reducing it to a singular or straightforward truth. The methodological value of this approach lies in its ability to open the body up so that we can take what we see as points of departure for exploration. Like photographs, the material produced through the project invites us to create many narratives rather than to construct a closed narrative, helping us to see in new ways (Silverman 2007: 14). As such, none of the methods are treated as offering any sort of privileged access to how people actually behave (a point that Silverman makes in regard to the research interview (2007: 91)). Instead, what is interesting about them is in the telling. Their analytic value comes from what can be found within them, and, through the shape of each participants' own understanding we gain insights that render the body knowable.

Pushing these methods further into new forms of sociological representation and animated description, they also invite participation from the reader or audience, drawing those on the outside into the project and bringing them closer to the lives of the participants; "engaging us, as embodied, sensual beings in the living details of the thing we seek to understand." (Halford and Knowles 2005: 1.9). The relationship of these representations to the text is continuing evidence of their agency. Working in relation to the text they appeal to different registers of feeling and substantively make their own claims. The ability of these representations to communicate the materiality of bodies and the interplay between representation and reality that they point out enables a more truthful representation of what has been the sociologically elusive

body. Clifford's (1986) description of good ethnographies as true fictions, deceptive and multi-layered, not transparent or descriptive of a stable reality but an engagement with that social reality fits, and the body is made more real through methods and devices that resonate and support its material qualities. Through sensuous scholarship (Stoller 1997) a research dialogue that takes the body seriously and unites the theoretical body with real life bodies is opened.

## CHAPTER 3

### *Bodyrhythms*

This chapter enters into the corporeality of bodies through their everyday rhythms and practices. It focuses on the seemingly mundane and ordinary needs of bodies to eat, exercise and sleep, shifting our attention from what illness is to the details of what bodies do. All bodies need nutrition, exertion and rest; these needs are so fundamental that we usually take them for granted. Careful attention to these corporeal rhythms of life, however, reveals the intricate ways in which bodies and their rhythms are significant. The needs of bodies for their own particular routines and structures speak of and against the social organisation of everyday life. Practices and rituals of eating, exercising and sleeping do not always fit neatly with social expectations, and the discord between them highlights the fact that bodies are in control of us as much as we are of them. Attention to corporeal rhythms and to bodies in motion also uncovers the importance of listening to the body, exposing its place at the centre of our understanding of what it means to be ill. Throughout this chapter, we discover the ways in which people listen to the rhythms of their bodies and their lives as they unfold. To listen to the body is to attend to it, to learn its needs and its limitations, and to care for it. Listening entails making choices, learning to refuse social demands, and finding other ways of living, but it also creates the possibility of choosing to ignore the body's own instructions. In these instances the importance of embracing life is made clear. Ultimately, the act of listening to the body speaks of our refusal to be confined by illness, showing that the imagined

borders between health and illness are redefined by bodies that beat to the rhythms of their own hearts.

Using rhythmanalysis and the ideas of Bachelard (2000), Edensor (2010) and Lefebvre (2004), I begin by outlining how rhythm animates the body and why it is both important to, and revealed by, illness. Taking this framework as a point of departure, we then move into the rhythms of Anna, Anwen, Imogen, Jeffrey, Kaldon, Kim, Martin, Matt, Meghan, Nell, Sophie and Xan via their everyday routines and practices, using rhythm to bring their bodies to the forefront. By attending to their bodies we can discover the sensual and corporeal rhythms within them, encounter the details of embodied life, and enliven the sociologically elusive body.

Each organ, function, or segment of the body has its own rhythm. Some, like the beating heart, remain mostly hidden, while others like respiration, are heard: “respiration announces itself. Running and emotion modify it” (Lefebvre 2004: 38). As Kaldon wrote in his journal:

My shoulders seem to have a little rhythm of their own. My right shoulder will be the main source of pain ‘till about 15:00 and then it’ll swap with the left shoulder...  
(Kaldon Journal)

In grasping the measure of these internal rhythms the living body is made present, animated by its own score. Maintaining attentive eyes and ears, a head, a memory and a heart (Lefebvre 2004: 36), the body becomes a constant reference point through which we can learn a symphony of rhythms. Using all our senses, our breathing, the circulation of our blood, and the beating of our hearts, we can think with our bodies, not in the abstract but in lived temporality (Lefebvre 2004: 21). The body serves as a metronome, marking the beats of life and entangling rhythms that circulate in and

outside the body through its corporeal capacities to sense rhythm (Edensor 2010: 18). Animated and animating, bodies become the point of contact between social and biological rhythms, ‘almost objects’ that contain by concealing this diversity (Lefebvre 2004: 10).

Residing at the intersection of so many different rhythmic pulls and flows, bodies become influenced and conditioned by time that is other than their own. Our social environments condition our biological rhythms of eating, exercising and sleeping, and our bodies are disciplined to fit into the rhythms of society. Lefebvre calls this training ‘dressage’: to bend oneself and to be bent through repetition to the ways of a group or a society (Lefebvre 2004: 39). The production of bodies through the work of dressage determines the majority of rhythms (Lefebvre 2004: 40), but it does not replace the organic rhythms that play at the heart of bodies. Instead, dressage evidences the body’s capacity to affect and be affected by a multitude of rhythms, substantiating its affective agency. As we will see in this chapter, bodies use rhythm to create rituals of care and to re-shape their own lives, establishing their significance through their own materiality.

Shaping human experience and pervading everyday life, body rhythms speak of and through their own animation, providing an essential tool for understanding local embodiment and our place in the world. Both Lefebvre and Bachelard suggest that the disruption of rhythm through illness enables us to get outside rhythm and thereby to grasp it, returning us to the idea that illness forces us to be aware of our bodies. When bodies beat louder and refuse to bend any further to the conventions and pressures of society, we must listen to the rhythms of our own lives and adapt to the new demands placed on them by illness. Entering into a negotiation with these

everyday rhythms, it becomes clear that, “the effort required to maintain rhythmic and temporal order should not be underestimated” (Edensor 2010: 15). The fluidity, speed and pulse of modern life do not neatly correspond with our own body rhythms, and adaptation and attunement entail work and sacrifice. But new rhythms can, and must, be found. Without rhythm, “life and thought cannot be stable and secure: repose is a happy vibration” (Bachelard 2000: 21). Using rhythm to our own advantage, we can make interventions (Lefebvre 2004: 67) and construct new schedules, routines and rituals that lend our everyday lives ontological predictability and security (Edensor 2010: 8). Rhythmic attentiveness and rhythmic repose (Bachelard 2000: 21) enable us to run again on our own time, and to live with illness, not by silencing our bodies but by learning to listen to them.

Through three sections – *Eat*, *Exercise* and *Sleep* – we discover the biological, social, personal, and emotional joys and struggles that are caught up in the harmonies and disharmonies between the rhythms of bodies and the rhythms of life. Following body rhythms that are made visible by the everyday management of illness and the maintenance of stability, we see how they influence notions of care, control, responsibility, and mortality in relation to notions of mind and body. Throughout this chapter the importance of each of these rhythms, and of listening to the body, is made clear. As Meghan knows well:

Which is why just in my head, and I even sometimes write it down, just sleep, exercise, fish, it just kind of recalibrates myself and refocuses myself, and then everything else kind of falls into place. (Meghan Interview)

## *Eat*

This section focuses on the importance of diet, showing how the basic need to eat can become a defining feature of our lives, whether we are calculating carbohydrates, seeking the nutrition that our bodies need, or managing their shape and size. Eating highlights the potential conflicts that illness can produce, conflicts between what a body wants to eat and what it needs to eat, in the demands that it places on how we buy and prepare food, and in when and where it can be eaten. Here, the ways in which rhythms of eating are transformed by the needs of bodies, and the ways in which medical and nutritional knowledge become embedded in daily routines are explored, showing how food is used to control illness and to care for the body. Doing so, it becomes possible to draw out the relationship between the eating body and the duty to be healthy, and to reconfigure illness from a moral project of the self to a felt responsibility towards the body.

One relationship to eating defines food as a way of controlling illness and caring for the body. To make this relationship, individuals must be disciplined in their approach to diet. Long lists of foods to eat and foods to avoid are formulated in order to minimise the impact of illness and increase a feeling of good health. Lists of foods are developed in response to instruction and advice, from personal research, and by listening to the body itself. While there may be evidence for many of these measures, and while they often make a difference, the underlying promise of disciplined eating is the feeling of control that it creates. Sometimes food is the main,

even the only, means available of controlling a condition that defies medical treatment, promising control of a condition that is otherwise uncontrollable:

Sometimes I think of going back to a nutritionist but I realise I am probably looking for something that no one can provide and that is a magic bullet, or more simply, a list of instructions which if I carefully adhered to would make me 100% not swollen and would guarantee that I'd have full function of my hands and feet for the rest of my life.

(Meghan Journal)

Meghan is thirty-two and has rheumatoid arthritis. Just as there is no known cause of rheumatoid arthritis there is also no known cure, and the course of the condition is impossible to predict. In her search for a magic bullet, Meghan has consulted nutritionists, bought and taken supplements, subscribed to diet and nutrition email lists, and read countless magazines, books and websites. Information continuously flows towards her body, demanding an investment of time and money but allowing her to stay active in her approach to living with illness. Because it is an inflammatory disease, rheumatoid arthritis can affect the heart and other internal organs, so, for example, people with rheumatoid arthritis have a higher incidence of heart attacks and heart disease. For this reason, Meghan has read books about inflammation in the body and has discovered that certain foods can exacerbate inflammation, and that foods containing Omega 3 and 6, like fish, are good to eat. The list of things she 'should' do daily includes drinking eight glasses of water, eating five servings of fruit and veg, taking a B12 supplement, and getting Omega 3s by eating nuts, seeds or oily fish (but not more than two servings per week). Things she should avoid, or at least not overindulge in, include: caffeine, sugar, alcohol, red meat, dairy, citrus fruits and vegetables in the nightshade family, and saturated fat. A video tour of her kitchen

cupboards reveals no less than ten types of tea, most of which owe their place in the cupboard to the health benefits that they offer. There is green tea, which has many health benefits; white tea, which is slightly less caffeinated than green and supposedly better; peppermint tea for digestion; pleasure tea that just tastes nice and does not have caffeine; fair trade tea bags for visitors looking for builders tea; camomile, a good detox; liquorice tea in the back; tea from Rwanda and Sri Lanka; and another tea containing cinnamon, cardamom and ginger, all supposedly good for inflammation.

The items on Meghan's list are well researched and specifically selected for their capacity to control inflammation in the body, but they are also controversial and sometimes contradictory. A conversation with her doctor, for example, can quickly undermine the power she ascribes to her diet:

I try not to eat that much dairy, and I really like eating cheese, so sometimes if I eat lots of cheese it makes me feel more swollen, so I'll start telling him this, and he'll just be like, there is no evidence that shows that what you eat affects your rheumatoid arthritis. And even though there might not be I believe it, I believe it's true, it's true for me. (Meghan Interview)

The hard line being drawn here between medical knowledge and personal truth only serves to make the search for answers harder. Because there is no certainty, keeping up a disciplined approach to eating can be difficult:

I suppose it's much easier to make sacrifices when you are promised - or guaranteed - results. But when you are making sacrifices + you still feel swollen in your hands, you wonder why you are bothering... (Meghan Journal)

Social situations often demand the consumption of foods that are on the list of items to be avoided, and visits with family and friends can easily lead to the rules being ignored. The consequences are manifested in swollen and sensitive joints, so that simple pleasures have become indulgences, and not caring for or paying attention to her body has an acutely felt price. While Meghan loves food and loves to cook, arthritis has transformed eating into a balancing act in which she thinks about food primarily in terms of what it gives her. It is a matter of constantly monitoring how swollen she feels and knowing when to be more careful without taking it too far – during the times when she has been more extreme about diet her friends have told her she is too thin. Now, she picks and chooses the indulgences to allow herself:

...it's just too boring of a life to avoid sugar, coffee and alcohol every day, so I try to pick one or two and just indulge moderately. (Meghan Video Diary)

Through her love of food, Meghan has made up for the instances when she feels deprived by the foods she should not eat by creating food rituals that give her pleasure. One of Meghan's rituals is a weekly walk to Greenwich through the foot tunnel to buy a loaf of rye bread at the bakery there. A nutritionist once told her to avoid eating wheat, and, while she was frustrated by the idea of adding another item to her list of things to avoid, and still is not completely convinced that it is a necessary measure, she does try to eat rye bread instead of wheat bread. She enjoys the morning walk and coming home with a beautiful rye loaf makes her feel less deprived, which is really, really important. Another ritual transforms making coffee, which strictly speaking she should not drink, into a special act of care:

I love coffee; I love its flavour, its warmth, it's very comforting to me. There's something about the sound of a coffee maker, it just makes you feel like your day is off to a really good start! When I do research about diet and arthritis, coffee is one thing that you're really supposed to avoid. But I feel so deprived without a cup a day, and sometimes I have two. Sometimes I have thought that making coffee is a meaningless ritual, and that I could just substitute it with something else. Instead of turning on the coffee maker I could make a cup of tea. But tea doesn't have the same texture to me, or the taste. The funny thing is, I don't know how to work this coffee machine, and my housemate sets it up the night before. And maybe that's a bit of what it's about, somebody looking after me in a way. My grandmother always had a coffee pot set to automatic, she didn't even have to hit the switch, it was just ready when she woke up. Making a cup of coffee this way takes so much longer than a cup of tea, you really have to be patient. (Meghan Video Diary)

Captured on video, the sounds of coffee brewing – the electric buzz of the machine, the gurgling water, and the drip of the coffee pot slowly filling up – evoke the smell of freshly brewed coffee filling the room and bring the intimacy of the ritual to the screen.

Anwen has Miyoshi-type muscular dystrophy, a form of distal myopathy. It is a genetic condition, and both parents must be carrying the gene in order to pass it on. Miyoshi's belongs to a group of muscular dystrophies called dysferlinopathies; the body fails to produce a protein called dysferlin, and this causes muscle deterioration. Miyoshi's is extremely rare and little is known about it, but it is known that the condition isolates itself to the distal muscles – the muscles furthest away from the centre of the body – and that it manifests itself differently in different people's bodies. At the age of thirty-one, Anwen has now lost most of the muscles in both her legs:

her gastrocnemius, the anterior of her lower legs and her quadriceps, and the condition is starting to take out her pectorals and the muscles in her arms. It is a rare condition with no medication or treatment, and no one can really provide the answers that Anwen needs. As a result, Anwen has had to work it out for herself. Like Meghan, one of the ways in which she tries to stay healthy is by paying attention to diet:

I guess the other part is diet, that's also your body saying I need to eat this; I need to not touch this. And I always think, you know, I never know how much real logic there is to that, sometimes you could be saying I shouldn't eat this or I should eat this, and it might not actually have an effect at all, but it gives you a sense that you've got some kind of control. (Anwen Interview)

Although the value of food is hard to be sure of, Anwen's approach to diet originates from her body's needs. She listens to what it wants and to what it does not, and tries to respond to those requests. So, for example, she avoids processed foods, stays away from things containing wheat and gluten, eats lots of yeast, tries to have lots of good oils and fats and avoid the bad ones, eats lots of vegetables and not much meat, and avoids caffeine and alcohol. These measures help her digestion and provide valuable energy, so that her body is able to focus on all the other things it needs to do. This eating regime is not only about what works, it is also about maintaining a sense of control. The effort required to maintain a disciplined approach to eating puts Anwen in touch with her body and makes her active against her condition, transforming food into an essential and positive aspect of her life, so that through eating she is able to reclaim her body from the grip of illness.

Anna is forty-three and has been living with depression since her childhood. Like Meghan and Anwen, her diet is strictly controlled, something other people might perceive as a form of extremism. She does not drink or smoke, and she is virtually vegetarian. Diet is one of the ways in which she is able to construct a routine and feel healthy through her body:

It works for me. It feels like I've found a way to feel better. I imagine that if I stopped it wouldn't be very good. I was ill over Christmas with flu, and I felt a real plunge. But as soon as I started to re-do the things I do I felt fine. (Anna Interview)

Jeffrey, is thirty-four and has bi-polar disorder. Also known as manic-depressive illness, bi-polar disorder is a mood disorder characterised by rapid or significant changes in mood, specifically between a manic, elevated mood with associated behaviours, and a low, depressive mood. For the last two years Jeffrey has been managing his condition without taking medication. He has put certain things that he can rely on in place, like diet, so that he now feels self-sufficient and able to take care of himself. The extent to which Jeffrey is following his beliefs about eating is a good indicator of his health. His ability to maintain his diet, which for six years was strictly vegetarian, and his grip on other demands in his life and his mood are interrelated and dependent on one another, evidencing the far reaches of control that can be gained, and lost, through the eating body:

I think a lot about it [diet], I have lots of beliefs about it - that I don't always follow because, again, like, if the mood gets away from you then other things crumble, but then if those things crumble that will exacerbate the mood. (Jeffrey Interview)

For Meghan, Anwen, Anna, and Jeffrey, disciplined eating forms part of a strategy for health. Routines structured around food reveal significant dedication to caring for the body, provide a sense of security and control, and unite mind and body together in an attempt to manage illness. But maintaining these regimes requires energy, motivation, and work, all of which can be hard to find.

When disciplined eating fails, another relationship to eating is constructed. This relationship is characterised by feeling unable to cope with the body and its needs. As a result, mind and body are distanced from each other, leading to feelings of guilt towards the body. Sophie is twenty-four and has been living with depression for the last four years. The tiredness, anxiety, and lack of motivation symptomatic of being depressed affect her ability to look after herself and make healthy eating difficult. During her first serious attack she visited a psychiatrist who advised her to stop drinking alcohol and to get her diet under control. But even though she really wanted to try to do this, Sophie didn't feel at that moment like she had the agency and the will power to be able to take control of her life in that way. Instead she binged on comfort food, not having the energy or the drive to go grocery shopping or to cook. Just walking to the shops had become too stressful and exhausting. This, combined with medication, which had increased her appetite and simultaneously decreased her metabolism, meant that by her twenty-first birthday Sophie had put on a significant amount of weight, leaving her feeling horrible and heavy. She had no sex drive and she hated being touched. Her body felt different than it had before. Not that it had become alien to her, but rather that she had become trapped in it. It seems obvious to think that people who have depression are trapped in their minds, and the feeling was like that, but it was not just that; Sophie had also become trapped in her

body. It was a sensation of being blocked, of feeling like a stone. The interdependence of eating and depression continue to affect Sophie's life, and her depression is not located, but felt, in her stomach, which is the register of the bad effects of her condition:

...when I feel bad and I feel like I'm not healthy enough to do things like go outside and achieve things and stuff like that, it's often because I haven't eaten enough, or I've eaten too much, or I've eaten the wrong thing, and it's combined with feeling bad and having not slept and stuff, so a lot of the time I feel quite shaky or empty when I'm going through these periods. (Sophie Interview)

Similarly, Kim recognises the snowball effect that connects the frequency of her epileptic seizures to her alcohol consumption and diet. Over the last few years she has begun to improve her lifestyle – eating healthily, avoiding alcohol, and sleeping regularly – in order to reduce the number of seizures that she has. But Kim finds it hard to maintain a healthy lifestyle, and at the age of twenty-eight she still goes out drinking when she should not, ruining the hard work that she has put in. As a consequence, she worries that she does not look after her body well enough, and it leaves her feeling disappointed. Her frustration shows that illness transforms eating from a taken for granted activity into an act with significant physical and emotional repercussions:

I feel disappointed, slightly angry, because I'm a bit cross with myself for letting it happen, because it can be controlled. (Kim Interview)

For others food seems less significant. Nell and Kaldon both choose not to pay too much attention to the dietary recommendations associated with their conditions, instead eating the things that they like:

I shouldn't have milk, but I'm a dairy fiend. I'm not allergic to milk, but I've been told that milk is not good for asthmatics, because of the mucous and everything, the traces that are left behind, but I can't help it, I love milk. (Nell Interview)

I take supplements, cod liver oil, and I eat a lot of fish, stuff like that. But I'm a bit of a hypocrite in that way, in that I shouldn't eat tomato and I shouldn't eat eggplant... I decide on how convenient and tasty it is - like not eating tomato, are you kidding? You try doing that, I like tomato and it's a base for so many things, like if I just want a quick pasta... But I don't notice that much of a difference with it anyway... I don't know, I'm not saying it doesn't work, but if I skip tomato for two days then of course I'm not going to feel any difference. (Kaldon Interview)

In these instances diet is less central. But eating is not simply about prohibition: as Nell and Kaldon show, illness forces us to consider all of the ways in which diet might help or hinder our bodies. The fact that a glass of milk or a tomato sauce could have been a serious threat to the body heightens our awareness of all that we are privileged to.

For Matt, who is twenty-three and has been living with type 1 diabetes since he was eighteen, ignoring the needs of his body in relation to eating is a more definite risk. Matt has to check his sugar levels on a regular basis: when he wakes up in the morning, before he eats, a couple of hours after he eats, and before he goes to bed. Every time he eats he takes an insulin injection, and once every twenty-four hours he takes a base insulin injection. If he keeps to this routine he feels fine, but every now

and then he will lose his pens, or forget an injection, or just not be disciplined enough, and then he can feel the sugar building up, the stiffness setting in, he will get ratty and snap at people. While Matt knows that eating healthily is an important part of living with diabetes, he describes his attitude to diet as 'a bit lazy':

But when I eat, yeah, cutting out all the sugary drinks, the full sugar cokes and everything like that, that was alright, I wasn't too bad about that, but it's the sweets - I've got a real bad sweet tooth, chocolate, and sticky toffee puddings and donuts, they're the hard ones, they're the devil! But in those cases I should take a little shot of insulin, it's there for me to do it, but I'm just a bit lazy, that's all. (Matt Interview)

His attitude toward eating has led to arguments with his girlfriend. Matt thinks that while he is young he should just enjoy himself. His girlfriend thinks that if he does not look after himself now he will not be able to enjoy himself later on in life. Matt knows she is right, that if he does not take care there could be complications, that diabetes can lead to loss of limbs, blindness, or kidney disease, but for now he is trying not to think about that. Perhaps when he is a bit older, in a couple of years, he will take it more seriously, but right now he just wants to have fun. Having to eat when he does not necessarily want to, needing to be disciplined about eating and to keep to a routine all conflict with Matt's outlook, changing the meaning of food, demanding that his body act against its own desires and constantly reminding him of the presence of illness. His attitude to eating represents a third relationship, in which the body's needs are ignored and its vulnerability denied.

To different degrees, eating is significant for everyone. Food forms part of a search for answers and can be a source of control, offering the possibility of becoming healthier in response to illness. The control that food seems to offer

through the certainty of cause and effect is reassuring, but it is also tainted. As Meghan explained, it is a sense of control that is not necessarily true – but even knowing that she cannot control her arthritis is somehow control, in a way. What is important is that she knows her condition, that it is familiar and that she understands it, and diet is one way of making that relationship. But diet can also be misleading. In his thirteen-year search for a diagnosis to explain his pain, food allergy was one of the many dead ends that Martin pursued. And, when food is made important, it inevitably entails the possibility that the body will become a source of guilt. The demands of disciplined eating make the body dependent, regimented and inflexible, and the heightened awareness of what should and should not be consumed is only intensified by the potential list of things that might happen if good control is not kept.

For Imogen, who is twenty-five and has type 1 diabetes, this list includes: blindness, kidney failure, stroke, heart attack, gangrene, numbness (in feet and hands), producing sick children, not producing children at all, depression, and loss of sex drive. Type 1 diabetes typically strikes in adolescence, and unlike type 2 diabetes it is unpreventable. In type 1, which accounts for about 10% of all diabetics, the pancreas stops producing insulin, which means that the body can't break down any sort of carbohydrate or glucose. If untreated, this will trigger a famine reaction in the body, and it will begin eating itself, starting with its fatty reserves.

Having diabetes involved the imposition of an inconvenient regime on Imogen's teenage life, including an injection at 7 o'clock in the morning – fine on a school day but not so convenient on weekends – and dinner by 7 o'clock in the evening, which didn't fit in with the family routine. But, with the support of her

family helping her to cope, she imagined that her new regime would be a really good way to be healthy. It was not until she left home for university that life with diabetes started to get really difficult; the problem with diabetes, she told me, is that the minute you change your regime in any way your body reacts, the slightest change in your life, the slightest stress, will affect it. At home she had felt pretty confident and relaxed, but university life, with its pressures and alcohol driven social scene, threw her, and it threw the diabetes. Imogen began to feel insecure, that she was failing. Even today, after ten years of coping with diabetes on a daily basis, Imogen feels like she is constantly failing her body exam.

The regime she is on now, called DAFNE (Dose Adjustment For Normal Eating), involves having to inject five times a day; two long term acting insulin injections, one in the morning and one at night, and one regular insulin injection for each meal she has. DAFNE is designed to enable greater flexibility with eating, but it means that Imogen has to be aware of how much carbohydrate is in everything. She has to weigh everything out, perhaps check her book, which lists how much carbohydrate is in most things, and work out the ratio of insulin to carbohydrate, which can vary depending on her sugar levels. This means that she has numbers in her head all the time and that she is constantly trying to do maths. Breakfast is quite easy, because she is normally at home and she knows how much carbohydrate is in a banana, and how much is in a small bowl of muesli with milk. But the problems start around lunchtime, when she is out. A sandwich is ok, and if she is having a salad then she does not need to inject, because there is no carbohydrate in that. But a hot chocolate would be more complicated to work out, and not everything can be found in the book. Even if she gets the maths right, there are a host of other things that can

throw Imogen's diabetes off balance, and a drop in her sugar levels can trigger a 'hypo' – a hypoglycaemic episode. Everything has to be factored in to a strict regime, and even then there are no guarantees.

For Imogen, the consumption of food is legislated by more than a list of instructions. What she eats is continuously redefined in response to her condition. The need to constantly monitor her body and be reactive to it, to eat or drink what and when she does not want to, turns food from a source of nourishment into a form of medication that often contradicts the attempts she makes to control her weight and be otherwise healthy:

It's quite frustrating in that sense. Especially if you're exercising to lose weight, it's very frustrating to have to have some Lucozade after, or eat something; it kind of misses the point really. Yesterday I was trying to be very good... but I hypo-ed three times in the day and it lead to having to eat a load of crap. (Imogen Interview)

Conducting a 'Spendaholics' or 'You are What You Eat' shock tactic for herself, Imogen decided to record a tidy up of her bedroom on video. She found twenty-two empty Lucozade bottles in her room and lined them up along the foot of her bed; six weeks' worth of bottles, not including her glucose tables or the bottles she had left at her boyfriend's or drank while she was out. Lucozade has a high glucose content and can be rapidly absorbed by the body, so when Imogen's sugar levels are low it is the perfect thing to reach for in order to prevent a hypo. The display quantified the presence of Lucozade in Imogen's body and her life, and amounted to a worrying, but medically necessary, consumption of sugar and unhealthy chemicals.

In listening to the body, the significance of the basic need to eat becomes clear. No longer a basic bodily drive that can be taken for granted, eating reveals the

centrality of the body in our attempts to live with illness. Through eating, the processes and practices that create routines, rules, cures, and rituals of care become visible, and the ways in which the body is reconfigured by its material needs become apparent. The rhythms that surround food show how eating and illness are tangled up in and made present by everyday acts and in everyday places. Sometimes they reinforce the negative presence of illness, but they can also help to make positive connections to the body. As a significant form of managing illness eating is a way of caring for the body, but it is one that creates conflict, turning eating into a duty and a reward. The making and breaking of routines is intimately linked to our ability to look after our bodies, both connecting us to them and distancing us from them. Ultimately, these rhythms of eating begin to reveal a picture of illness in which, instead of trying to silence our bodies, we learn to listen to them.

## *Exercise*

This section considers the rhythm of our bodies in motion and the complex relationships between exercise and illness, as both a necessity and a joy. Like eating, the significance of exercise is redefined by illness, and the body is maintained, challenged, and re-known through it. Exercise regimes can provide control, treatment and an alternative form of medication so that through physical activity bodies feel strong, independent, and free in spite of illness. But ill bodies are prone to overexertion, and exercise can reinforce their dependence and vulnerability as well as their strength.

Exercise is an essential part of Anna's daily routine. Her day typically starts with ten touch-toe stretches, five or six holds with the head between the knees, and several touches of the hands behind the back. The movements are like a checklist, and her day will not feel right if these simple exercises are not performed. At least four times a week she does something more physically active, either running on the common or cycling through the city. Regular physical activity structures her week and works as a sort of self-medication. Not exercising, on the other hand, can have a horrible effect. Her mood will plummet quickly, and she will feel heavy, squashed somehow, penned in, trapped inside herself, irritated, and annoyed. So it is vital that exercise is incorporated into her everyday life. In a month she can accumulate seven hours spent running and three hundred miles cycled. A treadmill sits at home in case the weather is too bad to run outside, although it is hardly ever used because of the noise it makes (good for a thirty-minute run at most).

When she is running or cycling, Anna feels at peace with herself. There is something about physical exercise that stops the otherwise incessant critical commentary, the negative thoughts that trouble her mind:

Forced myself out for a run in the amazing sun. One thing I've noticed when I run, I never worry about how far I've got to go, I just think about each step. My mind does wander but the point is with running & my cycling I don't deploy the negative sort of constant self-evaluation & anxious anticipation that I seem to do with everything else, if I could live the way I run it would really help. The body seems able to do a lot of things without worrying about them or planning ahead; if my body was like my mind I'd be up all night worrying about how I was going to breathe in 2 weeks time! (Anna Journal)

A blast of icy wind, the exhausted feeling afterwards, can halt her otherwise incessant internal monologue and give Anna a rest from herself, relaxing her mind and allowing her to feel more integrated, like she is not just a mind. When she is running, there is a sort of fluidity between her mind and her body, because she thinks a lot when she is running, and it feels like her thoughts are in tune with her movements, there is a sort of rhythm to it. When she is really fit, it feels like there is no effort involved at all, like she is gliding, and for ten or twenty minutes after she feels absolutely fantastic, exhausted, relaxed, and ecstatic.

Jeffrey also uses exercise as a form of medication. His regime changes all the time, but a typical week might include running three miles a day, doing weights every other day, cycling to work, taking two or three contemporary dance classes, and perhaps fitting in some swimming, yoga, and pilates too. Last summer this regime reached an Olympic training style peak, which even Jeffrey can conceive was a little

too much, while this summer it has been ground to a temporary halt by a hernia. But while there may be wild variations, depending on where he is and what is available (it's really frustrating, for example, that the gym does not open until 10am at weekends, when Jeffrey wakes up at 5:30am every morning), there is always some sort of exercise going on. A day or two without it and he will immediately notice a change in his mood, and the few times in the last year when there has been nothing going on at all have been very dark times. There is a symbiotic relationship between Jeffrey's body and his soul, and he feels better or worse depending on how well he takes care of himself physically. If something causes him to miss his exercise, or if something gets him down and he does not feel like doing it, then he will not, and if he does not, then he will not be in a better mood, and he might not go to work the next day, creating a constant pressure, a background feeling of panic; nothing must slip, the momentum must be maintained.

There is no medication for Miyoshi-type muscular dystrophy. Instead, Anwen tries to stay fit and healthy, like anybody, except that if she gets unfit it means that she can hardly walk. To maintain her independence and prevent the need for a wheelchair, she has also worked out what her body needs to stay strong, developing her own strengthening exercises. Swimming is one of the best things that she can do, but she also practices walking and standing exercises in the pool. Seeking advice from a physiotherapist, she found that many of the exercises she had developed herself were the same as those the physiotherapist recommended, evidence that her embodied intuition can be trusted. Working at this kind of awareness is one of the best things that Anwen can do, and she compares it to the sort of physical awareness gained through the practice of martial arts or yoga. Perhaps it is an awareness that is

also gained through illness. Regardless of the gradual and unhalting deterioration of her material being Anwen does not separate mind from body as one might expect. Instead of fighting against her body, Anwen accepts that she is her body, and she uses it to her advantage.

Meghan's condition also requires her to take extra care. Rheumatoid arthritis can cause inflammation of the arteries, which increases the risk of a heart attack, so regular cardio activity is important. Lifting weights also helps; by building muscle strength she can protect her vulnerable joints from stress. Meghan's day usually starts with some sun salutations, and her yoga matt remains out on the floor throughout the day so that she can take lots of breaks. She cannot sit for many hours at a time without getting stiff and needing to roll around a bit. This need or desire to get down onto the floor more than once or twice a day does not make her the ideal candidate for a nine to five job, so although it sometimes gets lonely she is happy to have the freedom and flexibility of working from home. She walks whenever she can, using exercise to make her body feel powerful and strong:

This morning after I left the gym, where I had spent 30 minutes lifting some weights, all I could think of was: I want to be strong!! Even though my legs feel stronger after all of the walking, I am still so weak when it comes to lifting weight. I could only do 15 reps of leg extensions before I was too tired to continue. (Meghan Journal)

Kaldon also has rheumatoid arthritis. It now affects his knees, feet, hands, neck, and jaw, having spread to new parts of his body over the years, but it is predominantly in his shoulders, and it makes his joints prone to pain – pretty much at any given moment he has a certain level of pain, which can easily rise to a severe, acute level if a joint becomes aggravated or inflamed. The condition makes Kaldon's body weak, but

it is invisible to the eye, and he looks strong, fit, and healthy. To compensate, Kaldon exercises. Swimming, which he normally does three times a week, is very good for his condition, because it builds up the muscles around his shoulders, the strength protecting his joints from aggravation. But Kaldon's main passion is for martial arts, specifically Muay Thai (Thai Kickboxing). Kickboxing is, quite probably, the highest impact martial art that there is, so it is by his own admittance a very silly thing to do. His mum thinks he is an idiot and his doctor has told him it is not good for his body, but it is obvious how important it is to him, and he trains and fights two to three times a week. It is frustrating sometimes because he cannot push his body as far as other people can push their bodies, he cannot train as hard for a tournament and he has to take really small steps and be quite controlled about it. But training is a way of saying this is what I want to do and I am going to do it, of being in control of his body, and of choosing pain. Because, for Kaldon, fighting is not about releasing his anger on others, it is about pushing his body, feeling the pain in his muscles when he does weights, and it is about getting hit – about focusing on a split lip or tasting the blood in his mouth, and knowing that the wound is going to go away in a week, and it is never going to come back and annoy him again. Unlike arthritis, a black eye, a cut, or a bruise will all heal and disappear. Exercise is, then, a mix of care and control, an attempt both to protect his body from the arthritis and to be tougher in response to it, because arthritis can be emotionally emasculating. Day to day activities, like grocery shopping, or taking the tube to work, can hurt, reminding Kaldon of his weakness, and becoming fitter and stronger is one way to counter that.

For Anna, Jeffrey, Anwen, Meghan, and Kaldon, exercise forms a positive relation to the body. Like disciplined eating, regular exercise is a form of dedication

to the body, a way of listening to it and caring for it, and, through exercise, bodies become stronger and healthier in response to illness. In contrast, Martin's exercise routine, which he captured on video, is a painful and tedious obligation. Every evening he spends half an hour performing a series of moves and stretches which are designed to work out the stiffness and soreness that has built up in his body throughout the day. Although this exercise is not a positive experience, it is still a significant form of dedication.

Regular exercise is important for Imogen too. But diabetes and exercise are caught up in a vicious circle. Imogen's sugar level initially goes up when she is exercising in the gym or swimming, because adrenalin is running through her body. But her level will then plummet at some point in the next twenty-four hours. It is difficult to know when this will happen, and it makes managing her levels a case of pure guesswork. It is likely that after exercising Imogen will need to eat something, or drink some Lucozade, a need that undoes the hard work she has just put in. This in itself is enough to make mustering up the motivation to go for a swim difficult. But the situation is further complicated by the fact that going swimming involves putting on a swimming costume and revealing the bruises from her injection sites that cover her thighs. These bruises, and the physical and emotional battle of going for a swim, are pointed out to the video camera and presented in the film that accompanies the thesis, highlighting the fact that bodies can undermine their needs and efforts through their own materiality and drawing out the tension between being aware of the body and feeling self-conscious of it.

Managing her body through exercise is also a delicate balancing act for Xan. She grew up playing squash, basketball, running and swimming for her school, and it

was not until the age of sixteen, when she still showed no signs of hitting puberty, that her parents first started to worry. Tests showed abnormally low hormone levels in her blood and she was sent for an ultrasound scan to check her internal physiology, which showed, as expected, a uterus and what seemed like ovaries. At this point it was assumed that Xan was just a late developer, and that her athleticism was delaying the onset of puberty. Only at the age of nineteen did doctors discover she is intersex. During the fourth to sixth week of gestation in her mother's womb a mutation in the Y chromosome caused a malformation of the testes, which then failed to produce testosterone and so did not trigger differentiation into the male form. Xan was born a girl but her chromosomes are XY, the male chromatic structure. This means that her body does not produce any hormones at all. Now, Xan carefully manages her body, and although exercise is still important to her she has stopped working out as much as she used to, because being fit and burning fat makes her look more androgynous. She is already tall and broad; her body did not receive the signal to stop growing until she started hormone replacement therapy at nineteen, and she is conscious of how big her presence is, and by exercising less she can maintain her curves and conform her body to a more feminine shape.

Each of these examples shows how exercise is used to strengthen and manage the body in response to illness. For the most part, exercise enables the body itself to fight back, bringing mind and body together in a shared attempt to counter illness. But exercise can also reinforce the dependence and vulnerability of the body. Sometimes, the good exercise that bodies do has repercussions that make exercising more complicated and add another source of frustration to living with illness. Apart from these dangers, there are also other more natural forms of exercise that can easily

undermine the body's strength. The physical activity of making love, for instance, can hurt bodies, aggravating arthritic hip joints or causing sugar levels to plummet and allowing illness to once again rupture normality even in the most intimate moments:

I feel I should discuss a topic which may be at the risk of sharing too much information, but bloody hell diabetes is part of my life and it does effect what I want to discuss - sex. Now as many a good diabetic nurse has informed DAFNE attendees and anyone reading some girl mag will tell you sex is excellent exercise. I know this because (well other than the obvious) my sugar levels always plummet after or even during love making. This has proved a frustrating part of my diabetes in recent years, as it completely interrupts the process, well at least it tries to. Sometimes I can feel it dropping but I am determined not to let it interrupt. I want, quite frankly, to be in control when I lose control. It's a very strange feeling to be (& here's the bit that I'm cautious to say) post-orgasm & hypoing, because it's a real mix of feeling, because in many ways it's the closest I ever get to a feeling of zen-like hedonism. I lie there in a state of absolute bliss & I can feel my body quietly slowing down as the sugar levels drop, I find I can't move & my mouth won't form words properly & it feels good! The fact that hypos lead to bad things however means a part of my brain is going - 'Imogen? Imogen? Move, come on, get some Lucozade down you!' And another part is going 'what does it matter? I can just lie here, just lie here and be.' At this point I scramble around the side of the bed to find the Lucozade & glug it down. I then want to sleep, but I can't, I have to eat something, but I'm lying on a bed which I feel partially paralyzed on (by this I mean it feels like trying to get up in the morning) & I'm naked. (Imogen Journal)

For a moment, Imogen hears her body but does not care. Her desire for complete abandon communicates an embrace of life and its pleasures regardless of the physical

risks involved, and it speaks of her refusal to be confined by illness. The hypo, brought on by a severe drop in the sugar level in her blood, will make her feel dizzy and weak, and failure to react could lead to loss of consciousness and permanent physical damage. Despite these dangers, there are times when we refuse to let illness interrupt our lives.

## *Sleep*

This section looks at how the demands of our working and social lives can conflict with the demands of our body, and at how illness redefines our lives through sleep. While rest is sometimes the best cure for illness, sleep clashes with social expectations, destroys routines, and causes conflicts. The need to sleep is perhaps the most delicate revelation of the body's vulnerability, and, unlike eating and exercising, it often leads to a negative relationship between mind and body.

Anna's depression makes her want to sleep, slowing her down and making her feel tired and heavy:

My body feels really different when I am depressed. It feels so heavy, which is a bit of a paradox having talked about feeling light and out of my body, but at the same time it's feeling heavy, not being able to, losing fluidity, just wanting to sleep all the time, not wanting to wake up, a sort of hang-over feeling from sleeping so much or just from being depressed, I don't know which. It's a real slowing down for me. (Anna Interview)

During these times she will return to bed, not so much because she wants to sleep but because she does not want to be awake. Together with depression, Anna also suffers from insomnia and sporadic sleep disturbance. The word insomnia is logged six times in her journal which she kept for one month, and her sleepless nights are captured on video and included in the film that accompanies the thesis. Negative thoughts often keep her awake, spinning around in her head when she is most

vulnerable to them, and lack of sleep later contributes to her gloomy mood, leaving her feeling tired and lacking in motivation during the day:

I fell asleep reading this afternoon, it's the insomnia catching up with me, it leaves me very flat & low, wiped out and lacking enthusiasm. Really drained. Don't feel good about myself, feel like I am a stupid waste of space; that's the sort of thing my therapist would say is not me speaking but other voices I shouldn't allow in. It's hard not to allow in the idea that everything I do is wrong at the moment. The physical exhaustion I'm feeling today adds to the feeling that I can't cope with things very well and screw things up. (Anna Journal)

Together, depression and insomnia turn sleep into a problem for Anna's body, and the link between not having enough sleep and feeling depressed means that sleep is both hard to find and really, really important.

Like Anna, Sophie suffers from depression together with insomnia and distressed sleep. Bad periods of depression affect her sleeping patterns, and make her want to sleep throughout the afternoons. These are times when life stops happening, and days and weeks cannot be remembered. They are marked by apathy, and stand out in contrast to the times when she is kept busy and active with work. Sometimes her body feels light, and can achieve what she wants it to do; these are times when she is confident about her potentials – if not in life, career or future, then as a person, managing to survive. But at other times Sophie feels too unhealthy and foggy to get anything done, even sitting at the computer and certainly not going outside, because that would be too difficult. It is as though the world is projected onto her and her body does not have the agency to perform the tasks that it has the potential to do; instead she feels heavy, tired, low, apathetic, hopeless, tormented and stuck. The

fluctuation between these two states, marked by lightness and heaviness, reveals the codependent relationship between Sophie's mind and her body; her state of mind effects her body so much, and vice versa, her body can make her feel heavy or light in her mind. But it is not that Sophie's body betrays her, or that she does not trust her body, which changes so much; rather it is that sometimes she does not do it justice. A bad night of sleep, a night of teeth grinding and distress, leaves her feeling tired and in turn affects her stomach; either she will not eat enough, or she will eat too much, or the wrong thing, and this combined with feeling bad and not having slept means that a lot of the time she feels quite shaky or empty, and therefore not healthy enough to go outside and achieve things.

Imogen's nights are also often disturbed. In order to fend off a night time hypo she can drink some Lucozade or eat a crumpet before going to bed, but these measures do not always prevent her sugar level dropping while she is sleeping, triggering a hypo which will then wake her up:

When you have a night time hypo, it's different for people, sometimes you can sleep through one, and your body will find a natural reserve in itself, but that's a dangerous thing to let it do. It's quite scary to have a night time hypo. Interestingly my body usually wakes me up, it incorporates it into a dream, you can feel it, it starts to come through in the dream, the feeling is kind of, well it varies, in my case I find that I shake a lot, it's like fainting, a very sluggish feeling, also I stumble over my words terribly, I really stutter. (Imogen Interview)

One of these interrupted nights was captured on video, and is included in the film that accompanies the thesis. In the video, Imogen describes the sensation of being woken by a hypo, checks her sugar level (something she normally wouldn't do,

because why else would she wake up in the night), and tries to work out the chain of events that have led to this moment. Hypoing at night ruptures the next day, and because she does not want this to happen Imogen sometimes over-compensates, eating before going to bed so that she can sleep through the night without being woken by her diabetes. But this in turn means that she risks having a high sugar level the next day; there is simply no respite.

For Meghan and Kaldon sleeping well is a preventative measure. Getting a good amount of sleep every night helps their bodies rest and recuperate, and, vice versa, not getting enough sleep means that their conditions are more likely to flare up and cause them problems. It seems straightforward, but getting eight hours sleep every night is actually quite hard. Social pressures and the demands of work mean that sleep has to be defended:

...it's very easy to only sleep 6 hours during the week, and really that's not enough for me, but it's quite hard to get 8 hours every night. So, it's almost like I had to learn to give myself permission to sleep 8 or 9 hours. Some people think that that's so much, because everybody is so busy, and especially when you're young, you should be out having fun and staying up until 4 in the morning, so then to actually get a proper 8 hours of sleep it's so hard to fight for. (Meghan Interview)

While defending the need to sleep or lie-in is hard, ignoring this need has directly felt consequences. Lack of sleep quickly leads to increased levels of pain, exhaustion, and bad moods:

Quite knackered by the end of this week - just doing too much and not getting enough sleep. Too little sleep means that I'm pretty sore today: nowhere in particular generally

just all the affected joints. So a lot of pain today has put me in a bad/snappy mood.

(Kaldon Journal)

The need to get an early night, to refuse social engagements or to leave early, is in itself a reminder of the frailty of their bodies, and it is one that transports illness from the body into social situations that, like bodies, have to be dealt with. Keeping up with the pace of modern life is a recipe for disaster, highlighting the tension that exists between body rhythms and social rhythms. There is simply no space for the needs of ill bodies when it comes to employment, for example:

Too much. I was lying in bed fighting to will myself out of bed. The pain is there, and usually pretty bad in the mornings anyway, but it's the fatigue. Your body feels as though it's submerged in sand and every effort requires too much effort. I was lying in bed, not after a late night - just recent physical activity, and my body was screaming for sleep to rest and rejuvenate. Rest works better than any drug but with a modern life in London it's the hardest thing to come by. Lying in bed after numerous 'snoozes' I'm thinking if I was ill, like with a cold or gastro or whatever I could call work and say I'm not well enough to come in, but I can't (or is it won't) call to say my A. won't allow me to get to work. I could say I'd be late but then people stop depending on you - you get put in the faulty basket. (Kaldon Journal)

For Kim, being stressed and tired is a trigger for a night time seizure, leading to further lack of sleep and exhaustion. Kim discovered that she has epilepsy when she was eleven years old. Lying in bed one night on holiday in a foreign country, she suddenly woke up. Her whole body was rigid, moving, out of control. She tried to speak, to call out for help, but nothing came out. She lost consciousness. Waking up for a second time she wondered if it had been a bad dream, but then the first of what

was to become many epileptic seizures took hold of her. The third time she woke up she found herself in an ambulance, on her way to hospital. Some time after this event Kim's condition was medically diagnosed: she has an unusual form of epilepsy, manifesting in nocturnal seizures that occur between shallow and deep sleep. The diagnosis was difficult to reach – MRI (magnetic resonance imaging) and EEG (electroencephalogram) tests, which create pictures of the brain and record its electrical activity, failed to reveal the condition because you can't see it unless it is actually happening. Several weeks spent in hospital eventually allowed doctors to see the symptoms and to make the diagnosis.

As a child, seizures only ever happened at night, when Kim was asleep. Night time seizures are especially dangerous, because it is possible to lose consciousness without realising. But the fact that they only happened at night offered Kim invisibility; just as the condition had been invisible to medical tests, it was also invisible to Kim's friends, and there was no need to tell anyone about her condition unless she wanted to spend a night away from home. As she grew older, and stayed up later, the seizures inevitably began to invade Kim's evenings. Kim can not trust her body when she is tired, and going out at night is now a risk. The need to run on her body's time is perhaps one of the most annoying features of living with illness:

That's what annoys me about having a long-term illness; you have to take these 'preventative' measures into account in daily life. (Kim Journal)

Other seemingly small details that can disrupt the sleeping body and cause pain include the beds we sleep on themselves, and the mattresses and pillows that they are made up of. Martin has joint hypermobility syndrome, a long-term inherited genetic disorder that affects the collagen in his ligaments, making them too stretchy and

weak to provide the strong scaffolding required to hold skeleton and muscles firmly together. This means that his joints go through a greater range of movement than they should do, overextending his body. In most people it causes no pain whatsoever; the only symptom is increased flexibility. But for a small subset of those people, the condition is not a party trick; instead, it is a significant cause of pain. Martin has inherited a not optimal set of bones and muscles, and they hurt. Every morning when he wakes up, his back has already started hurting. In an attempt to improve his sleep, Martin has purchased a mattress and pillows that should offer his body the right support. All the same, he simply never wakes up with his back feeling like it has been rested:

I toss and turn most of the night, every night, every time because my body doesn't feel right, doesn't feel comfortable. (Martin Journal)

This situation is made even worse if Martin is not sleeping at home. A work trip or a holiday is guaranteed to mean an uncomfortable bed, a bad night's sleep, and more pain. So, while Martin would love to wake up one morning and not feel some part of his spinal region aching, the thought is more wishful thinking than attainable reality.

Each of these examples shows how the sleeping body lies at the heart of everyday life with illness. The basic need to sleep underscores our lives, and bodies that need to sleep more simply do not fit in with the demands of modern life. As such, they present themselves as things that demand care, that are frail and difficult to manage, forcing a divide between mind and body in which the body is resented and people made to feel less able.

## *Conclusion*

Eating, exercising and sleeping each highlight the significance of the body in everyday life. By looking at what happens to these usually taken for granted processes when illness is present, it becomes possible to trace the ways in which illness restructures our lives through its influence and demands on the body. Shifting our attention from what illness is to what bodies do allows us to understand how illness is transported from bodies into the social world and gives us a tighter fit between the body's social and physical dimensions. It also reveals a very different picture of what living with illness is like. The rhythms of eating, exercising, and sleeping reveal and hide the presence of illness, showing us that bodies are both vulnerable and strong. These bodies are not lesser, incapable or mute, repressed or restricted by illness. Instead they are bodies with voices and they demand our attention and care.

The rhythms of eating, exercising, and sleeping show us that the abstract, quantitative time on which everyday modern life is modelled, and on which aspects of the everyday, from work to the hours of sleep and waking, meal-times, and the hours of private life (Lefebvre and Régulier 2004: 73), is not bodily rhythm. As Lefebvre and Régulier suggest, this model of time sooner or later gives rise to the dispossession of the body (Lefebvre and Régulier 2004: 75). This dispossession might also be thought of as Leder's absent body, and what we have come to understand as the normal status of our embodied lives; lives in which we take our bodies for granted as they silently perform their duties. By contrast, in illness everyday life is shot through with the vital rhythms of bodies. The body is no longer a passive

instrument and we are forced to pay attention to the rhythmic movements of the body itself. By examining these movements, it becomes possible to grasp the commonalities between bodies, regardless of medical diagnoses or categorisation. And, while medical regimes, medications, and hospital visits all become a part of everyday life with illness, examining rhythm shows that there are more basic everyday patterns to illness, and that it is in these patterns that illness, bodies, and social worlds become entangled. Through the common needs of bodies to eat, exercise and sleep, we can begin to understand the significance of routine, control and care, and the role of these rhythms in defining our different ways of being.

Ill bodies demand a particular predictability and structure to the day. They need a routine, a particular time to wake up or to eat, or a time dedicated to exercising. These are things that all bodies need, but they take on a special significance for ill bodies. Meghan's morning routine, captured on video and presented in the film that accompanies the thesis, vividly shows how exercise and diet are interconnected in a ritual of care that is dependent on a good night's sleep. This routine, which begins with several yoga sun salutations and ends by drinking a glass of water with freshly squeezed lemon, keeps Meghan busy for an hour every morning. Through attending to these needs, people are brought closer to their bodies. They learn to listen to their bodies so that mind and body can work together in order to mitigate the effects of illness. But routines are hard to keep and structure is not always desired; they can make bodies feel dependent and regimented. Illness and the apathy that can accompany it, which makes managing time difficult, can also drive people to ignore their bodies, and to deny for a moment the presence of illness. When so much is unclear, and when the preventative measures that are taken are not

guaranteed to be effective, the temptation to feel distant from illness and from the body that it resides in is easy to understand. It is hard to accept that bodies are faulty and that sometimes we have no control over them, and continuously looking for cause and effect patterns, answers, and solutions when there may not be any is ultimately frustrating.

As such, rhythms reveal the shifting nature of illness and of bodies, from presence to absence, and acceptance to denial. But denial is no resting place; a long list of things threatens those who do not take care or keep good control. Blindness, kidney failure, or heart attack all pose the risk of a more certain outcome for the body. There is both sadness and joy in the awareness that we have of our bodies. As Anwen wrote:

I've been thinking that there are some stories I could be telling but that I'm not. There are times when I feel that the daily peculiarities of my illness, its chronic-ness, dominate my life to the extent that everything else seems to hinge upon them. It's like walking around with a gaping wound. Then everything calms down, or you force it to so that it doesn't make you mad and/or bitter and so you can get on with things without the drama. In the calm periods, I don't want to relate those things so much because A) I'm calmer and I don't need to so much B) I'm calmer and they seem boring C) They seem boring because they're the same things happening over and over D) I'm afraid that if I talk about them I'll get worked up all over again and tie myself up in knots of frustration. (Anwen Journal)

While listening to bodies can be tiring, frustrating, and saddening, the act of listening also illuminates the trust that we put in them and the positive relationships that we can build through caring for them. Being ill gives us a reason to take care of our

bodies and to protect them, providing the justification we need to do simple things, like spending money on a massage or taking extra time in the shower. Instead of seeing illness as the body letting us down, responsibility is transferred and we invest ourselves in being healthy so that we will not let our bodies down:

Yes, sometimes I think, actually I'm probably so much healthier now that I have this, because, it gives you permission to look after yourself. And, for some reason looking after yourself, it seems so simple but it's so hard, and not just the logistics of it but mentally accepting that. I think it's taught me a lot too about taking responsibility, because, I think, you know it's so easy to wish that somebody will come and take care of you, and that you can just abdicate responsibility for yourself, and it's so easy to get caught up in those fantasies I think, no matter how independent you are, but this is something that has finally made me say, ok I have to take responsibility for myself.

(Meghan Interview)

This transformation of illness, performed by and through the body, forces us to question what concepts of health and illness really mean. Body rhythms show us that it is possible to be both healthy and ill at the same time, and that the structures and practices of everyday life are made and re-made by bodies that realise their own self-managing strategies and create new rhythms of life, and that choose to live free and make their own choices, even if there are consequences to pay.

## CHAPTER 4

### *Bodyscapes*

This chapter explores bodyscapes – the internal worlds of our bodies, the external environments they inhabit, and the spaces and places they long for – in order to show how physical bodies and social worlds are entangled. It looks at both the structure of the body and the structure of illness, and at the connections between anatomical and geographical space, showing how the body is in dialogue with itself and with its environment. Each section presents different fragments of the body starting with genes and organs, then feet and legs, before finally ending with hands and hearts. Traversing these corporeal scales we move through the spaces of the body and follow the moment of the body through space, tracing illness from its material roots within the body to its social permutations in the world. The chapter reveals the ways in which illness permeates the skin and bodies navigate everyday life in spite of their differences.

Our spatial exploration of the body starts from the inside. How do the interiors of our bodies structure and influence our exterior surfaces and identities and shape our daily lives? How do the inner workings of our bodies, the circulations of blood and the flows of air, affect and betray us? *Genes and Organs* traces the transmission of conditions from their origins in defective genes and malfunctioning organs to everyday life, and looks at how these interior landscapes of the body are kept hidden and made visible. To start with genes and organs is to start by thinking about where illness originates in the body. Isolating the physical source, we can begin to trace the

transmission of illness through the body, from its biological existence to its affective material and social qualities. Entering inner bodily space, which is usually hidden from vision and immediately detectable only by the body itself, we begin to expose the social and material entanglement of body, mind and illness.

Moving from the interior to the exterior, our exploration of the body continues with *Feet and Legs*, body parts that, as our connection to the earth and our way of physically navigating through the world, are perhaps our most direct link to the external environments in which we live. How do our feet and legs, as well as the shoes and canes that accompany them, connect us to, negotiate us through, and redefine how we know the built environment? How do our bodies redefine the topography of our worlds? This section considers the importance of these seemingly simple body parts and the influence that illness can have on the ways in which we move, dress and travel.

The final section of this chapter, *Hands and Hearts*, considers the emotional connections between hands, hearts and minds. We regard our hands as commonplace and self-evident members of the body (Pallasmaa 2009: 25-26), but they often hold more significance than their physical presence first suggests; “Even the hand has its dreams and assumptions. It helps us understand the innermost essence of matter” (Bachelard 1969: 137). The examples in this section illuminate the meanings hidden within our hands and take them as starting points from which to re-imagine the body’s connections to the mind and to the world. In the end, the spatial imagination of the heart illuminates the ways in which our bodies truly define our being in the world.

## *Genes and Organs*

The presence of illness drives our need to understand our bodies. When a part of our bodies no longer works or causes us pain, we seek answers to tell us why. But finding out what is wrong is not always a simple or straightforward process. Sometimes answers do not exist and when they do they do not necessarily provide a solution. This is especially true in the case of chronic illness, which often challenges medical expertise, can take years to diagnose, and habitually defies treatment. While, "...it's so easy for people to believe there's like a solution for everything in a way, ok you're blind well just get a dog and then everything will be ok, oh you're in a wheelchair just start going to church, Jesus will save you," (Meghan Interview), in reality we cannot always solve our problems or cure our bodies. But we can develop tactics with which to look after them.

We can, for example, learn the particular warning signals that our bodies send out. An asthma attack begins with a whistling, wheezy sound originating from Nell's chest, and a tight feeling in her shoulders. You can tell when her breathing is getting bad by the way her shoulders start to heave up and down as she struggles to get oxygen into her lungs. Her chest starts to feel hot and raw, and she can feel the pockets in her lungs fighting really hard as they begin to close up. The lack of oxygen circulating in her body means that her teeth start to hurt and her head begins to ache. It gets worse, and worse. Nell takes her inhaler, presses it, breathes it in, and hopes that in a minute it will all go away. Up to this point Nell's actions follow a routine procedure. The wheezing is Nell's warning signal, telling her to watch out for asthma,

to take care and to use her medication. Up to this point, the attack does not frighten her, because her body is telling her exactly what is happening inside. But if the inhaler does not dispel the wheezing as it should, the attack will continue, and it will get worse. This is the point at which asthma becomes frightening. All of a sudden Nell will feel really weak, her chest and her head will start to hurt even more, her muscles, strained from the effort of trying to breathe, will begin to ache, and she will have to reach for the phone and call the emergency services. In this moment illness is transported from the safe interior of Nell's body to the outside world, transforming itself from a quietly sleeping beast to a life-threatening predator. Nell listens for these signals on a daily basis. She is equipped with a peak flow, with which she can measure her lung capacity, and with two different inhalers, two medications that she takes each morning, and four medications that she takes each night. Her symptoms, equipment and medication are shown to the camera in her video diary, which is included in the film that accompanies this thesis.

Kim knows that her epileptic seizures tend to happen in the evening. As a child, they only ever happened when she was asleep, when she did not know what was happening and could easily lose consciousness without realising, where there was no one to see or to help. They can last from a couple of minutes to three and a half hours, on and off, and are preceded by a ten second to five minute warning. The warning is what people classify as an 'aura'; it is different for everyone and no one else would be able to perceive the signal. In Kim's case, it is a slight loss of control of her arms; they start to snap, and then she feels dizzy and just knows that something is not right. When this happens she has to lie on the ground. But, once a seizure starts, that is it, she is committed for the long haul; it is a case of sitting through it because

there is simply no way to stop it. Her arms stiffen, her head is thrown back, and she loses control of her body. There might be small breaks between moments of seizures, but there is no way of knowing how long the entire episode will last. It is exhausting, and the more tired Kim gets the harder it is to control. Perhaps the worst aspect of the seizures, worse than actually having the seizure itself and worse than the horrific bruises acquired as her flailing arms hit the walls or the ground, is the look of panic on the faces of those who witness this event. During this time Kim can hear everything that is going on around her but is unable to speak, to tell them it is all right and do not panic; there is nothing you can do. People close to her now understand and know what to do, but sometimes people will try to hold her down when she should not be held down, or they will call an ambulance and she will end up spending the evening in the local accident and emergency department.

Learning these warning signals and developing an awareness of the body's needs involves developing a physiological understanding of how bodies work. Martin's awareness of the muscular-skeletal structure of his body has changed in response to living with joint hypermobility syndrome, so that over time he has learnt about muscle groups and how they interact, and Anwen has tried to learn as much as she can about Miyoshi-type muscular dystrophy, so that she can understand what is happening to her body:

I have to understand it as much as I can. It's a difficult thing to understand, without going and doing a lot more serious reading, I remember that at one point with my reading I had to open the medical dictionary at every other word. When you're trying to understand things on a molecular level it's impossible, it's impossible for me to understand that but it's important for me to try and understand what the condition

actually is, and to get an idea of how much I don't know, if anything. (Anwen Interview)

Through the process of knowledge acquisition we give attention to the body and identify and isolate the source of illness within it. Illness becomes attributed not to a failure of the body but to a single malfunctioning body part, a part that unlike the rest of the body is incapable of rejuvenation or repair:

My pancreas - that's the main thing, that's the part of my body that's been sick. Because other things, they break, and they fix, they come back, you cut yourself and the skin heals back, but that is sick, it's not working, basically. (Matt Interview)

By identifying a malfunctioning body part the mechanism of dualism is brought to life. The body becomes re-known as a series of interconnected but distinct functioning and malfunctioning parts, and we learn the value of their individual functions, status, and relations. Once a part has been isolated, we can attribute illness to the invader that feels like it has taken home inside us:

I feel it's invaded my body. I don't resent my body; I resent the diabetes in my body. Yes, I do think it's very separate. I resent my pancreas a hell of a lot, it's obviously working in some way but it did fail me. (Imogen Interview)

The body becomes a fortress under attack, infiltrated by an illness that is in the body but not of it. The presence of the invader, the attack on one of our vital parts, forces the rest of the body to work harder, and the knowledge of what our bodies are coping with makes us more aware of their vulnerability:

The one thing that has made me really aware of my body is the fact that one thing goes, one part of my pancreas goes, and everything else is fucked; you have to work

twice as hard. There's an absurd statistic for diabetics about cigarettes, which is that for every cigarette a normal person smokes, that's like smoking five for a diabetic. Your body is constantly overworking. (Imogen Interview)

The shifting interconnections between this tripartite assemblage, made up of mind, body, and illness, show how illness fragments the body. Illness is both within the body and separate from it, and, while it is always there, its presence fluctuates depending on how obvious it is at any given moment. This shift can depend on how we are physically feeling on a particular day, and it be activated by our social relations and actions. The question, 'How is your arthritis?' for example, seems to identify Meghan with her joints. Not seeing her rheumatologist for some time, in contrast, makes her feel distant from the arthritis.

Identifying and isolating illness within the body means that it is an invisible, hidden secret that can be kept private. Many conditions have no externally visible presence and those that do exist, such as bruises and injection marks, can be disguised or covered. This means that on a day-to-day basis no one needs to know, no one can tell, that illness is living inside our bodies. But illness is affective, and as it travels from its interior and invisible source into the outside world of everyday life, it becomes harder to hide and to separate from the rest of us. When meeting a friend for a coffee, Meghan might let slip that she is feeling tired. This can easily backfire, as for example, when her friend with a two year-old daughter retorts, 'Why are you tired? You don't have a two-year old!' Similarly, a work colleague has started to think that she is a hypochondriac due to her frequent verbalisations of malaise. Meghan understands that these mischaracterisations are not other peoples' fault; after all she hasn't explained the background or the context of her remarks, that feeling tired, run

down, and swollen are the symptoms of her condition and her everyday reality. At the same time, it never ceases to amaze her how people can assume that because she is young and single she should be out having fun, drinking and clubbing and staying up until four in the morning without feeling any the worse for wear the next day.

As illness moves beyond the body and is rendered visible, it affectively becomes a source of social stigma. Asthma inhalers and insulin injection pens stand out and announce the presence of illness. These material signifiers can be construed as signs of weakness and experienced as sources of embarrassment. As a child, Nell would wait until she was in a place where she could hide and take her inhaler, suffering a little bit more in order to avoid the glances of others. Even without such obvious physical markers, the question of whether other people notice or can tell that illness is hiding inside us lingers:

I wouldn't tell people. I haven't put myself in a situation where people would know...I just don't believe that people won't make assumptions...I might be kidding myself, maybe people do realise... (Anna Interview)

But I wonder whether people don't notice, I'm sure people must notice. There are times when it feels like it's this blaring siren on top of my head. (Anwen Interview)

Whether or not they can guess, there are times when we want to let people into our worlds and to do this we need to tell them about our conditions. But telling people can be an issue; it can be hard to find the right time, people can be a bit standoffish, which is upsetting, and often they are shocked; because you look perfectly healthy from the outside they just do not expect it. You never can tell how others will

respond or what assumptions they might make. Even doctors can make the wrong assumptions, reinforcing a negative stereotype of illness:

I went to the doctor a few weeks ago with something completely physical, and it was a locum, I'd never seen him before. I think he must have flashed up my record and seen 'depressive episode', and all he talked about was, was I feeling ok, was I active, was I socialising, totally focusing on my mental health. It feels like a really dangerous label, a filter through which he's seeing me. (Anna Interview)

Ultimately, it is not our bodies that take issue with illness; they can learn to live with the conditions that they face. But society places a high premium on the healthy, fully functioning body and singles ill bodies out as different, making them feel like they do not fit in:

Do I want to get away from it? I want to get away from the things that make you very conscious of your body in society, but I love my body when I don't have to wear anything man-made, and by that I do include injection kits, and clothes, and all of that. I feel very comfortable with myself when nothing else is there. It's when everything else is there that I feel very aware of it; it doesn't fit in right, it's not quite there, I have to use things to make it do what I'm told it's meant to do. (Imogen Interview)

It is impossible to escape the fact that the public realm is a place reserved for healthy bodies, and that illness is deemed a wholly private matter. Imogen's encounter on the bus perfectly illustrates the point:

As I sat trying to find a safe (technical term for bit of flesh you feel comfortable injecting) I got uncomfortably conscious of 2 separate people who sat beside me and

behind me. The guy next to me was muttering to himself as he looked at his phone and the woman behind me had a very loud flemmy cough. The man then answered a phone call from his 'sister'. He said 'yeah I'm alright, I'm on depression tablets... gotta go and see one of those quacks that are on Lordship Lane. I'll take 'em but I'm not going.' At this point the woman's cough had got really loud and my instinctive thought about these 2 people and myself as I sat trying to inject and to block out the world was 'you bunch of freaks!' But then I realised it's not that the 3 of us are freaks, but that none of us were hiding our physiological conditions. It's not that as individuals we are freakish but that our confident acts of 'I'm injecting no matter what' and 'I'm "confessing" to depression no matter who hears' and 'I'm gonna cough because it really bloody hurts and I can't suppress it anyway' are freakishly uncommon in the public realm. Our bodies were public something that is usually only reserved for a supposedly healthy physiology. (Imogen Journal)

The significance of our internal bodies is exposed when it means that they resist being defined, categorised, or typified by society. The discovery of gonads, which had previously been mistaken for ovaries, within Xan's body led to a life changing series of events. Things happened rapidly; within a few days of the discovery Xan was put under general anaesthesia and a gonad rectomy was carried out. The operation was performed laproscopically; a tube with a video camera was inserted through Xan's navel to isolate the gonads and tiny one-centimetre incisions were made to take out the inactive material. Tissue that lies fallow in the body is the perfect place for cancer cells to start growing, so it was imperative that the gonads were removed from Xan's body.

Aside from having to come to terms with the fact that she is infertile – IVF and adoption are both possibilities – and getting used to her new body – because hitting

puberty in your twenties takes a bit of getting used to – Xan has grown into a happy, healthy, woman. The HRT that she takes is easily mistakable for the contraceptive pill, something totally normal for a young woman to take. The scars from her operation have faded in time; they are miniscule in comparison to the six centimetre railroad appendix scar left from an emergency operation in a rural hospital in India when she was eight, a scar that has grown with her, becoming a three-dimensional thing with its own texture. But the surface of Xan’s female body belies her internal biology, and Xan knows that being a woman is not quite as simple as it appears. Although she enjoys performing her newly discovered femininity – finding a different way of carrying herself, a different way of walking, buying new clothes and wearing makeup and high heels – the question that remains fundamental to her is, “I have XY chromosomes, and if everything went to ‘plan’ then I would have been a man. How do you feel about that?” (Xan Interview).

She cannot forget this question; it has been a defining aspect of her life. Conforming to society starts at an early age, and Xan had already decided that she was a woman and figured out what that meant, at least for her, before she found out that her biology was telling different stories. But she is also aware of the ways in which her biology has affected and will affect who she is, in different and telling ways, and there are still parts of her body that she does not understand, and that are changing beyond her control. She does not know, for example, what is going to happen to her body as she grows old. HRT does not just make Xan more feminine. Her body needs the hormones in order to maintain basic stability, to solidify her bones and to nourish her hair and skin. If she stopped taking her pills she would, in effect, become a post-menopausal woman – and these are the women her pills are

designed for, women in their fifties who will only need to take the treatment for a few years to assist them as their bodies change. Because HRT is only intended for short usage Xan does not know how it will affect her in the long run; it is possible that she might age differently to other women, and that at some point she will have to stop the treatment. These questions and fears are captured on video in an intimate conversation between Xan and her boyfriend, which is included in the film that accompanies this thesis. Hidden behind a book, Xan's boyfriend uses a camera phone to look back at the video camera while she asks him a series of uncompromisingly honest questions: What do you think about my body? Do you think it is unusual? Do you think it is different? How do you feel about the fact that I'm intersex? How do you feel about the fact that I'm barren? These are questions that cannot be ignored.

The internal parts of the body, a fallow gonad, chromatic structure, failing pancreas, defective gene, narrowing bronchi, or electrochemical impulse, each show us the significance of our biological foundations. Hidden inside the body they speak of the importance of invisibility; these are the private conditions of our lives, ours to keep secret if we wish. But as distinct and malfunctioning parts they also speak of fragmentation. Through their substantive failure they disrupt the interconnectedness of the body, allowing illness to affectively leak out of our bodies and into everyday life, and, as our interiority flows outwards our bodies no longer seem natural or normal; instead we are made to feel socially out of place.

## *Feet and Legs*

The revelation that she can be in touch with her feelings through her body really surprised Anna, because in some ways she has always tried to pretend that she did not really have a body. Now, when she is feeling anxious, floaty, or groundless, she will allow herself to stop and catch her breath. Placing both feet on the ground, she can feel her feet being connected to the world, and it is just amazingly helpful to feel the solidity of this physical attachment. She will breathe deeply into her belly, calmly, counting her breaths, really filling her belly up. And as she breathes she will try to feel how and where her anxiousness is manifesting in her body: the tightness in her chest, the trembling, her face turning red. She goes through each part of her body, identifying where the anxious feelings are located and pinpointing them. Then, when she knows each physiological expression of her emotion, she will imagine a stillness in her belly, so that the very centre of her being becomes a still, big, solid, safe place. As Anna slows her heart rate down and makes herself big and solid, she envisages her body as a vast landscape, a really big Antarctic wilderness or an Alpine mountain range, a place so big that nothing could undermine it, and in this way she is able to establish a non-threatening connection to the world through her feet. Any bad feeling can be overcome using this technique that suspends the chain of thought, stopping thoughts from being piled onto emotions, and instead locating feelings in the body, where they can be felt and stilled:

Second panic attack yesterday, I somehow 'caught'; suddenly had an insightful view of myself and saw I was shaking & cold, nauseous, remembered to allow myself to feel

what was happening in my body. To place both my feet on the ground, breathe slowly, acknowledge this trembly, frightened feeling in my chest and gut, weakness in my hands. Then I visualised an immense landscape. Somewhere like the Alps or Antarctica, a place I always visualise when I remember to do this. The place is wild and uninhabited, somewhere I would feel safe from other people and where my anxieties are neutralised and scaled down. After doing this exercise (or meditation) I went into the meeting that had triggered these feelings. I felt completely calm and safe, nothing the people might say or do could harm me - it's as if the immense landscape is internalised, is actually me beyond my anxieties. (Anna Journal)

Slowing her breathing and grounding herself through her feet, Anna uses her physical connection to the world to help her cope with depression. For others, the felt connection to the world that feet provide plays the opposite role. For Martin, they provide a painful reminder of the presence of his condition:

6.39am Arrive at station, walk to Tube station. Good to get some walking in the morning, although the shoes I wear make a big difference to comfort levels. The combination of plastic orthoses and smart leather office shoes makes my back judder with each step. Not always noticeable, but when I stop to think about it, it feels like its not helping when I walk. As a result I tend to wear (where I can get away with it) trainer/pumps; a little like women wearing trainers instead of heels to commute, only a little less dramatic a change. (Martin Journal)

Martin's feet are a site of experimentation on which different insoles and shoes are tried out in an attempt to counter pain. Like Martin, one way in which Meghan is made aware of her condition is through her feet and her choice of footwear. In her video diary (included in the accompanying film), Meghan recorded two pairs of

shoes – a comfortable pair of pumps and a beautiful pair of high heels – that evidence the constraints arthritis places on her love of walking and her love of fashion. The arthritis, which has spread from her hands to her knees and feet, means that wearing comfortable shoes is important. But, while she tries to be nice to her feet and not squeeze them into shoes that are uncomfortable or that hurt, sometimes she cannot resist the attraction of a pair of high heels. Shoes are just one item of apparel among many that can become signifiers of the presence of illness, compromising our choices and tastes through the unwelcome social signals that they send out. Meghan's father once bought her a magnetic bracelet, which was supposed to get rid of pain when she wore it:

And I wore it for a few times, but it wasn't that attractive and I felt I had to draw the line somewhere, although I'm in to alternative medicine and believe anything could work really. I just felt funny wearing it, as if everyone who saw me wearing it knew that I was wearing it to get rid of pain... (Meghan Video Diary)

Having to regularly inject into her legs has left a mark on Imogen's body. Injection sites leave visible lumps and bruises, and she now feels uncomfortable wearing summer clothes that will reveal these marks of illness:

I've got lumpy legs from it; I can't stand summer because I'm so aware of it, if I go into the sea or something, here are my bruises. (Imogen Interview)

Having diabetes creates practical, as well as emotional, relationships with clothing. Imogen has to carefully consider what to wear before she goes out on any given day. The need to inject throughout the day means that she needs to be able to access her leg or stomach, and the question of whether there is a way of injecting with any

decorum is one that she often faces. While injecting is very discreet, it took Imogen five years to stop feeling uncomfortable and conscious about injecting in public places. If she is wearing a dress or a skirt she might be able position the fabric like a pair of shorts, but if that is not possible then she will have to search out a toilet to provide some privacy:

The only thing now is, like today, I'm wearing a dress and it can be a bit difficult, having to find a loo can be quite frustrating. There's always an element, like it's a bit scummy having to do it in the toilet. (Imogen Interview)

Injecting insulin is a daily event for Imogen, and so she recorded it on video for the project. The moment is included in the film that accompanies this thesis, the camera held close as the tiny needle is inserted into Imogen's skin while text from her interview highlights the discomfort that others can feel – and cause – if Imogen injects in a public place:

“Do you have to do that here?...When you inject it's very discreet really, it's into the belly, and quite frankly my attitude is that if someone doesn't like it then look the fuck away, because I can't look away, I have to put it in my body... I said, 'But it's not like I'm injecting heroin!' and she said, 'Well really what's the difference?' Where do I begin with that?” (Imogen Interview)

The injection kit, which is contained within a small black case, has become another material fragment of Imogen's everyday life. More domesticated object than medical instrument, it is always with her, both physically and emotionally:

The injection pens that you use are amazingly, you know, they look like a pen and the needle's tiny, I mean it's smaller than your finger tip, so I feel that it's a very

domesticated thing and I do feel like the pens and my blood test, I keep them with me, there's an element of... However small it is, psychologically it's a lot bigger than a little purse. It's a very frustrating thing. I feel attached to it, I have to know where it is; I don't leave the house without it, ever. These things are always, always on my person.

(Imogen Interview)

The attachment that Imogen feels to the kit demonstrates the significance of this small object, which has in a sense replaced the function of her pancreas. Her body, and her life, is dependent on it. The kit is always close to her, not a part of her body but a part of illness, an ever-present reminder of the dependence and fragility of her body.

Muscular dystrophy is slowly taking Anwen's legs away from her. At the age of thirty-one, she has now lost most of the muscles in both her legs, including her gastrocnemius, the anterior of her lower legs and her quadriceps. Each time she loses a bit of her body, Anwen has to find another bit to take over. The worry is that the more the disease affects her body the fewer bits there will be left to compensate. When she first started losing her calf she fell quite a lot. These are the really scary moments, when she does not know if her body is going to find a way around the latest loss or not. But once she got used to not having the muscle in her calf she found that there were other strong muscles in her legs that could take over. Now Anwen can still walk, even though the condition has taken out her quadriceps, which means that putting weight into a bent knee is impossible. She uses her core strength and each time searches to find the adjustments that will work, making gradual changes to the way that she moves and finding ways to get around the problem. It is doubtful that, if somebody who had normal legs suddenly had Anwen's legs, they would be

able to walk at all; it would be like learning to walk all over again with prosthetic legs, because essentially that is what they are now:

My legs really are like prosthetics, in a way, not to insult them or anything, but in terms of how I use them. (Anwen Interview)

It is hard to say how apparent Anwen's condition is to the outside world. She is young, attractive and fit, but she also walks awkwardly, has really thin legs and uses a cane. The cane itself is an elegant specimen of blond maple wood with charred stripes, nothing glamorous but a solid and essential companion. The idiocies of the well-meaning but insensible, the romantically inclined and the just plain rude have included enquiries as to whether there is a reason for it and asking whether the cane is a fashion statement. Even neighbours who do know Anwen can be ridiculously inconsiderate, chaining their bikes to the handrail and making it impossible for her to negotiate the two steps down and one step up into her flat. The camera wobbles as she records this entrance on video; she needs both hands for the step and has to walk right over the mail, which lies scattered across the doormat.

The inconsideration of individuals is however matched, if not exceeded, by the kindness of strangers. Last year Anwen went through a phase of falling a lot. In fact she got to a point where she would catch a cab somewhere, get out, and hit the pavement. Falling itself happens so suddenly that it is hard to know what has happened: caught at the wrong angle her ankle will collapse like a puppet, and she will hit the ground really hard, and really fast. People who witness this might think that she has had a heart attack, because it simply does not make any sense, it does not fit into anything that anyone is used to seeing. But each time she fell there was someone there, instantly, offering to help, offering to call an ambulance and trying to

assist her back up to her feet. This is no mean feat, because with no leg strength Anwen cannot use a helping hand to pull herself up. Further panicking and confusion will ensue from both Anwen and the unsuspecting stranger as she attempts to explain her condition, that she is not trying to be brave, that she really just cannot get up that way, before she finally manages to lift herself up using her hands, with her legs carefully balanced underneath her and using whatever solid object is available nearby to her advantage.

The soles of our feet and our legs are the starting points with which we relate to the broader environments in which we live. The surfaces of the body bring us into contact with the surfaces of the world, highlighting points of connection and of disjunction in our everyday lives. Through the individual needs and restrictions of our bodies we develop particular relations to the environment. In Anwen's case this means that she has developed an intimate knowledge of her local neighbourhood and how to navigate through it:

It's my everyday reality; how can I safely get about the place and maintain my independence, my sanity, and all the rest of it. I know my environment in great detail and how to move through it; with new things I make an educated guess and I never take stupid risks. So if I've found a way better than a wheelchair, I believe I deserve respect for the amount of strategic thought that involves, as well as the accomplishment of staying out of one. (Anwen Journal)

Anwen knows exactly where places are, where to get coffee or a sandwich, and how far they are from the other places she needs to be. It can be hard to eat on the move, and if she thinks it is going to be a problem then she will eat at home before going out or wait until she gets home again. She uses the same strategy with transport. She

knows the distances, the obstacles, how tired she is likely to be and when. And, if she gets tired, then she has to make do with the closest option. For Anwen, these measures are a way of living independently. But other people, family and friends, can get frustrated that she moves slowly, or with the limitations of how far she can go and where she needs to stop. They have suggested that it would be easier if she were in a wheelchair. This suggestion highlights the tension between Anwen's body and social expectations of it. Once again, the problem of illness is transported beyond the physical boundaries of the body.

There are many things for Anwen to watch out for in the streets: uneven, narrow pavements, prams and their militant drivers. Everyone else in the street moves too fast, and it is not obvious to them that Anwen might fall if they touch her only slightly:

I walk carefully, slowly. A few weeks ago as I slowly and carefully crossed at a zebra crossing, the men in the waiting car furiously honked at me and yelled at me from the windows. The man in the passenger seat had such an ugly face. Sometimes I don't go out because it has become too frightening and too much hard work dealing with people - asking for a seat, asking people to move, needing help up off the pavement.

(Anwen Journal)

It would be easy not to bother, which is one way of dealing with it. Anwen is able to work from home and can do her grocery shopping online, so there is not that much need to leave the environment that works for her. Sometimes she cannot be bothered to walk down the hill from her flat to her local shops, not because it is difficult, but because it will take so long. The daily interactions with people that she faces when she does go out do not make it any more appealing. The man furiously honking his

horn at the pedestrian crossing or the people on the bus who do not think to give up their seats make the outside world an ugly place:

Some people can take one look at somebody with a cane and just know that hills and stairs are or could be a problem, and other people, I don't know what they think canes are for, I don't know what they think is going on. It's like people who don't give their seats to old ladies, things like that, what do they think is going on there? They've just got no concept. (Anwen Interview)

Despite these difficulties and dangers, Anwen does not feel trapped by the things that limit her. In her video diary (which is included in the accompanying film), she contemplates the steep metal staircase that leads from her flat down to a communal garden. Stairs pose a problem for Anwen, and she rarely risks the descent to the garden. But she has always found them really beautiful, ever since she was a child:

I think stairs are really beautiful. I always thought stairs were pretty great, ever since I was a little kid. I grew up in an area where it was pretty flat, and we never had stairs in our houses when I was a kid, except for the house when we lived in the Northern Territory - all the houses there were on stilts, for cyclone reasons. But most of the houses in Perth, Western Australia, all the other houses I lived in, they didn't have stairs. So when I was tiny I used to get really excited by stairs. And of course even now I see places that have got a spiral staircase in them, and I snap out of my usual attitude, which is oh fuck, a set of stairs, and think how beautiful they are, how nice they are. (Anwen Video Diary)

Anwen's attention to the politics of priority seating on public transport is shared by others who also depend on their feet and legs to move through public space. These seats highlight the ignorance of society, but they also symbolise disability. When

Kaldon's arthritis is aggravated, especially if it is in his feet, knees, or hips, he would love to be able to sit down on the tube. But he would be too embarrassed not to give up his seat to the people who more obviously, more visibly, need priority seats. The day Kaldon does not give up his seat, or, even worse, takes the seat of another, is when he will feel as though he has lost. So, despite the fact that getting on a crowded tube is likely to strain his arm or pull it in the wrong direction, so that pain cuts through and he loses his grip and falls, and that he always notices his knees going down the escalators to the tube, morning and evening, he will not give in. Being out in public spaces means that Kaldon is at risk of getting caught out by his arthritis. His knees can give in on a simple shopping trip or his foot might start hurting out of nowhere and cause him to limp. It is embarrassing to be limping down the street, and, more importantly, there is that nagging fear asking how long it will last. Seemingly mundane instances like these illustrate how the internal movement of illness leaks out as the body moves through space.

For Martin, however, it is the very need to sit on the daily commute to work that causes his body problems. The journey – recorded on video and included in the film that accompanies the thesis – begins with a cycle to the train station. At 6.04am he gets on his usual train and on his usual carriage; commuter heaven or commuter hell, depending on how you look at it. The train service is excellent, the problem, though, is the design of the seat. It simply is not comfortable, and it causes Martin pain. He can slouch, which is initially more comfortable, but the pressure required on his legs to support his weight, subtle as that is, is sufficient to cause a throbbing in his hips and glute muscles which then lasts much of the rest of the day. Or he can support himself with no backrest. This is much better posturally, but before long it

makes his mid-back ache like mad. The last option is to stand, which he does sometimes, but not often. The journey affects Martin's hips every morning, so that by the time he gets off the train at 6:35am his body is already throbbing in pain. It is a journey that always seems to hurt him in some way.

Driving a car, airports and aeroplanes all cause similar problems for Martin, making getting about in the world a difficult and painful process. Airport chairs rarely offer back support, and travelling on business trips involves lots of walking in uncomfortable smart shoes. It does not get any better once he has boarded the plane:

Now time for my 6am flight to Zurich. Only 90 mins, and I fall asleep, but the damage is done. It is, frankly, impossible for me to sit on an aeroplane seat in comfort. They force you to slouch, basically. Sometimes I sit cross legged (yes, correct!) on plane seats with shoes off. I'm small enough to do it. I get odd looks but I don't care if it helps ease the discomfort. Looking a bit odd comes with the territory. Maybe I'm a bit eccentric anyway, but I will often stand and stretch my back, legs, neck, wherever I happen to be, especially when travelling. (Martin Journal)

Other, simpler, everyday discomforts include sitting on a park bench or a wooden chair. At home in the kitchen Martin has a cushion on his chair for comfort. He admires how his children can sit on anything with perfectly pain-free backs; he was like that once.

Moving, walking, and sitting, bodies encounter obstacles and negotiate their own ways through the world. As Fraser and Greco (2005: 27) write, the material fabric of everyday life seems to be designed in order to put bodies on display. Social space engenders the public consumption of bodies and conspires against their material flesh, changing the topography of our worlds by making our bodies feel

materially, as well as socially, out of place. Plastic orthoses, injection kits and canes draw our attention to the material discomfort of our being in the world. These objects highlight the needs and the deficits of our bodies, which are dependent on them. But they also show how, through constant adaptation, we compose new ways of being. By keeping these objects close to our bodies and incorporating them into our everyday lives, we form new partnerships that help us to overcome the presence of illness and allow us to navigate new ways through the world.

## *Hand and Hearts*

In the video diaries made for this project, hands feature more than any other body part. Fingers point out bruises, apply medications, and toy with pills, nails are painted, and objects are held. Holding more significance than their physical presence first suggests, hands perform acts of care, enclose pain, and symbolise strength, and, in this final section, they speak of the interconnections between mind, body and world.

Anna trusts her hands. Focusing on her hands in her video diary (which is included in the accompanying film), she shows her confidence in them to the video camera. Her hands can draw and play musical instruments, they are sensitive to textures, and they are strong and flexible. She does not have any of the same doubts about her hands that she does about her mind and its thoughts. She never thinks twice about their ability to do things, and they do not seem to suffer from anxiety of self-hatred. She imagines that if her mind were as reliable as her hands then things would have been a lot easier. Unlike her mind, Anna's hands just get on with things, without worry or doubt. Her thumbs are even a source of comfort and self-assurance, something to hold onto when she is feeling anxious. Like her feet, Anna's hands provide her with a sense of her material presence in the world. They are symbolic of her whole body, which stands in polarity with her mind. But this does not mean that her body is unshakeable. There are days when Anna feels like she has no skeleton to hold her together, days when she feels like a jelly that will wobble any time someone sneezes or breathes heavily around her. It can feel like even light criticism will

demolish her, like a badly built house in strong wind. On these days her sense of not being good enough is expressed in her body's shakiness and tiredness. This visceral anxiety, a shift of bad feelings from her mind to her body, hints at a connection between the two. It is not simply that Anna's mind is weak and her body strong. Depression runs through her entire being, affecting both mind and body. But there is a difference between these two parts of herself, and the difference is trust. When Anna's thoughts drive her round and round in circles and drive her to delusions, she knows that her mind is being destructive and unhelpful, that it is getting her into trouble. But when her body throws her into the state of panic, it is not lying to her or trying to trick her. Instead, it is telling her something she needs to know. So Anna has come to rely on all her physicality to save her, and, she knows that her body has the power to transport her away from depression.

In her video diary Anna also recorded a short clip of a ruined old house, for which she wrote the accompanying note:

The point is it looks how I feel, or rather how I felt yesterday, like a horrible old house with grumpy monsters inside it bashing their heads against the walls. The monsters are responsible for the ruined state of the house, as I feel I've somehow chosen to be like this – if only I could make better choices, do things more constructively, if only I really wanted to be happy I could be. I feel cross with myself for making things like this. (Anna Video Diary)

On the days when she feel like this she knows that she can get out of her real house and go onto the common. Looking at the trees and the distant places, the external things that are bigger than her, things that are solid and immune to ruminations, the bad feelings evaporate. Faced with the immensity of the landscape, whether a real

London park or an imagined Alaska or South Pole, anxieties become scaled down, neutralised, unreal. Depression has influenced Anna's life in every way, and that is probably the most depressing thing about it. It has held her back and restricted what she has felt able to do, and her constant checking on what she is feeling, managing her emotions and monitoring her body, is a form of training that she imagines is a fairly contrived process. But learning to live with depression has also brought a new, positive, connection to her body: now, she feels that it is her body that can help her, on a good day. So, some things it has taken away and some things it has given her, and other things remain to be reclaimed. But despite all the ways of being in her body that Anna relies on, she still feels an extreme mind body divide in which her mind has precedence. Anna has been socialised to deny her body; that view has been a big part of her background and it is something that continues to be enforced by contemporary culture. So, while Anna knows that it is problematic to think of the mind and the body as two distinct things, and that not everybody in every culture feels that distinct separation, she can not get away from that way of looking at things: she is separate. More than anything, she aspires to not feel that split. But it is almost like she can feel where the perimeters of this territory are, it is just so clear, the barbed wire, and the guard post.

Matt remembers the sensation of the skin covering his hands drying out and cracking as his body, attacked by diabetes, suddenly lost the hydration and nutrients that it needs to maintain elasticity. It was one of the first signs that something was really wrong. Now, his hands are marked by little pinpricks, tiny little dots, which last for a couple of days and then are gone, before new ones quickly appear to replace them. When he gets in the shower or the bath and he looks at his fingers that are

made vulnerable by the water, he can see all the holes. Matt has to check his sugar levels by pricking his fingers. He has been pricking the final third of his finger for four years now, and the skin is starting to thicken out a bit, so he has to search a bit harder to find a little soft spot. These marked hands and the memory contained within them are a reminder of illness. The toughening of the skin in response to the routine of injecting is a private and intimate mark that can be felt but hardly seen.

Meghan's hands also embody her condition, and are included in her video diary and in the film that accompanies this thesis. Some days she is extremely aware of her fingers that feel big and fat and unfeminine. While arthritis has spread to other parts of her body now, her feet, knees, and her neck, her hands remain the most significantly affected. They were the place where arthritis first manifested and presented itself, and they are how she continues to monitor its progress:

The symptoms started 10 years ago; I was 20 at the time. Skin stretched and burned red to accommodate the swelling of my finger joints. Blood seemed to pool in my hands. I walked with slightly clenched fists to alleviate the feeling. I thought this is what it must feel like to trek through the tropics on a diet of too much salt. (Meghan 'Hands')

Meghan's hands are an ever-present symbol of illness, connecting her to her past and to her future. A photograph of her mother reveals an uncanny family resemblance; matching pairs of hands that appear identically swollen. But Meghan's mother does not have arthritis. And the childhood memory of seeing an old woman's rigid, curled, and frozen fingers has imprinted itself on her, as though it knew its own significance was to come years later. Meghan's hands seem to haunt her. It is not that the arthritis incapacitates her, or that it is painful, but that it is always present. It is always, always

there in her hands, making her bodily awareness acute and insisting that she listen to her body:

I've been disabused of the notion that one can control everything, that our human minds can outwit our human bodies. But I know now my body will always do what it wants, I can only try not to provoke it. I can only be kind. And listen, as attentively as I would to a child. (Meghan 'Hands')

Through the ongoing act of listening to her body, Meghan's entire relationship to life has changed:

Despite these physical changes, it's my relationship to time that has changed the most. None of us are promised things will unfold as we wish, yet taking note of the small yet discernable shifts in my body has made me more aware of the small and discernable shifts everywhere. My body, with its hyper sensitive antennae, is always responding, making me take note not just to it, but to the life around me. (Meghan 'Hands')

Beyond the physical reaches of our fingertips, our hearts beat not with illness but with the vitality of life. Our bodies tell us of their presence, but they also tell us of the presence of life. They tune our attention to the details of our material being, to the environments we inhabit, and to the small and ordinary things in everyday life. Imogen's body leads her; if it feels tired then she cannot ignore it, she must really listen to what it is doing. It can make her appear a bit wishy-washy or moany about things, and it can make her seem like quite an ill person sometimes. But during the moments when she feels like not bothering or giving up, her body has other ideas. It tells her that she is not allowed to ignore it, that she has got to continue and do what it needs her to do, so that she can stay alive. Since the age of fifteen she has been

aware of the fact that at some point she is going to be vulnerable, at some point she is going to die, and she holds dear this fact. It has made her conscious of what she is going to do with her life, what is important to her, and what can make her happy.

For Imogen, the dynamic between mind and body sometimes seems like a battle between two opposed forces. Anna tangibly feels the split. But other examples make clear how, in the end, mind and body cannot be separated. Kaldon describes his mind and body as good friends. For almost ten years he has been asking his body ‘why?’ when he is getting off the bus or walking to the tube and one of his joints protests. He is in constant dialogue with his right shoulder, the most affected area, and a part of his body that he uses every single day. They do not always agree, but the shoulder always wins, and the more it wins the less they disagree. The arthritis is a personality in itself, a constant entity that he is catering for and carrying with him, that he is always trying to establish a good dialogue with and trying not to hurt. As soon as he is not mindful of his body it becomes vocal in making him mindful of it. Kaldon’s video diary (which is included in the accompanying film) captures an intimate moment between him and his shoulder as his fingers apply a medicated rub and he explains the actions that triggered the pain. For Kaldon, mind and body are symbiotic. Having arthritis does not define him and it does not destroy his life, it just means that he has to do things differently, like a tall person has to duck when they walk through a door, and a short person has to stand on a stool to use a top cupboard. Being tall or short does not make a person’s life unliveable or not as good as an average sized person; it simply means that they negotiate the world differently.

Depression is not specifically located in Sophie’s head; it is not even necessarily there at all. Her mind can feel like it is too full of stuff, but the parts of her body that

are in pain when she feels depressed – not a physical pain, but a feeling of badness – are her stomach and her heart. The feeling in her stomach is akin to the bad effects of not eating and sleeping well, while the pain in her heart is a heavy, constricted feeling that sits across her chest, different from the sort of sadness that can make your heart ache. The interconnectedness of head, torso and stomach make it hard for Sophie to separate out her mind from her body, they have such a large impact on each other. But the experience of depression as a whole has made Sophie more aware of her body. When she is not feeling very good she will try to ignore it, because it bothers her that she has had an impact on it, and, vice versa, when her body is feeling better she enjoys her awareness of it. It follows that when Sophie is feeling good her body feels more like a part of her, and that when she is feeling bad it feels less a part of her, something she regards from afar. Because of these experiences Sophie continues to feel quite negatively about her body. There is a certain seriousness about how she has felt in her body that continues to occupy her mind.

The fluctuating interconnections between mind, body and illness mean that we can never separate ourselves from the conditions of our lives. For Ben, learning to live with the threat of pain is a lesson of acceptance that binds his condition with his heart, where life, desire, fear, and love are crystallised. For the last thirteen years, Ben has been living with what he describes as a bomb in his throat. Fifteen years old and lying in bed one night trying to sleep, something suddenly twisted without warning. It felt like somebody had grabbed him by the neck and was trying to kill him, the pain spun in his throat and he could not open his mouth to speak. This strange and sporadic assault by his body has continued to date. Approximately twice a year the muscle in Ben's neck will spasm and the pain will attack, consuming his life for a

week or possibly two, rendering it difficult for him to speak, drink, eat, or sleep and leaving him feeling depressed and defeated. Despite numerous medical consultations and tests the problem remains undiagnosed, so that it now seems like a mythical curse. The pain has been traced to a weakness in Ben's organs: to his cold stomach, his nervous heart, and his weak liver, and it has been attributed to an out of control nervous system, mental stress, and embodied spiritual unrest. Perhaps it is related to a traumatic experience, perhaps his body is trying to tell him something; perhaps it remembers the past and is trying to speak out through pain. The idea that the uprising is an emotional memory stored in his body appeals to Ben, because it represents his cultural heritage and the Chinese belief in the interconnection of mind, body and spirit. But it does not reflect how he feels. In contradiction with his culture, the Western idea of mind body dualism has taken hold of Ben, and he feels like he is trapped inside a body that he wishes he could escape from. Treating this mysterious condition has become a ritual in-itself. In his video diary (included in the accompanying film) Ben shows the video camera the Chinese herbal medicine that his mother posts to him from Taiwan. The pills taste awful and they have not helped to prevent or alleviate Ben's pain, but they must be taken – they are both a ritual and an obligation.

Martin's pain shifts around his body, seeking the path of least resistance: through the entire length of his spine from his lower back to his neck, extending down towards his shoulders or up into his head. It moves fast; fifteen minutes ago he had a throbbing sensation just off to the right hand side of his lower back, a low, dull ache in his right hip, and a little bit of a tingling sensation just off to the left hand side of the C6 joint in his neck. Now, most of the back pain is gone and the pain he is

experiencing in his hip has doubled. But regardless of where it is the pain is always present, constantly moving but never leaving. It is a low-level, headache sensation, and it consumes whatever available mental bandwidth it can so that at any point in time a certain amount of Martin's mental capacity is absorbed by the fact that he is hurting. When he is engrossed in something his consciousness can push the pain to one side, so working hard is good, but conversely when his brain is less active the pain will rush in. Martin's body is shouting at him, all the time. But there is not much that he can actually do about it; there is nothing that will materially change the fact of the matter. So instead of listening to his body he tries to concentrate hard on other things, and, in doing so, he can take his mind away from the pain. There is no doubt an element of mind over matter in living a life of daily pain.

Minds and bodies find their own routes through the rhythms and spaces of everyday life, flowing and fluctuating between interconnection and separation in their efforts to live life. Their relations are often defined by their immediate conditions, but they also speak of a connection to landscapes and their belonging in the world. Anna has built up a solid relationship with her immediate local environment, and photos and drawings of large, blossoming trees featured in her journal. They are trees that she has been photographing and drawing for nearly twenty-five years. She runs past them several times a week, and simply looking at them feels beneficial. Nell's garden (which she recorded in her video diary and is included in the accompanying film) is a place that gives her a sense of accomplishment and peace. The tomatoes, chilies and flowers that she grows show her that with care life can flourish. Kaldon's rheumatologist warned him that his psoriasis, which made his mouth dry, left him constantly thirsty, and covered his

hands in paper-like cuts that cracked and made the skin split, would get worse in London where the climate is so much dryer than his home in Sydney, Australia. In fact the condition has almost entirely disappeared during the five years that he has been living here. Xan can never live in a remote village somewhere cut off from civilization, because every six months she needs blood tests to check her hormone levels are correct, and every 28 days she has to visit the doctor to get a new prescription. She has to make a special case if she is travelling for a length of time. Apart from the necessity for careful monitoring, no more than a six month supply can ever be obtained because the hormones in the pills are active and have a very short validity; after six months they will expire, becoming useless. Once, in the humidity of her southern Indian home, all those pills melted, the sugar coating attracting ants. Up until a certain point Anwen's life seemed to be defined by Australia's beaches. She grew up strong, swimming and body surfing at every free moment, aware of the powerful ocean. Her likes and dislikes were determined by her physicality and she was immersed in a landscape of bush walking and ocean swimming. Now, she wonders if she can face going back to that landscape. Before she left Perth two and half years ago, she could no longer get down to the beach and into that ocean unassisted, and the long hot summers were excruciating. The physicality of Australia's landscape creates differences between people, and perhaps going home now would be like shoving a square peg into a round hole. England's landscape, by contrast, could be a chance for Anwen to continue redefining what she loves about life.

As LaBelle writes, "Home weaves together the idea of place with belonging; to return home is to retrieve the locus of one's first experiences" (LaBelle 2010: 48). For

Anwen, the idea of returning home to re-live a life is now lost; her body no longer fits into the landscape of her childhood. What this tells us is that, if to be home is to belong, then where home is must be defined not only by where we have come from but also by where we fit in. The conditions of belonging exist in our histories and memories, in our social relationships and environments, and in our material bodies. Ultimately, our bodies are our final resting place, and our feelings towards them speak of the ways in which we truly inhabit the world. Just as our hands are in all our actions and thoughts (Pallasmaa 2009: 31), our bodies are our homes, because, while they do not always provide us with peace, shelter, and stability (Honkasalo 1998: 48), in the end home is, quite literally, where the heart is.

## *Conclusion*

Bodyscapes illuminate the sheer physicality of our being in the world and they reveal how illness flows through the material spaces of the body, reshaping the details of our lives at every scale. From internal fragmentation to external placelessness, the interiors of our bodies and their external surfaces act as spatial registers of illness, creating points of disjunction between body, mind, illness, and world. We try to keep illness hidden inside the closed spaces of our bodies, disconnected from the outside world, and we learn to recognise the signals that it sends out from within so that we can still it. But despite our best efforts illness sometimes refuses to be contained. It affectively leaks out of our bodies and announces its presence to the world. At other times, the world challenges our bodies from the outside, revealing and reinforcing their deficits and their vulnerability. Attending to the spatiality of the body shows how bodies are made to feel dysfunctional, out of place, and lost in the world, both socially and materially. But moving through the body and following the movements of the body through space also reveals something else. Just as these spatial scales fragment and disconnect us, they also create points of connection, tuning our attention to our bodies and our lives, and heightening our awareness of our corporeality and mortality. Using the materiality of the world in partnership with our material bodies, we are able to adapt to the conditions of our lives and find new ways of being in the world.

Space, then, illuminates a series of fluctuations: between visibility and invisibility, stability and instability, and placelessness and belonging. It shows how,

through various activities, we change and manage our boundaries. There are instances when our bodies are confronted by the world, times when we feel alienated – from our bodies and from the world – and moments when we feel connected to and through our embodiment and environment. As such, bodyscapes trouble our ideas about bodies and illness and question definitive conceptions of the body, illness and belonging in the world. Our bodies are ours to hold onto, and the ways that we live in them and through them on a daily basis remind us of what is at stake. Just as illness refuses to be contained within bodies, bodies refuse to be confined by illness. They are a vital force, and, ultimately, they urge us to embrace life.

## *Conclusion: Learning to Listen*

Throughout this thesis, the act of listening has illuminated the body. Careful attention has shown that the bodies in this project are not mute, invisible or absent, but communicative, visible and present. These vital bodies speak of a trust in life. They possess a three-fold urge: to live, to live well, and to live better (Whitehead 1958: 8). At the same time, their visible and audible presence makes their vulnerability immediately apparent, so that the unavoidable reality of human mortality must be acknowledged. In this conclusion, I want to return to the idea of listening. In the following pages, I discuss the ways in which listening to the body presents challenges to existing ideas about the nature of the body and its place in society within the context of this project. I suggest that ‘the art of life’ (Whitehead 1958) and ‘the art of listening’ (Back 2007) together reveal what is at stake in the details of personal everyday life and in the sociology of the body.

This thesis started with the contention that the sociological body has been muted by social constructivism. I argued that rather than being silenced or controlled bodies need to be listened and attended to, and that in order to hear them we need to begin from a theoretical position that recognises their value and ability to speak. Conceptually, the act of listening to the body involves appreciating that bodies have agency, and consequently that they have at least as much power over us as we do over them. This idea seems foreign to sociology, which has focused for so long on what we can do to bodies without asking what they can do to us. But, as Latimer writes, “illness and disability can make visible how bodies have lives of their own” (Latimer

2009: 4). To the participants in this project it is glaringly obvious; their bodies control, define, and react to how they live in innumerable ways on a daily basis, and it makes perfect sense to ask their bodies what they need and establish what they are averse to, in other words, to listen to them.

These acts of listening reveal how bodies are both social in their materiality and productive in their own right, two claims that I made in the conclusion of chapter 1. By demanding a particular predictability and structure to the day, a time to eat, exercise and sleep, ill bodies produce their own rhythms. Their material needs reshape the social organisation of everyday life, and in doing so they highlight the conflicts between the body and society. Ill bodies also change what the built environment means, as Anwen showed, a flight of stairs takes on new significance when it presents itself as an obstacle. They produce their own landscapes in response to their material conditions, and can be made to feel out of place if they fail to adapt (to) their environments. These processes of production and adaptation suggest that the social and the material matter of bodies is inextricably tangled up in the act of living.

The body demands attention through its own materiality, and listening engenders an awareness of its parts or fragments. An aching shoulder, a failing pancreas or a wheezing lung each speaks in its own way, as the bodies in this project have shown. Learning to hear them takes time, skill and dedication. Through careful attention the participants in this project have developed the ability to hear their bodies and understand bodily sensations, sounds and signs. When Imogen's tongue feels fat, for instance, she knows that her sugar level is high, and when Nell's chest starts to emit a small wheezing sound she knows that she needs to closely monitor

the health of her lungs. Their acts of listening extend beyond the ear and the bounds of language to a felt understanding of the body and a finely tuned attention to the small details in everyday life.

Listening also implies a relationship: when we hear bodies, we can choose to react to them or to ignore them. This choice is at the heart of the everyday management of illness and it influences notions of care, control and responsibility, as described in chapter 3. When bodies become too demanding or interruptive they can make us want to deny their needs and escape their bounds. In these instances the act of listening evidences a division between mind and body. But bodyrhythms and bodyscapes also reveal instances of loving attention that bring mind and body together in their efforts to live life. Caring requires work but it also develops a trusting and protective relationship that brings body and mind together. The choices created by listening thereby reveal the different relationships that exist between mind and body and the presence of dualism in everyday life.

The qualities of listening make the body present but they also reveal its shifting nature. Throughout this project bodies have shifted between presence and absence, visibility and invisibility, stability and instability, and placelessness and belonging. Bodies are intimate, but they are also public – a fact that makes the social dimensions of illness troubling. As has been shown there are times when it is important to let the body slip and seep through life without being pinned down, making Shilling's pronouncement of the body an "absent presence" (Shilling 1993: 8) as appropriate for describing the nature of the body in everyday life as it was for capturing the status of the body within social theory. Recognising this the task of knowing bodies becomes even more complex, as Latimer writes:

The related issues that arise here over presence and absence are not to be underestimated... the materiality of bodies may be better understood in terms of their intermittency than their more permanent features. Indeed, if the body is to be understood today as 'project', in line with Shilling, then surely part of that wider project is also to be better able to note its appearances and absences? As Goffman (1959, 1963, 1966) has so deftly depicted, persons learn, wittingly or unwittingly, to make bodily affect 'visible' in their presentations of self in everyday life. Hopefully this direction will help us depart from accounts that both dwell on the spatiality of the body and ignore its inconvenient and surprising irruptions. (Latimer 2009: 9)

The body, as presented in this thesis, is made present not simply through its own materiality but also through its clashes with the social and material fabric of everyday life. Learning how bodies make their appearances and irruptions, for example how illness leaks out of bodies and into the world, and identifying their absences, for instance the moments when we are made to feel distant from them, helps to create an account of the body as productive and material but also divided, fragmented and entangled within and without its own skin. It also calls into question the idea that a healthy body is a silent body. The association of health with silence and presence with illness fails to capture the subtle matter of bodies, which are heavy, inadequate, unstable, fragile, broken, useless, pained, weak, and alien, but also fluctuating, dynamic, present, useful, flexible, and strong. Each of these descriptions, which the participants wrote on their questionnaires in response to the question, 'three words that describe my body', illustrates the diversity of the body.

Finally, listening is an act of recognition. While the dominant discourse of medicine constructs sick and diseased bodies as simply unknowing (Latimer 2009: 10), the act of listening appreciates the body as knowing. In doing so, it offers the

possibility of finding other ways of knowing, and of understanding illness as other than suffering. The rhythms of eating, exercising and sleeping and the places and spaces of the body reveal and hide the presence of illness, showing us that bodies are both vulnerable and strong. These bodies are not lesser, incapable, or mute, and they are not repressed or restricted by illness. Instead they are bodies that make and re-make the structures of everyday life through their own self-managing strategies, rhythms and ways of being in the world. Ultimately, the act of listening to the body speaks of our refusal to be confined by illness, showing that vital bodies can redefine the imagined borders between health and illness.

To reach this conclusion I also had to learn how to listen. As Back (2007) writes, sociology is a listener's art: an attentive and emphatic practice that seeks to understand and recount the lives of people. This is the art that I have tried to practice. Attending to everyday, small stories and using methods to recalibrate the relationship between observers and observed (Back 2009: 212), I discovered the sociological body in the ways that people live. Working visually became a way of doing sociology (Halford and Knowles 2005: 1.1), in other words, a way of listening with both my ears and my eyes. This has been a craft that has challenged and disrupted the usual ways of showing bodies and telling illness, from the ways that I engaged with the participants and their bodies to the ways that I hope to have engaged the readers and viewers of this thesis and the accompanying film.

As Becker writes, there are many ways to tell a story about society (Becker 2007: 3). These ways of telling encompass genres, methods and formats, and they pervade both the doing and the telling of sociology. I have tried to use ways of telling, by which I include methods, devices, formats, and modes of writing, which offered

something of their own qualities to the challenge of presenting the body on the page and on the screen. Video diaries brought dynamism, capturing the sensual and dynamic aspects of bodies and engaging with the ongoing and embodied practice of everyday life (Halford and Knowles 2005: 1.2), Polaroids and drawings took the material body seriously and brought it closer both through its parts and fragments and through their own tactility, and thick description (Geertz 1986) portrayed the felt and lived reality of embodiment in words. In creating a sociological text with texture (Smart 2009: 299) and constructing an alternative vision of everyday life with illness I hope to have overcome the dissonance between real life and what Halford and Knowles describe as the “inanimate surfaces on which sociological work is usually rendered” (Halford and Knowles 2005: 1.1), and to have shown that the sociological body is vibrant, vital and alive.

The overall aim of this thesis has not been to fix the elusive sociological body within these pages, but to make it knowable in new ways. And bodies are just one of the many elusive things in the world that sociology seeks to know; “much of the world is vague, diffuse or unspecific, slippery, emotional, ephemeral, elusive or indistinct” (Law 2004: 2). As Law writes, social research is not well equipped to rise to this challenge, methods of inquiry often fail to catch the texture of the world, and “talk of ‘method’ still tends to summon up a relatively limited repertoire of responses” (Law 2004: 3). Finding ways of knowing things that are elusive and messy requires new ways of thinking, practicing, relating, and knowing (Law 2004: 2), in other words, greater methodological variety. Law and Urry (2004) write that methods of social inquiry need to be reimagined in order to keep pace with social and physical changes in the world. They argue that the world is becoming multiple, fluid and

decentred, and that methods need to be developed in order to resonate with these new realities. They also argue for an ontological politics, suggesting that the role of social research is to help shape new realities.

With them, I want to encourage a 'sociology of the elusive' (Law and Urry 2004: 391), but my reasons are quite different. Instead of an ontological politics, I suggest that what sociology needs to engage more readily in is a politics of craft: an attention not to the kinds of worlds we want to make but to the kinds of worlds we want to make visible. A politics of craft promotes a sociology that is less reliant on dominant theories and standardised ways of doing social research, without which it becomes possible to broaden and complicate sociological categories. It seeks to practice sociology in ways that imaginatively engage with problems and pay attention to the small details of life, so that the things that matter are not lost. While the world may be becoming more fluid and decentred, it is the potential of sociological research to capture the richness of the world rather than its multiplicity, and to present that richness through different modes of representation, that I have tried to make use of. As Law and Urry write, current methods deal poorly with many aspects of reality, including the elusive, the sensory, and the emotional (Law and Urry 2004: 403). Vision, sound, taste, and smell, outbursts of anger, pain, rage, pleasure, and desire (Law and Urry 2004: 403) are just some of the details that make up the richness of the social world and that an imaginative engagement with method can re-enchant. In attempting to present a richer sense of bodily experience through a visual and sensory engagement with method, I hope that this thesis will help to expand the sociological repertoire and our ways of doing sociology and telling about the social world.

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