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A TABLE OF METAPHORS:  
THE VISUAL REPRESENTATION  
OF CHRONIC ILLNESS

A thesis presented in partial fulfilment of the requirements for the degree  
of

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In  
Social Anthropology

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## ABSTRACT

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For people who live with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity syndrome illness is a hidden construct. The body does not display the chronicity of the internal experience. This thesis removes the barrier between what is experienced and what is visible by creating visual means of communicating the body's hidden experience. The place of the viewer is part of this discussion. Through visual methods digital photographic techniques and the current interest in sensory anthropology the embodied sensory chronic illness experience is explored. The hidden experiences were made visual creating "MeBoxes" and masks which showed both the external and embodied internal experiences of chronic illness.

As the process of working with and walking beside the participants developed, I found that the discourse on imaging within the literature was inadequate to show the real lived experiences of those with chronic illness. My interactions with the people of this thesis and the process of honouring their experiences required a model that would encourage the viewer to new and perhaps unrealised depths of participation to understand the participant's multi-faceted and multi-layered experiences. Part of the discussion is the ability of images to communicate sensory experience as is the case with Munch's *The Scream* and Picasso's *Guernica*. Through the use of a hypertextual self-scape I show how participants created access to their experiences through their visual representations and through a collaborative approach became composite hypertextual self-scape metaphors.

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## CHAPTER 1

### INTRODUCTION

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My research began with a desire to find hidden stories about chronic illness and make them visible. Illness is a sensory experience and my aim has been to find a way to communicate these experiences. In my previous research project in 2008 I looked at the experiences of long term Myalgic Encephalopathy /Chronic Fatigue Syndrome, I wrote up the verbal stories but found that they only relayed a part of the illness experience (Gibbons 2008). It was out of a desire to find the hiddenness of chronic illness experiences that I began looking at how to visually represent them.

Through the research method and representation, layers of detail create a depth of interpretation rather than a breadth of information. By changing the context the focus on the data is changed but the focal point, the information given by the participants, remains unchanged. This enables a peeling away of the layers of meaning allowing for the depth and complexity of embodied experience to be uncovered. This results because of the way the information is communicated and represented creates new perspectives on the data.

#### TOPIC AND APPROACH

In this thesis I have approached the literature as a place to build bridges between medical, visual and sensory anthropology. My intention was not to enter into mainstream discussions of chronic illness within a medical anthropology framework but to approach chronic illness experiences from multiple fields of discourse. This is reflected in the literature which is gathered from the fields mentioned as well as from photography, phenomenology of art, and art's discourses. 'Relationships and appropriations between scholarly research, arts practises and applied



interventions will depend on the aims and frames of each unique project' (Pink 2009:133). Therefore the thesis connects several theoretical perspectives and techniques which I discuss at relevant points through the following chapters. The representation of the images and narratives evolves throughout the thesis and the literature is part of this progression. The method I have used in this research is original as I have used "MeBoxes", masks and artistic methods through objects and images to communicate hidden experiences. These culminate in composite images of chronic illness in chapter six. I have used this method because 'Surface information does not always make illness and disability visible; thus, invisibility further complicates how people think, feel, and act toward their bodies and how others view and reflect images of these bodies' (Charmaz 2006:41).

The reason for making choosing to create visible images is that visibility often assigns authenticity to an experience. 'The seen is considered as evidence, as truth and fact' (Bal 2003:14 ). In making chronic illnesses which are not easily visible, visible, participants make their experiences more concrete to an external observer. Due to the importance of the visual I also include different forms of connecting narrative through hypertextual frames and surfaces. Throughout chapters four to six the frames and surfaces merge in different configurations to create a visual narrative. These vary from traditional scholarly practise to more innovative methods.

## CHAPTER OVERVIEW

In chapter two I discuss some of the literature around visual representation and the hidden experiences of the chronic illnesses Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity. This chapter lists symptoms and questions if it is possible to understand chronic illness from a symptom list. I also discuss visual formats which have been used by InvestinME and in the book *Creative for a Second* as a way to communicate the

embodied experience of ME/CFS<sup>1</sup>. I discuss the importance of visual anthropology and its ability to communicate information.

Chapter three describes the method I used in approaching the question of visibility in illness and lays out how I developed the method of creating a “MeBox”. This chapter also discusses the development of the use of masks to visually represent the internal and external experience of chronic illness. The method chapter plainly describes how I did my research and a brief overview of participants’ reaction to the method. I describe processes and outcomes of the method and practise used.

Chapter four begins the discussions of the data gathered in the field. I begin by looking at the objects gathered by participants in their “MeBox” and follow with a discussion of the photographic images and groupings of the objects from the boxes. How participants chose to represent their experiences and crafted their narratives is part of this discussion as ‘visibility is also a practise, even a strategy, of selection that determines what other aspects or even objects remain visible’ (Bal 2003:11). In this chapter I also begin a discussion around the hypertextual self-scape as a model of reading, interpreting and creating sensory awareness of chronic illness experience. The hypertextual frame, its hypertextual surface and ability to create links are the layers on which meaning is created and communicated. ‘They can thus be understood as categories and routes through which embodied ways of knowing are created’ (Pink 2009:152).

Chapter five focuses on masks that the participants painted and wrote on. The masks confront the internal and external experiences of chronic illness. I briefly discuss how different levels of interaction with an image impact on the depth of relationship a viewer has to it using Paskow’s theory of spectatorship. The hypertextual self-scape is discussed as visibility and the viewers are explored. The masks show how participants themselves merged narrative and visual components of their

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<sup>1</sup> Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

experiences. Through the masks and the interaction by the spectator the sensory experience of chronic illness begins to be translated from the chronically ill body.

Chapter six is the culmination of the thesis as I bring together the narratives and the visual, creating composite images. The images invite the viewer into an understanding of the sensory experience of chronic illness. I return to the discussion of the hypertextual self-scape as a place to link the known internal sensory experience of chronic illness to the external viewer. I discuss literature around photographic method, digital technique as well as visual and sensory anthropology. In this chapter I discuss the ability of images to communicate sensory information through a discussion of *The Scream* by Munch. Through the composite hypertextual self-scape images spectators are invited into the hypertextual frame and through its surface into a level of sensory experience of chronic illness.

## MEANING AND COMMUNICATION

Due to the visible nature of this thesis it is important to state here that there is always a viewer. Viewing of the images from different perspectives and contexts creates several levels through which it is possible to engage with the visual representation of illness. Because of the images relationships are created between the participants embodied knowledge, researcher and audiences. The objects take on meaning through the narrative of the participant but are viewed by an external audience. In some situations the significance assigned by a participant aligned with a pre-existing meaning, for example a shoe is already a shoe not an ostrich, the narrative was then expanded along its existing designation into representing walking. In other situations the object appears abstract without any meaning until it is assigned by the participant. Meaning is not stagnant and whilst these images represent a specific time for the participants the audience in viewing them will also assign meaning through how they interact with them.

The world is never something finished, something which thought can bring to a close; the world is always in the making, and our thoughts, like our actions, have meaning only in relation to the practical and social life in which we are engaged (Jackson 1996:4).

### PERSONAL INTEREST

As someone who was diagnosed over twenty years ago with ME/CFS I have access to knowledge about the sensory experience of chronic illness. As an insider researcher I was therefore aware of the complexities connected with communicating experience. Through the method and practice I was able to draw on my own experiences to gain clarification on sensory information. Participants also felt comfortable as they felt they were not being judged as I “knew”. Anthropology values participants and honours who they are by their method and practice and due to my insider status I believe this was enhanced. I was able to clarify comments and behaviours which could have been taken out of context as one participant explained had taken place in research she had been involved in previously.

Three participants referred to my insider status in relation to a particular object they had chosen. This was a piece of paper which none of them wanted to bend or write on. They referred to it as being ‘OCD’ (Obsessive Compulsive Disorder), whilst this was not something I had experienced I knew to get clarification. When I questioned why they felt that way and asked if it related to having something uncluttered, they explained that it was something that didn’t have to show the chaos they lived with, it was something beautiful and perfect and they wanted it to be part of their box. In some literature this behaviour of wanting order has been misrepresented and regarded as a psychological problem (Moss-Morris and Petire 2000:64).

Creative ways of communicating are important to me. In high school I took classes in photography and achieved a bursary in photography. During that time I learnt about photographic and darkroom techniques which have informed this research. I focused on the arts and also took art history. I was fascinated about how information could be communicated through a purely artistic form and how art throughout history has had a role in communication.

### RESEARCH FOCUS

The central idea for this research is to show chronic illness experience as an embodied sensory life experience. Chronic illnesses as represented by these participants have in the past been expressed through a written format which cannot convey all of the complexities of chronic illness experience.

There are a good number of techniques through which ethnographers might go about inviting audiences to engage in the empathies, intimacies, self-reflexivity and intellectual/scholarly engagements that we would hope could bring them closer to imagining and comprehending the lives of others (Pink 2009:153).

The outcome of this research is that through objects and images participants are able to communicate their internal experience of chronic illness. Novitz in examining the connections between art and narrative stated that 'when I take a good look at myself, I do not see very much at all. Nor do I really look at myself. The reason is obvious. There is more to my person than the body I stand up in' (Novitz in Hinchman and Hinchman 2001:144). This research enables an examination of the multiple aspects of self which encompass the chronic illness experience. Those who view the objects and images and the theoretical information are able to access a deeper understanding of the chronic illness experience than writing alone can achieve; thereby communicating and creating a level of embodied knowing about the illness experience.

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## CHAPTER 2

### WORDS AND VISION

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This chapter begins the exploration into the existing literature around visual anthropology and chronic illness that will continue throughout the thesis. Anthropology through its ethnographic method has engaged with people and expanded our understanding of what it means to be human and visual methods have informed this project (Schultz and Lavenda 2001:19). This has also been the case with my own research with people who are experiencing chronic illness. Anthropology values participant observation but when researching with people who are ill this is not always possible or suitable, however visual methods enable collecting data that is not usually accessible in an interviewing project.

In this chapter I will begin by looking at chronic illness as represented by the participants in this research. Then I will move on to discuss visual anthropology and the advantage of researching illness experiences using visual method and representation. Using visual methods has enabled gathering and representing data that would not be possible with people with chronic illness if using more established ethnographic methods. Illness for my participants is often a private experience and using visual methods, which I will discuss further in the following chapter, participants revealed their experiences in a substantive visual representation. I will begin by explaining the literature associated with the symptoms and characteristics of the chronic illnesses of my participants.

#### WHAT IS CHRONIC ILLNESS?

Chronic illness is the label given to a variety of different illness experiences including Diabetes, Migraines and Myalgic Encephalomyelitis. The use of 'chronic', in medical terminology comes from the Greek 'chronos' which means long term and is used to define

an ongoing issue which is severe and often debilitating<sup>2</sup>. The categorisation, chronic illness, is applied to a multitude of different experiences and symptoms and creates a confusing ideological space that encompasses both scientifically testable and diagnosed problems, along with those that can involve multivalent diagnosis. In my research the term chronic illness is used in reference to my participants who represented three of the latter, which are labelled Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity Syndrome. These chronic illnesses are often hidden within the confines of the skin and are consequently experienced away from social insignia of illness (Frank 2002:13, Goffman 1968:67). Due to this concealed phenomenon the illnesses create a challenge between public and private reading of the body, creating confusion about the legitimacy of the illness experience.

Chronic illness is privately experienced and coping mechanisms to live with this changed existence are approached through awareness of the body. The place of the body is increased as it dictates the way the self is able to relate to the world around it. This internal experience can be exposed in places like doctors offices, with close personal friends and within support groups but it is through the choice of the individual and not through external visual recognition of symptoms<sup>3</sup> that this information is given. There are various reasons for this hiddenness ranging from symptoms such as fatigue, pain and chemical intolerances, to not wanting to be judged or seen as a person who lives with a malfunctioning body (Good, Brodwin, Godd and Kleinman 1992:169). Other difficulties can stem from misunderstandings around the illnesses mentioned, resulting in questions over the validity of the illness experience (Barker 1991:1, Moss-Morris and Petrie 2000:10). Due to the symptomology the body can become a hindrance, a place where frustration is experienced

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[http://search.medicinenet.com/search/search\\_results/default.aspx?Searchwhat=1&query=chronic+illness&I1.x=42&I1.y=17](http://search.medicinenet.com/search/search_results/default.aspx?Searchwhat=1&query=chronic+illness&I1.x=42&I1.y=17)

<sup>3</sup> Through long term relationships with the illness many people become attuned to the small visual signals of the illness but when not attuned to them it is possible to miss these subtle cues.

as dreams and desires are withheld (James and Hockey 2007:12-13). These difficulties and the coping strategies which people use to manage illness have the ability to inform and expand our understanding of the human condition. Through this research with people who exist on the margins of biomedical health culture, questions about health and illness are raised and knowledge about societal expectations of illness are challenged (James et. Al. 2007: 132,174).

How the body is read and interpreted is integral to the chronic illness experience. The first place where this occurs for most westerners is in a general practitioner's office where a record of symptoms is followed by medical tests. I will therefore follow the process of my participants by first approaching biomedical knowledge and list the symptoms for each of the illnesses represented by my participants. The first will be ME/CFS<sup>4</sup> as this category is the most represented in the research group. These participants experience a variety of different symptoms and without a clearly defined diagnostic test it can take up to two years and a minimum of six months to receive a diagnosis in New Zealand (Horne 1990:82, [http://www.anzmes.org.nz/what\\_is\\_me.htm](http://www.anzmes.org.nz/what_is_me.htm)). The list below does not convey the experience of living with ME/CFS as they are isolated from the individual but are a summary of the symptom lists used by medical practitioners in finding a diagnosis:

Physical and cognitive fatigue/exhaustion

Poor concentration

Extra sensitivity to light and noise

Poor short-term memory

Difficulty with aphasia (word finding) and complex or multiple tasks

Flu-like malaise exacerbated by exertion

Post-exertional fatigue

Muscle pain, twitching, cramping, joint pain, neuropathic pain,

Fibromyalgia

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<sup>4</sup> Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome



Headaches  
Insomnia, early-morning waking  
Unrefreshing sleep  
Hypersomnia  
Gastrointestinal problems  
Nausea  
Loss of appetite  
Abdominal cramps  
Breathlessness  
Food intolerance  
Chemical sensitivity  
Low grade Fever, heat or cold intolerance  
Balance problems, spatial disorientation  
Vision problems, painful eyes  
Weight gain  
Urogenital pain  
Irritability, mood swings,  
Depression, Anxiety  
(Bell 1995:10-11, Berne 2002:63-79, Health wise 2006, Moss-Morris and Petrie 2000:17-85, Horne 1990).

#### MULTIPLE CHEMICAL SENSITIVITY

This illness has been linked with multiple possible causal factors but the most common explanation from members of this group is over exposure to chemical products. As with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome 'The idiopathic or "not understood" nature of MCS<sup>5</sup> means that doctors & others are often highly skeptical about the reality of – and nature of - the MCS condition'<sup>6</sup>. Like Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome its cause and treatment are still under discussion and whether it is medical or psychological appears to be a recurring debate (Leznoff 1997:438, Borschein, Hausteiner, Zilker and Forstyl 2002:187). The unknown nature of the illness pathogen has

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<sup>5</sup> Multiple Chemical Sensitivity

<sup>6</sup> (<http://www.multiplechemicalsensitivity.org/index.php#symptoms>)

resulted in it becoming unpopular and disregarded in biomedical practises but alternative health practitioners give possible causal links as enzyme deficiency, conditioning caused by over exposure to chemicals and immune damage creating greater vulnerability to toxins. However despite debates over whether it is a legitimate illness or not the affliction experienced by the person continues. The debates which exist within the medical professions, whether biomedical or psychological, cease to relieve the difficulties of living with this illness.

As with ME/CFS and Fibromyalgia, Multiple Chemical Sensitivity challenges existing interpretations of disease and reveals the need to expand medical knowledge. If medicine limits its criteria to the seen it is like trying to squeeze the round body into a square hole. The symptomology of MCS is somewhat different to Myalgic Encephalomyelitis /Chronic Fatigue Syndrome and Fibromyalgia in that symptoms are often triggered by an encounter with cleaning products, garden sprays, deodorants etc... (Wittenberg 1996:19, 32, 34, Pall 2007:128). These can in severe cases also exist longer term with constant low grade symptoms, but in our chemical environment many members of this group experience this list of symptoms regularly.

Confusion, dizziness

Disorientation

Slurred speech

Anger or irritation

Light and sound sensitivity

Flushing of face and chest

Breathlessness – asthma type symptoms

Sleep problems

Headache

Nausea

Itchy eyes

Stinging eyes and nose

Eczema

Stomach pain

(Berne 2002:101-102, <http://www.multiplechemicalsensitivity.org>,  
Wittenberg 1996:21-24, Pall 2007:114-115)

## FIBROMYALGIA

Fibromyalgia and ME/CFS have many similar symptoms which create a convergence between them but for diagnosis the main distinguishing feature is the type and position of pain. Pain is the distinguishing representation of Fibromyalgia with widespread pain and aching muscles lasting 3 or more months at 11 of 18 tenderpoint sites (Wittenberg 1996:44-45). There is no visible wasting of muscles or wasting of joints but due to its predominate presentation of pain it is linked with Arthritis New Zealand for support<sup>7</sup>. The pain is not relieved by rest and 'pain and stiffness are often worse in the morning and with repetitive motion' (Berne 2002:29). It is not uncommon for people with ME/CFS to also be diagnosed with Fibromyalgia and vice-versa if the symptoms which the individual presents with do not fit into a single category. The following are a list of symptoms specific to diagnosing Fibromyalgia:

Pain in tenderpoints either when pressed or knocked

These are - Occipital, Low Cervical, Trapezius, Second Rib,  
Supraspinatus, Lateral epicondyle, Gluteal, Greater Trochanter, Knee  
Steady pain in tenderpoints

Widespread Pain

Morning Stiffness

Sleep disturbance

Fatigue

([http://www.arthritis.org.nz/index.php/Fibromyalgia.html#Diagnosing\\_fibromyalgia](http://www.arthritis.org.nz/index.php/Fibromyalgia.html#Diagnosing_fibromyalgia), Berne 2002:29-34, K.Barker 2005:5-7)

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<sup>7</sup> <http://www.arthritis.org.nz/index.php/Fibromyalgia.html>

All the symptomology lists show just how confusing diagnosing these illnesses can be, as well as giving a clinical description of the body with chronic illness. The manifestations of the symptoms are kaleidoscopic, with members of these communities of chronic illness having varying symptom severity and numbers of symptoms. The three illnesses I have listed overlap each other in some of their characteristics and may be one of the reasons that people from these different illness categories could be found at the ME/CFS support groups I visited during my research. The above inventories show there can only be a limited understanding of an illness when it is confined to a list of symptoms. I will continue by looking at visual anthropology and how it can enable a greater understanding of the illness experience by looking beyond symptomology.

### VISUAL ANTHROPOLOGY

Visual anthropology has historically been seen as a methodology as well as a sub-discipline and has expressed the dominant features of anthropology in its production and creation of images (Prosser 1998:10). Historically the 'project of ethnography was largely 'to translate the visual into words' (Wright 1998:20). This approach was formed to attach scientific practice to visual research as images were regarded as unstable data. The cataloguing of people groups with photographs as illustrations, the use of representational photographs of activities, to photographing a 'native' environment have all informed the visual anthropological project (Pink 2006: 6-11, Collier 1967:5, Ruby 2000:45-54 ). 'For many years, the still camera has been a normal part of most cultural anthropologists' field equipment. A conservative estimate would place the number of photographs taken by anthropologists in the millions' (Ruby 2000:53). Most of these photographs were used as illustrations with the text being the primary focus. This privileging of the written had dictated the boundaries of the visual ethnographic project. The modern focus, Pink states, should be to align the written and the visual and give them equal value as together they offer greater depth to research method and representation (Pink 2007:94). Questions over

how images inform and communicate have played a part in the debates about the place of the visual in anthropology.

The challenges to reassessments of the relationship between, vision observation and truth influenced how the visual was approached across the disciplines, emphasizing the arbitrariness of visual meanings and the potential of the visual for the representation of ethnographic knowledge (Pink 2007:16).

This has resulted in an expansion of the understanding of visual interaction with theoretical analysis. The debates have also raised questions about 'representation, interpretation and the authoring of knowledge' (Pink 2007:17-18). These areas of concern have become part of the reflexive process that all visual anthropologists should examine their work by (Ruby 2000:167). Visual anthropology acknowledges that images are not created in isolation. Images are influenced by the photographer, environment, photographed, photographic traditions, the viewers or audience as well as academic requirements. 'Visual images thus take historically specific forms linked to political, economic and social relations, which determine both their mode of production and their ability to constitute the social world itself' (Harrison 2002:857). These influences are not limited to visual methods but also impact the writing and presentation of theoretical data.

The use of camera equipment for both film and still photography has impacted on their application in the field. Anthropology has been quick to make use of technical advances and add them to existing participant observation resources as with the early use of photography (Prosser 1998:11, Pink 2006:5-16). This continues as 'coupled with the rapid developments in visual and digital technologies that now facilitate visual research and representation, it represents a new context for visual anthropology and ethnography' (Pink 2004:2). The advances in digital technologies have also been picked up by anthropologists and have been integrated into visual methodologies, through the use of the internet

and other imaging technologies (Pink 2007:191). Photographs that were previously about capturing light onto a light sensitive film and then processing the film in a dark room (which I know personally could take hours) can now be accessible within minutes allowing a researcher to discuss a photographed event soon after or during the event being photographed (Pink 2007:84). This instantaneous image created by digital method enables the researcher through the use of a laptop to discuss the photographs on site, rather than managing a delay of days or weeks until the photograph is processed and the researcher has time to visit again with a participant to conduct photo elicitation (Bank 2001:114, Pink 2009:93). With the accessibility of digital technologies the role of the visual anthropologist continues to develop.

Visual anthropology has the opportunity to make the hidden visible and accessible due to its method and representations. As stated earlier the ability of the body to display its status, ill or well, enables society as the viewer to read it (Ware 1992:350). Visibility exists on many levels and through visual anthropology this complex maze of the seen and unseen can be explored (Edgar in Pink et.al. 2004:1996). For example one level of visibility in illness is accessed by medical professionals who use methods not available (for example blood tests) to the general public to see into the body. This knowledge is often surrounded in technical vocabulary which cages medically visible knowledge in language that distances itself from the experience of illness. The use of exclusive language to analyze experience results in privileging of certain types of knowledge (Chaplin 1994:111). In doing this it adds to the complexities which exist around access to knowledge and visibility (Moss and Dyck 2002:36). Terminology also has power of its own to bestow authenticity to the illness experience, when the criteria for diagnosis is achieved, or challenge the person's understanding of their authentic self when the biomedical tests fail to line up with their experiences (Bell 1993:19).

In academia representation of knowledge has tended to promote the written word translating the visual into definable written criteria (Wright

1998:20). This system, which formed the basis of scientific approaches to visual research, assumes that 'ethnographic knowledge is produced through the translation and abstraction of this data into written text' (Pink 2007:119). Acknowledging the body experience does not mean a wholesale selling out of academic knowledge and writing, but supports broader levels of research and representation (Pink 2007:94). Through the expansion into studying human experience.

A focus on the body, the emotions and the senses has acknowledged that human beings live in sensory worlds as well as cognitive ones, and while constrained and bounded by the systems that anthropology previously made its focus, we not only think our way through these systems we experience them (Banks in Prosser 1998:9).

Combining visual and written forms of representation expands the type of data gained in the field as well as the type of information that can be communicated.

### WHY THE VISUAL IN RELATION TO CHRONIC ILLNESS

As mentioned above the chronic illness experience is one which is hidden and therefore our ability to comprehend it is predominately limited to verbal narrative and written texts. Whilst the written can enable a level of understanding I believe that visual methods have the opportunity to bring new understanding to current perceptions of chronic illness. The hiddenness of chronic illness is being addressed within the ME/CFS community through art, poetry and visual story telling. This has resulted in an 'emphasis on narratives as ways of "telling", stressing the particular experiences, views and situations of the subject/author, has expanded from language texts to include imagery as well as music and performance' (Harrison 2002:858).

Images whether photographic or video create potential, potential knowledge, potential representation and potential connection with the

hidden experience of illness. Pink calls this the 'transformative' ability of images (Pink 2007:17). The visual has long been used in the medical profession through x-ray, cat-scans, microscopes, photography of body parts, video and the human body as cadavers, all aimed at understanding and interpreting the physical body. Science values the visible as it makes something concrete and identifiable, for example the ability to look at a photograph of a diseased liver enables medical students to know what to look for in the future (Albrecht, Fitzpatrick, Scrimshaw and Scrimshaw 1999:51). Unfortunately these visual procedures isolate the body from its owner and it can create body as object not body as part of self.

One study which addresses the separation of the body away from the experience of illness was undertaken with adolescent patients who created video diaries of their lives. The outcome of their diaries was wide ranging with the authors of the research recommending their use in training doctors to understand the illness experience beyond its symptomology (Rich, Lamola, Gordon and Chalfen 2000:162-164). This technique begins to address illness as more than the fleshy body. It begins to acknowledge that the body exists in society, within relationships, as a 'spiritual' being, and within political environments that all impact on the illness experience (Csordas1994:5-6).

To be visual does not necessarily make the chronic illness experience easier and in many cases being labelled with a recognised illness or disability can make it harder, but for people who do not have medically visual symbols the lack of visibility leads to questions about the legitimacy of the illness experience (Ware 1992:348-349). Visibility creates access to the bodies altered experience of chronic illness for both constructive and unconstructive reactions from medical professionals and the public (Beatson 2004: 201, Frank 1995:32). In the chronic illnesses represented by participants the body becomes stigmatized for what is not seen (Goffman 1969:67,152, Albrecht, Seelman and Bury 2001:253). The visual carries credibility and for the



people I have been researching with the lack of the visual is often a hindrance to diagnosis, health and acceptance within the wider community (Frank 2002:13, Horne 1990:82, Low in Csordas 1994:141,).

#### BEGINNING ON THE PATH TO VISIBILITY FOR ME/CFS

As mentioned earlier hiddenness is being addressed and one of the groups doing this are InvestinME in the United Kingdom who recently asked members to make their experience of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome visible to show non-participants that the illness they live with is legitimate. InvestinME then selected some of the stories, images and poetry to develop into the book *Lost Voices* (InvestinME 2008:7). The photographs tell visual stories of pain, suffering and loss. They are powerful, but if the medical symbols of illness such as the oxygen masks and wheel chairs, which appear in many of the images, are removed it can be difficult to read the complications of living with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome that these images are trying to express.

Kirrily Anderson, who is based in Australia, connected with artists from around the world with ME/CFS through the web forum “notcrazy”. She noticed that people were creative and floated the idea of a book, from this suggestion people contributed images and poetry; some reflected their illnesses and others did not directly address their illness experience (Anderson 2008:11). The focus of the book was not to visually represent ME/CFS. However all of the artists whose work is represented have ME/CFS and therefore the book would not exist without this chronic illness identity (Anderson 2008:16-17). The images created by artists for *Creative for a Second* which relate to chronic illness are usually more abstract than those created for *Lost Voices*, but the stories they convey resonate with the images and narratives from *Lost Voices*. I have found similarities with the visual narratives created by participants of this project with those from these two books. An example of this is Anderson’s image which begins in a chaotic scribble and evolves into a beautiful intricate design; the image is called *Where Dreams meet*

*Reality* (Anderson 2008:118). The place of chaos and loss reflected in the image and in the illness experience is one I saw created during the research process. A participant used a piece of knotted up wire to explain her loss of stability and desire to find some control. In InvestinME loss of control of the body is shown in a photograph of a wall with the words 'do you wanna dance,' a woman is sitting in a wheel chair dressed in a tutu with her hands lifted in ballet's fifth position. This image reflects on to the wall in shadow below the words (InvestinMe 2008:31). This photograph reflects Anderson's where the dream of dancing is met with the reality of life in a wheel chair. These images show how 'chronic illness, with its inherent fluctuations, undermines the expected stability of the material body' (Moss and Dyck 2002:105).

The images call out for the viewer to understand and for the reality of the illness experience to be seen rather than hidden away. In this situation without the artistic representations privileging the visual image there would be a failure to perceive the truth. Without the visual symbols of illness having conviction in the illness narrative becomes the only way to connect with an illness identity. Having faith in a person being sick when the medical tests are not definitive is not something that comes easily due to the privileging of certain types of knowledge. Looking, in relation to people with chronic illness, is often linked with judging if an illness experience is authentic. For people with ME/CFS, MCS and Fibromyalgia the visual appearance of illness is not readily evident and this is true for many people who live with chronic illnesses. The visible, from the perspective of these chronic illnesses has the possibility of granting legitimacy to the illness experience. Gaining legitimacy means not having to justify the self (Moss et.al. 2002:87). When the body does not display its circumstances and is not visible, validity and acknowledgement of the illness experience is often removed along with it (Berne 2002:196). The sensory knowledge of the body experience is less valued if it can not be visible outside of the body. As Edwards and Bhaumik state sight is privileged in the 'western ... sensory hierarchy' (2008:6).

## COMMUNICATING THROUGH THE VISUAL

Visual representations and narratives when connected create a dynamic conversation of the senses. Where words confined to technical language may limit access to information an image can be more approachable. For example Munch's *The Scream* is an image which is seen through the eyes linking with the mind and body creating a holistic reaction. The response may be empathetic, fear or disgust, but what is relevant is that images have an ability to connect and transmit information. Munch in painting the image explained that he saw a scream rising in the countryside and he painted it. In connecting Munch's narrative with the image a greater depth of understanding of the picture is created and can alter how the viewer responds to it. 'All representations can be shown to 'work' as forms of discourse, not forgetting the potential to reconstitute issues in more radical and empowering directions' (Harrison 2002:867).

In Medieval and Renaissance art communication to an illiterate populace was often achieved through the art practices of the times (Crenshaw, Tucker and Bonfante-Warren 2009:32, Levy 2007:73). Whole stories and events were recorded and embellished through tapestry, iconography, frescoes etc... Images were the way to communicate theological and cultural knowledge to the illiterate populace (Levey 1977:12). An example of this is the use of animals to convey information relevant to the narration of the artwork. As in Durer's *The Adoration of the Trinity* (1511) a white dove appears above the crucified Christ and crowned Father as the representation of the Divine Spirit (Crenshaw et.al 2009:13,141).

## QUESTIONS OF REPRESENTATION

It is important to note that it is possible for images and writing to be taken out of context which makes representation precarious as it is necessary to keep everything in balance (Pink 2007:16, Prosser 1998:61). The power of images to convey emotion adds to the ethical issues of a

researcher (Pink 2009:58). Added to this complexity are issues of vulnerability for people who are chronically ill. Doing justice to the participants and to the data becomes a mine field of possible difficulties as the researcher seeks not to confuse the audience but honour both the verbal and visual narratives of the participants. 'For in creating either [narrative identity or art] we are brought to explore a range of human values in a way which tests, teases, and adds to our moral aesthetic understanding' (Novitz in Hinchman et.al. 2001:158). Both the gathering of material and the type and format of representation impact on accessibility and perception of the experiences participants reveal.

## VISIBILITY AND PERFORMANCE

Who a person is and who they choose to reveal themselves to be can alter depending on the environment and society in which they situate themselves (Rapport and Overing 2000:179). We make visible who we are by our actions, speech, dress etc... but this does not mean that we "perform" who we are and are therefore only our performance (Sardan 2005:37). The privileging of the visual as performance of chronic illness over every other sense becomes problematic as humans are sensing feeling beings and are more than an external visible construction or presentation. In relation to my participants, to describe their chronic illness as a performance belittles an intensely private experience which may only be, in part, shared with a few very close friends and family (Ware 1991:151, Charmaz 1997:108-110, Moss and Dyck 2002:141, James and Hockey 2007:16-17).

Through selecting and collecting objects that reflected their illness participants took their private experiences and created images which expanded access to their knowingness of chronic illness; but this visible display was not and can not be isolated from other senses. The chronically ill body also challenges the western privileging of the five senses through the experiences of the embodied self (Waskul and Vannini 2006:37). The visual representations of illness chosen by participants are not held in isolation from the sensory knowledge of the

body and self. They challenge the privileging of the visible through biomedical testing and viewing the outside body in authenticating the illness experience. The visible representations reveal how these external forms of judgment remove ownership of the body and challenge the individual's sensory integrity in relation to their embodied experience of chronic illness.

### LOOKING IN: VISUAL IMAGES AND SEEING

Looking is not pure as multiple factors impact on the viewing process. Bal in examining the place of the visual explains this process of entanglement within the body by saying that 'the act of looking is profoundly 'impure' (2003:9). She continues to unpack this statement by explaining that the body's senses are enmeshed and that in looking, other senses, memories and experiences are triggered to create a more holistic looking. When we really look at an object, sculpture, artwork or image Paskow explains that multiple layers of spectatorship exist (Paskow 2004:160 ). Both of these authors show that in the act of looking senses and self are involved as we engage with the item. An example of the enmeshment of the senses happened during the research process, as when looking at the chosen objects participants' pitch of speech altered to reflect the narrative of the object and the way the object was held or referred to added to its meaning. The context and the way they expected me to respond also added to the sensory communication of the illness experience.

### IMAGES IN CONTEXT

Context is usually created through time, place and narrative which ground the image within a specific framework. It is common in visual anthropology for photographic images to be indicative of a time and place. Collier's image of a Navaho weaver is situated in time and place by the photographic equipment used, the clothing of the people in the image and the scene in which they are pictured (Collier 1967:1). Whilst my research does not have some of the same visual signals such as a dress or landscape, the "abstract" objects are still bounded in the time

and place framework. As with all images the photographer or researcher captures a moment on film or digital file that may not exist in another instance. In my research the photograph's time and place are predominately set by the discussions that accompanied them. The photographs of the objects without their narratives become abstract and ungrounded, without time and place.

Collier's images of technology and cultural practices, for example the image mentioned above, are visually accessible on some level due to its imagery (Collier 1967:1). Even without the title of the image it is possible to have a level of interaction with the photograph by looking at the woman's surroundings and her face. With my photographs the collection of objects can look confusing and whilst recognizing a piece of wire or a piece of fabric as what they physically are, there is no way of identifying them within the context that makes them relevant to the chronic illness experience. The connection between the story and the image must be upheld for both to find their true identities (Pink et.al. 2004:6). Research which uses drawing also can appear abstracted from its context as it can not be connected with a time and a place (Cross, Kabel and Lysack 2006:195). However they are bounded by the same time framework when connected with their narratives. Connecting the two in a visual dialogue broadens research methods and engages the body in the communication of experience. It also aids in assuring that the images are not taken out of context which continues to be a concern for visual methods.

### IMAGES AND ART

Few studies have been approached by asking people with disabilities and chronic illness to represent their experiences visually. Visual methods have been used with people with spinal injuries who were asked to draw pictures of themselves, to Harrison advocating the use of photography in eliciting an understanding of chronic illness and disability, to video diaries recorded by patients and photographic research

undertaken in hospitals (Cross et. Al. 2002, Harrison 2006:861, Rich and Chalfen 1998:).

Cross, Kabel and Lysack asked participants as part of their research process to draw two images of themselves which related to having a spinal cord injury. These simple line drawings resulted in more information than they expected, expanding their understanding of personhood for their participants (Cross et. Al.2006:190). The questions asked by the researchers related to how the participants saw their bodies after their changed status (Cross et.al. 2006:189). The images created both acknowledged the body and ignored it (through drawings of bodies and headless bodies) but all of the images spoke of the relationships participants had with their altered bodies. They stated that 'drawings allowed the investigations to enter and participate in the disability experience more deeply. This is an essential first step if efforts to advance theories of self, personhood and identity after disability are to succeed' (Cross et.al. 2006:192).

The dynamic of art forms to expand existing methods positively impacts on the ability of the researcher to facilitate the sensory dialogue. In *Working Images: Visual Research, and Representation in Ethnography* Pink, Laszlo and Afonso gathered together researchers from a variety of different fields who all used innovative visual methodologies and representations. Of particular interest is the work of Edgar, an anthropologist, who writes of his use of imagework to 'generate more holistic expressions of self-identities and implicit world-views than other current research methodologies' do (Pink et.al. 2004:90). His approach engages the participant's imagination as the start point and focus of the research process. Edgar describes four different types of imagework; introductory, memory, spontaneous and dream which involve varying outcomes and levels of involvement from the researcher (Pink et.al. 2004:93, 95-101).

Moreover, Perhaps uniquely in the visual anthropology field, imagework practice does not start with the production of external imagery, rather imagework begins with attending to the flow of the mind's inner imagery in a number of different ways.

Thereafter this inner world can be manifested in a number of external visual forms, such as artwork. (Pink et.al. 2004:95)

In the use of imagework Edgar explains how it is through verbal and art forms that the information is communicated (Edgar 2004:11). There are three main points of difference between the methods used by Edgar and my own. The first is the order of his process. Edgar's participants begin by visualising their experiences, then verbalise the reasons for their imagery followed by a visual representation. The second is that Edgar encourages participants to use the methods as a journey. One example of this is when he works with students and suggests they look at how they could alter their initial negative imaginings to give them a positive outcome (Edgar 2004:20). The final area of difference is that of representation where I use a collaborative approach to create composite hypertextual self-scape images.

### THE POLITICS OF VISION

The ability of the body, mind, spirit, self to display its status on its physical structure enables society to read it. As stated earlier a level of visibility is often restricted to professionals who use methods not available to the general public to see into the body. This knowledge is often surrounded in technical terminology which can be both comforting and confusing to the body's owner. Some of the ways we make visible who we are is by our actions, speech, dress, relationships etc...

However as stated this does not mean that chronic illness is merely a performance. In relation to my participants the "routine" of illness is an intensely private one which is shared only when trust is established. In creating the "MeBox" participants took their private experiences into a visual creation. This expanded how chronic illness was discussed and described especially when compared with interview methodologies.



The altering of speech during the interaction with the object and its explanation showed how the visual is not closed off from the body but is interwoven with memory, emotion, spirit, flesh, senses etc... Making an experience visible is therefore broader than recognition of a visual object captured by the eyes, which travels through the optical nerves to be translated by the brain into an image. The concept of visibility involves a tension between seeing, and looking with the senses creating something which is greater than the sum of an object's parts. Visual anthropology 'can not be used independently of other methods; neither a purely visual ethnography nor an exclusively visual approach to culture can exist' (Pink 2007:19). Visual and verbal narratives, when interconnected and kept in context, enable a greater understanding of the experiences of participants.

It is necessary to look at the different sensory modes, including vision, through which the world is presented to the mind, a fully synaesthetic and entwined integration of sensory modes to create the inner sensibility of human experience of which vision is integral (Csordas in Edwards and Bhaumik 2008:5).

The authority of visibility and vision on the body creates tensions when viewed from the perspective of the chronic illnesses ME/CFS, Fibromyalgia and Multiple Chemical Sensitivity. The lack of visibility on the body of its illness experience results in the self being misinterpreted. The visual signals on the body, in relationship to hidden chronic illness experiences, are over valued by society. Often 'seeing is believing' but in this case not seeing equals not believing.

## ARTFUL IMAGES

Images have a power to evoke comments and challenge preconceptions. Their ability to convey knowledge of their own has often been undervalued creating a poor cousin to the literary giant. Images have often been seen as less valuable in an academic environment as they

appear to be more open to misinterpretation and are more unruly than a precise flow of prose. Images however have the ability to engage the participant, researcher and viewer in a new expression of an activity or experience (Pink 2004:3, Pink 2009:122). Enabling a participant to communicate through visual and verbal systems supports the complexities of the chronic illness experience. The visual presentation chosen has the ability to create visual metaphors conveying sensory messages which mere words can not. In my method the objects become more than a single item within the boxes of participants but carry a story and embodied physical and emotional knowledge. The objects become metaphors of the lived illness experience and common western symbols like the clock can take on new meanings and new dimensions as will be discussed in chapter four.

The aim in anthropology is to create a rich knowledge about the people we are privileged to work with and the visual in medical anthropology has potential to do this. Visual methods have the opportunity to create a collaborative research process with participants connecting through the visual and the verbal using both to tell stories and explain experiences. Through this research I examine the value of both the verbal and the visual in communicating hidden illness experiences. As this is an academic work created for the completion of an MA the written will always need to play the main part but I hope to challenge the privileging of certain representations of data.

### SUMMARY

As a researcher I believe that it is important that I communicate the experiences of my participants who know personally of chronic illness. The best way to do this is through both visual and written communication. People with hidden illnesses need validation of their experiences of the body and through visual methods of creation and representation this data becomes more accessible. The fact that illness resides in the body means that communication of its experience also needs to engage the viewer's body to bring understanding of chronic

illness (Joralemon 2006:56). The literature exposes contradictions that exist around the privileging of visual in ways of communicating to “others” and the academic lessening of the role of the visual in scholarly representation. I continue to examine this concept of sensory and literary representation in chapter six.

Through the use of visual methods and later representation it is possible to reunite the written with the verbal to create images which expand our understanding of the chronic illness experience. This was done through the method of choosing objects to create metaphorical representations of the chronic illness experience. In the following chapter I will describe the method used in examining hidden experiences of illness.

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## CHAPTER 3

### METHOD AND PRACTICE

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In this chapter I will be describing the processes behind my visual method in preparation for the chapters that follow to situate the practice with the analysis. The research was undertaken in both group settings and in-depth individual sessions to look at how participants represented their illness experience. This focus on the visual came out of the research project I undertook in 2008, where my participants spoke about the difficulties of having ME/CFS<sup>8</sup> which can not be easily seen on or in the body. The struggle mentioned by my previous participants is one common to many people with chronic illnesses where their bodies can look well and yet they are in a great deal of discomfort or pain (Bell 1995:9, Wittenberg 1996:5-6, Charmaz 1997:108). The visibility of an illness influences the availability of help/aid and of being recognised as legitimately ill (James and Hockey 2007:133). The visual can lend social endorsement of an individual's experience. The visual therefore becomes privileged in knowledge hierarchy, the outcome being visibility = truth (Lipkin 2005:1). The importance of the visual signals of illness and "legitimate illness" was where I began thinking about my thesis.

The body presents the paradox of contained and container at once. Thus our attention is continually focused upon the boundaries or limits of the body; known from an exterior, the limits of the body as object; known from the interior, limits its extension into space (Stewart in Edwards et.al 2008:69).

The hidden experience of illness is often situated behind a variety of social and personal boundaries. Therefore the method and practise I used needed to address these boundaries in a respectful and

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<sup>8</sup> Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

appropriate manner. To address these boundaries I looked to different methods of gathering data which created an alternative participant observer dynamic. I chose a visual anthropological approach.

The research group was made up of 3 support group meetings, two from Auckland and one Hamilton support group, and nine in-depth participants from the same regions. The support groups are connected with the Associated New Zealand Myalgic Encephalopathy Society and people with ME/CFS, Fibromyalgia and Multiple Chemical Sensitivity attended these meetings. The 9 interview participants were from people who either had a chronic illness or lived with someone with a chronic illness. At the meetings and interview sessions participants were asked to put into a visual representation their experiences by choosing from a selection of different objects.

Whilst images should not necessarily replace words as the dominant mode of research or representation, they should be regarded as equally meaningful elements of ethnographic work. Thus visual images, objects, descriptions should be incorporated when it is appropriate, opportune or enlightening to do so (Pink 2007:6).

My original focus was to look at the rituals associated with chronic illness practise and with this artwork from participants which expressed living with chronic illness. As I spoke with people about the creative component of the research it became clear that this was the wrong approach. The ME/CFS support group I spoke with had many concerns about creating artwork or a craft project, which I will explain in greater detail shortly. Nevertheless the visual component has always remained important in gaining information and representing the embodied chronic illness experience as 'some aspects of knowledge can best be communicated by visual means...' (Pink 2006:16).

## CARE OF PARTICIPANTS

In putting the illness experience into a concrete visible form I was aware of the possible links to psychotherapy techniques (Rubin 2010:40, 270). This was not my aim and as I had participants who were concerned that the information they gave would be analysed in that way I was clear to explain this. I was aware in using this method that deeply personal experiences could be elicited and I ensured that should the need arise participants could access support through trained counsellors. I travelled with two trained counsellor's business cards so that help could be quickly accessed if needed. To look at a group of objects which could represent the illness experience could have been difficult and emotional but for the participants involved the comments they have made have shown it to have been a positive experience.

Energy levels and time available to give to the research also needed to be considered in designing my method. The time between the two interviews was therefore determined by the needs of participants to have space over the winter months for additional illnesses, as the bodies of people with chronic illness are more vulnerable to infections. It would have been helpful to me as a researcher if I had only separated the two interviews by a month. I instead separated the sessions by 2 ½ to 3 months as I wanted to give participants the opportunity to fully participate in the process and not be burdened with extra pressures.

### SUPPORT GROUPS

From the beginning I planned to go to several support groups and take a selection of objects for people to choose from, with the aim of making the hidden illness experience of these chronic illnesses more visible through the objects. I hoped that the objects would elicit conversation and that the objects would take something non-visual, illness experience, into a visual, object, realm.

I visited a total of three ME/CFS support groups in Auckland and Hamilton. These groups included people with ME/CFS, Fibromyalgia and Multiple Chemical Sensitivity which all have the common issue of

being difficult to diagnose due to their hidden etiology. Before the group met I would set up a table with all of the objects on it so that I didn't interrupt the meeting to set the table up. When it was my turn to speak I explained my research goal and asked participants to get up and look at the table and choose something they felt represented their chronic illness experience. As my research began before grant applications were due the objects I chose came predominately from around my house. The objects I chose to display had a variety of different textures, colours and shapes. I asked participants to choose something and then if they wanted to, to take it back to their seats with them. This made it important that people felt comfortable picking most of the objects up and turning them over.

One object could not be lifted, which was a broken pot, but participants spoke about it and usually referred to its size and weight as part of the reason for choosing it. The texture of the objects also became a potential piece of information participants could use to describe their experience. Each of the objects chosen for the table was carefully thought through although the reason for participant's choices often varied from my initial reasons for adding the objects. The following is a list of the objects chosen and the reasoning behind their original addition to the selection (Image 3.1 page 34).

- A. Pot:** Chosen because it was something broken, had a rough texture and sharp points; I thought this could be used to represent loss.
- B. Feathers:** Something soft and light which could relate to comments about 'brain fog'.
- C. Wire:** The wire was smooth and messy looking. It could also be changed into different shapes.
- D. Rocks:** I chose a variety of different types of stones thinking that participants would have a choice. These ranged from rose quartz to a dark roadside stone. The stone is something solid and rose quartz reflects light which could provide a person with the opportunity to talk about any positive or negative experiences.

**E. Fabric:** The fabric had attached to it small metal butterflies so this object to my mind had two different possible uses. The fabric is see-through and I thought that it may have been chosen and placed over someone's head to show hiddenness. The butterflies are fragile and are also the symbol used by the Australian ME/CFS society.

**F. Flowers:** These dried flowers could have been used to symbolise many different things. The two I thought of were that they were drained of their life and were now altered from their previous existence but still had a purpose. The second was because of a website I came across several years ago which was dedicated to obituaries written by people with ME/CFS saying good bye to their previous life.

**G. Book:** This was to add some brighter colours and had the connection to keeping records about health, journaling and narrative.

**H. Candles:** Most of the candles were slightly melted and I thought they may reflect fatigue.

**I. Candle Holder:** I wanted something with a spiral or Koru design for participants to talk about new life and family.

**J. Pearls:** This is an image which I added as it is an important symbol to me and I was curious about other people's reactions to it. For a pearl to grow it must begin with a grain of sand which gets into the oysters shell. The growth of the pearl almost kills the clam but out of it a treasure is created.

**K. Giraffe:** This object was given to me by my Supervisor and was an object she treasured because it showed grace in difficult circumstances.

**L. Pebbles:** These were smooth objects which I wanted people to feel comfortable turning through their hands. There were a large number so that people could pick up as many as they wanted and use them as markers to different experiences.

**M. Wide Weave Fabric:** This is a wide weave rough object. The variety of threads which linked and crossed looked like different roads or pathways.

**N. Glass:** Smooth cool object. This object was linked to the idea of drinking from the cup of life.



**O. Box:** This looks like a gift and I wanted to make sure that I included some positive images as well as ones that reflected a negative illness experience.

**P. Artificial Flowers:** The flowers again reflect the changed body experience of illness. I thought they also could represent artificial perfection and having to become aware of the real body's needs.

**Q. Spiral:** This was additional to the candle holder as I felt I needed a couple of objects to reflect these ideas. This spiral had beads at different points which I thought could be used as markers to a person's life.



### Image 3.1: Support Group Objects

The reaction to the table of objects varied widely with one person calling it a 'table of metaphors'. Another person thought it was an altar which included objects that the person whose home we were meeting in had found valuable and others approached the table warily. Many of the participants in these sessions told me that they believed nothing could express their illness experience.

At the support groups the objects chosen often focused on a single dominant aspect of the illness experience but as people spoke about

their own objects the rest of the support group would affirm the person's experience with narrative from their own life. One situation where this happened was when a woman chose the piece of wire. Mavis<sup>9</sup> came up to the table and made a comment that it wasn't possible to find anything, she said 'how can you represent ME in a physical tangible thing and yet after picking a few things up I found this.' Mavis had chosen the piece of wire (Image 3.1 item C previous page). As she explained her reasons for choosing the wire other members of the support group affirmed her. They also picked up on the fact that she had sat in her chair with the wire trying to unravel it and put it in order but was unable to do so. Mavis responded by saying

My life is chaotic and I like achieving goals and I'm achieving nothing, [lifting up the wire] it's up and down ... there's no structure it's all over the place.

Using participant observation enabled the gaining of this information which could not have been elicited in the same expressive way from only talking with participants. The visual component of the untangling of the wire created discussion and interest within the group and depth to her narrative.

The supportive story sharing was evident for all of the objects that people had chosen who had chronic illness and became symbols which elicited narrative. However whilst this happened for the members of the group with chronic illness this was not the case for one man who was accompanying his wife. He was given a limited length of time to explain his object as other members diverted the conversation away from his experiences to their own. I realised as I watched this happen that although people with chronic illness live a hidden experience the "voices" of the "carers" (to use the term adopted by WINZ and the Ministry of

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<sup>9</sup> All names have been changed

Health<sup>10</sup>) are even more hidden. As my ethics application had described participants as living with chronic illness I chose to include “carers” as participants of the in-depth sessions.

### INTERVIEW SESSION ONE :“MeBOX”

Initially I had planned on asking participants to create a visual representation of their illness experience through any medium they chose. I went along to one of the support groups with a “MeBox”<sup>11</sup> I had created (for an undergraduate paper) as I had used a variety of different mediums and I thought it would help to give people ideas of the possibilities. This support group which I had met with during my research project the previous year expressed their concern about this method. The difficulties they raised ranged from concerns about their abilities to create something artistic, not believing they thought in a visual way, to artists not wanting to be labelled as “chronic illness” artists. After hearing about their concerns I readjusted my practise to make it more accessible and people responded positively. I revisited the concept of the “MeBox” and it became an integral part of the research.

A “MeBox” is usually created by gathering together important items which represent different aspects of the person which can include hobbies, memories, important milestones family history etc... I refocused this creative project to centre on chronic illness experience. To help with the creation of the “MeBoxes” I altered the method I had used in the support group meetings and added a variety of different objects for people to choose from. The beginning of creating the “MeBoxes” would be at the first session by selecting from objects I had brought with me. Then participants were asked to add to them over a two month period between the interviews with anything else they wanted to.

For the interviews I again went through a process of collecting a variety of different objects which I would take to the participants for them to

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<sup>10</sup> <http://www.moh.govt.nz/moh.nsf/indexmh/disability-news-factsheets-carersguide>

<sup>11</sup> Appendix i

begin the process of creating their “MeBoxes”. The method in choosing the objects wasn’t as deliberate as the initial collection of objects for the support groups as I wanted to give as wide a range as possible. However I did include some of the objects from the support group table into the new selection. The objects were sourced from a variety of places (due to receiving a University grant) including emporiums, 123 Dollar store, e-thing, the garden and my own craft supplies. I added these to a large plastic box which I took to all of the sessions. I had planned to take the same objects to every participant but I found that as I went along many participants would mention things they felt should be in the large plastic box. I therefore added to it as the research progressed with the objects that participants suggested.

At the interview sessions I took along the large plastic box and a selection of coloured cardboard boxes (Image 3.2 this page). I began by laying out the objects and asking participants to choose a cardboard box to be their “MeBox” in which to put their objects.



The participants were told that the “MeBox” and everything they put in it would be theirs to keep after the research had finished as it would be representing their experiences. This enabled the participants to have ownership of the process and began a collaborative approach to the research. The “MeBox” format was also chosen to give participants a level of privacy as well as somewhere to keep the things they chose. This box was going to be with them in their homes as participants were

asked to add to the “MeBox” over a couple of months before the second interview and photographing took place. I had thought about using an art canvas and creating a collage of objects and items but dismissed this as I didn’t want the items to become awkward for participants to house. Next I asked participants if they would like to line the box with one of the coloured tissue papers that I had brought along. This became a very tactile way to connect with the box and participants often took great care over arranging the tissue in the box. I wanted this box to represent them and not simply to be part of my research so this physical connection became important. Only one person chose not to do this and they struggled with the rest of the task, their choice not to do this step may have contributed.

The next step was to ask participants to look through the objects and pick out anything that they believed represented their illness experience. The broad question was deliberate as it was to give participants time to look through the objects and give them time to think about what they would like to represent. Some participants were initially overwhelmed by the number of objects and wouldn’t know where to start. At the first session I displayed the objects on the large plastic box but I found this was clumsy and began to alter the way in which participants could access the objects.

Another issue related to the ownership of the objects and not wanting to mess up the display. Participants didn’t want to disturb anything, they were being polite. Before choosing the initial objects many participants would ask permission to select something placing the object in my ownership, but after they had chosen it and explained its meaning, they were placed in the participants “MeBox” and the objects changed to the participants’ ownership. To address the problems I changed the method by which objects were displayed making them more accessible. I added both a jewellery maker’s segmented display box and a shoe box which people could use their hands to explore through (Image 3.3 following page). Having the display container was very important as it allowed

easy visual access to the objects and an accessible place for participants to start by looking without having to touch. Usually after choosing a couple of objects participants became comfortable and were happy to rummage through the collection of things I had brought along.

As stated above participants were asked to select objects that they believed reflected their illness experience. How participants chose the objects varied widely but most began by looking at the changes in their life with the onset of illness; this resulted in creating a specific time frame for the “MeBox”, defining its narrative and visual description. I did not ask any more specific questions unless the participant was struggling for ideas. I would then ask about how they lived their daily lives with chronic illness and in doing this participant’s were able to find new ideas and concepts to visualise. These themes covered both positive and negative aspects of chronic illness. By the end of the session most participants were rattling through the shoe box and were much more comfortable with the process.



**Image 3.3 Large Plastic Box with display containers**

Once participants felt the possibilities for the objects had been exhausted I would draw the session to an end. This was often signalled by a verbal comment from the participant such as ‘well I think that’s it.’ The end of



the session would often involve discussions about what the participants would like to add to their “MeBox” over the coming months. On two occasion’s after I drew the session to a close, participants collected objects from their home and put them straight in their boxes. In one situation the participant went to collect something she had written some time earlier and read it to me before cutting it from the book she had written it in and placing it in the “MeBox”. She patted the box and stated ‘that feels good. It has somewhere to belong, that feels right.’ As I drew the sessions to a close I also asked participants to choose a mask and asked them to draw, write or paint on it which I will discuss in greater detail next.

### MASKS

The first mask I bought was a small one to add to the variety of objects in the large plastic box for the interviews. I had added it with the hope that it would be chosen and talked about in relation to the hidden illness experience. Towards the end of the first interview it was clear that the mask would not be chosen but I did not want to lose the possible information that could be gained from the mask. Instead at the end of the interview I handed the participant the mask and asked if before our second session they could write, paint or draw on it. This proved to be a valuable process for both participants and myself. The masks I gave out were unfortunately of varying shapes and sizes because of the availability of the paper and plaster of paris masks<sup>12</sup>.

On the front of the mask I asked participants to put what others saw of the illness experience and on the inside to put their own embodied knowledge. This task was approached in a variety of different ways. Not all participants chose to decorate the masks. One participant struggled with the process and chose not to do anything on his mask stating that he wasn’t a creative person and didn’t think that way. However a blank mask wasn’t always about difficulty with the activity. Another participant

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<sup>12</sup> I used this particular mask as it was strong and could hold paint, writing or collage.

didn't put anything on the mask as she believed it limited the masks potential. Instead she wrote in a separate journal the things she had thought about in relation to the mask. At her second session her motivation for leaving the mask blank was reflected in her using the mask to represent different embodied experiences in the photographing of the objects.

The masks are an important component because they enable a connection between the viewer and the creator. The reason the mask as an image is so important, I believe, is that the fabric of the mask has the ability to work as a representation of the boundary of the skin. The fabric of the mask stands between different places of experience. Another way to describe this is as a doorway where if you stand in the door jamb you can see two rooms allowing a level of access and visibility for the things contained in both places. Through these representations the viewer looks at the mask and they are invited to wear it and become connected to the person who made it. In creating the masks the participants have given viewers the opportunity to take on their experience and connect on a deeper level than words alone would allow. The masks can not reveal the whole story but enable different perspectives relating to the hiddenness of illness and how it can become visually accessible. Viewers are given a glimpse of the difficulties in living with an 'invisible' illness. The masks reveal how it is possible to be judged on what can not be seen.

The opportunity for participants to make such a personal experience visible shows how a simple visual method can reveal information about illness experience. The inconsistencies between the external assumptions and actual experience are clear in many of the masks and the distress and pain this causes are made visible. The narratives these masks tell are varied but they all communicate embodied truth through visible means. One mask focuses on the contradiction she feels between how she is perceived by others and how she sees herself. Another uses a reflective surface and asks the viewer to look into the



eyes of a person with ME/CFS and see the prison bars which represent being trapped in the body. The value of the masks was also reflected in how participants spoke about what they had created and their personal interactions with them. The masks will be discussed in greater depth in chapter five.

### INTERVIEW SESSION TWO: PHOTOGRAPHIC METHOD

At the second interview I took along a screen and cloth on which to display the variety of objects each person had chosen. After some deliberation I decided on red as the background colour as a place of unification for all of the photographs. The red was chosen as it represents the multiple blood tests many participants went through during the process of being diagnosed. The first photograph taken was often created together as we both displayed the objects for an overview of the “MeBox” and during that time we talked generally about the objects. On most occasions I would take the photographs but some participants chose to take them if they felt comfortable using the digital camera I had brought with me. After this initial image I asked participants to group the images under different headings. The questions I used related to issues associated with living with chronic illness which evolved from the first interviews. These were:

1. How does it feel physically to have a chronic illness?
2. What objects reflect loss due to your illness?
3. What objects reflect things you have gained from your illness?
4. Which objects reflect how you cope with chronic illness?
5. Are there any elements of the objects that are important, what other photographs need to be taken to reflect your experiences?
6. Is there anything that the objects or photographs miss?

For some this was easier than for others as the delay between the interviews meant some people had forgotten the meaning behind the objects they had chosen. In this situation I explained what I had recorded and asked what they thought they would choose them for now and we progressed this way. As we went on participants often

remembered the initial reasons for the objects and re-connected with them. In retrospect it would have been valuable to have pen and paper available at the first session so that participants could write down the object and why they chose it at the first interview<sup>13</sup>. Grouping the objects into these themes was effective in all but one meeting. The participant had struggled at the first meeting finding it difficult to choose objects that reflected his experiences and the outcome was a total of five objects. When I returned for the second interview he stated that he had put the 'MeBox' out of the way and in the process of moving had forgotten about it. At his second interview I took photographs, of the few objects he had chosen at the first session, without classifying them in the same way I had done in previous interviews (as I already had this information from the first session) and talked about a creative hobby of his instead. The information was still available as the participant used visual metaphors to describe his experiences, the information was very visual but it was not in the same format as other participants.

### PHOTOGRAPHIC PRACTICE

The photographer is often the unseen influence on the image and this effect can result in either support or domination of the subject being photographed (Prosser (ed) 1998:16,148, Pink 2007:99, Campany 2003:17). In the photographing of images the angle or viewpoint has the ability to impact on the way an image is represented. In rudimentary photographic technique an image taken from a high angle can give the impression of dominance over the object being photographed, where a low angle can show subservience to it<sup>14</sup>. In taking photographs I took this into consideration but due to the volume of objects I needed to take in one shot often the angle needed to come from above to fit everything in the frame. To combat this I also took individual close-ups that were taken on the same level to avoid dominating the objects or the person they were representing. Within the taking of the photographs I also

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<sup>13</sup> The reason for doing this rather than giving them a copy of the researchers notes is that it would take away from the ownership of the objects placing them back in the researchers ownership and the participant's connection with the objects was important.

<sup>14</sup> [http://photoinf.com/General/NAVY/Photographic\\_composition\\_Balance.htm](http://photoinf.com/General/NAVY/Photographic_composition_Balance.htm)

found that the final presentation of the images was an important consideration. These images were going to be representing my participants and I wanted to ensure that they did this as accurately as possible.

To finish the photographing interview I would plug my camera into my laptop and run through the images using the slideshow mode. This gave participants and myself the chance to look through the photographs, discuss their content and make sure that we had all of the images clearly photographed. This also gave a place to discuss the final two questions to gain clarity on what was important to participants. It ensured that information participants wanted to share that was not visual was also given an opportunity to be communicated. In all but two of the interviews I followed this method. The two I did not follow this method for were for two different reasons. The first because of the small number of objects chosen and the participant had struggled with the method at the previous interview. I altered this interview by taking the photographs and then talking about the illness in relation to his hobby. The second was due to comprehensive discussions about each of the objects, which covered the questions I would normally have asked. I had ensured that the photographs worked as I took the shots and the final two questions were discussed during the photographing rendering the finishing procedure unnecessary. Continuing to follow the same process as I had for other participants would have created an awkward and repetitive ending to the interview, from which she was already very tired, and I believe no new information would have been gained.

### THE MISSING

Many participants found that not all of the chronic illness experience could be shown through visual means. The main difficulty raised during the individual sessions related to how to show the “brain fog”. In the use of this metaphor a strong image is created but translating this into a physical object was one that many people struggled with. However it was interesting at the support group meetings that this was not the case.

On two occasions participants chose to describe their problems with their brains not working the way they wanted. The first person chose the small feathers and explained that they were her brain (Image 3.1 B. Page 34).

This is what my brain feels like, all fluffy. I can't capture my thoughts. My brain is all fuzzed up, it's just floating all over.

At another session a participant chose the piece of wide weave fabric and she sat gently working holes through it and separating out the thicker fibres. She also stated that it was her brain (Image 3.1 M. Page 34).

This is my brain. I chose this because I have Fibromyalgia and the worst thing for me is my foggy brain. It's loss in all sorts of ways. It's like you've lost bits of yourself all over the place.

Another area that was talked about was the insomnia and hypersomnia problems and not knowing how to represent them. At none of the sessions, whether the support groups or the individual sessions, did any of the participants find something that they felt represented this problem. One participant chose to include her medication for melatonin in a photograph about how she coped with chronic illness which could also represent her insomnia. Perhaps the closest image was of a sleeping bear for a participant who experienced hypersomnia sleeping periods.

### IMAGES OF CHRONIC ILLNESS

The final stage of my field work will be discussed in greater depth in chapter six but it involved posting back a combined version of the spoken and visual components of the two sessions together. Throughout the writing process my analysis and academic background inform the material I select and how I present it to the reader. This is also true of these images of chronic illness but due to their visual accessibility I have found the visual representations have resulted in a greater dialogue with

participants about the finished item. These images are designed to reflect in a visual format specific elements of both verbal and visual descriptions of living with chronic illness. Every participant received an image specifically created with their narratives and objects. Each image was posted out with a description of how it had been put together and I asked participants to comment on them or draw on them as they saw fit and return them to me. The comments that have come back have been very interesting and very encouraging as they have supported a collaborative approach to this research process

### SUMMARY

The place of the visible as expressive and representational is integral to my research method and practise. This focus has been essential as I found with previous research with people with ME/CFS a recurring theme was the hidden nature of the symptoms and experience of living with chronic illness. The 2008 research project, I believed, would give voice to the experiences of people living with this illness, therefore removing it from the invisible to the visible, but to be visible and communicate illness requires more than a written account. With this in mind I began by looking at how things became visible and took it to the literal representation of illness through a physical medium. This resulted in working both with groups and with interview sessions. The group, individual or couple interviews resulted in different images and alternative approaches as how to visually represent the hidden illness experience. In the following chapter I discuss the objects and the meanings assigned to them by participants. The objects reflected a variety of different experiences which expanded the narratives and expressions of chronic illness. In chapter five are the masks that participants created which directly refer to the physical hiddenness experienced by many people who live with chronic illness.

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## CHAPTER 4

### OBJECTS, NARRATIVE AND HYPERTEXT

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In this chapter I will be discussing the objects placed by participants in their “MeBoxes”. The objects chosen by participants show both common experiences and points of difference which make chronic illness an individual experience. Issues around lifestyle, pain and managing illness are all part of the illness experience and all are represented by the objects in the “MeBoxes”. Through the objects, metaphors for illness are imagined and meaning is assigned. ‘Metaphor involves a process of discovery or invention. Hence, metaphor is essentially creative of meaning’ (Kirmayer 1992:32). Participants have been able to express both the internal knowing and social expectations of the self through the objects in their “MeBoxes”. ‘Images play a central role in the human mind and in human discourses which are “metaphorically grounded” (Strecker in Pink 2007:32). I will therefore be discussing the visual representation of internal experiences and describing the hypertextual self-scape which frames and enables engagement with the embodied knowledge of chronic illness. I will discuss hypertextual flexibility and its creation by participants through verbal and visual communication.

I will begin by discussing looking-glass theory which looks at reflective surfaces to show the difference between hypertextual reflexivity and Cooley’s surface of the looking-glass self.

#### THE DISADVANTAGE OF MIRRORS

In focusing on the body’s physical representation or performance, whether healthy or ill, an inadequate picture of the whole person or “self” is seen. It is like looking into a mirror where reflected back is an insufficient two dimensional representation of the reality of self. In using the term self I am referring to an inclusive image of the body, mind, spirit,

relationships and social interactions. In illness all of these components become part of the chronic illness experience. For Cooley the looking-glass self represented how a person sees themselves reflected through “others” reactions (Charmaz and Rosenfeld 2006:37). This has some relevance to the hidden and visible chronic illness experience as “other’s” opinions and reactions to the way a person exists in the world impacts on how people interact and move through the world. Charmaz in examining Cooley’s looking-glass self writes about how the gaze of others can result in people with chronic illness being confronted by the ill body. ‘People’s assumptions about themselves may shatter when observers attribute to them the ‘worst’ qualities they can envision’ (Charmaz 2006:42). However illness is more than the assumptions by an outsider about the body.

The mirror Charmaz describes being lifted up by an observer limits the individual’s relationship to their own body. The self may be confronted by the misunderstanding of physical symbols but the relationship with the chronically ill body is unchanged. Its embodied sensory experience remains hidden. The lack of visible signs plays a part in the experience of chronic illness in the misinterpretations of the body and challenges to self. However this is a societal pressure on the self and does not encompass the whole chronic illness experience. The masks in the following chapter address this difference between external assumptions and internal experiences. The chronic illnesses ME/CFS, Fibromyalgia and Multiple Chemical Sensitivity do not exist in the reflections of others but in the body, hidden away from an audience. Using this traditional mirror metaphor confines the detail and complexity of the lived chronic illness experience to how “others” interpret the body.

### THE HYPERTEXTUAL SELF-SCAPE

Hypertext is a method of storing data through a computer programme that allows users to create and link fields of information and retrieve data

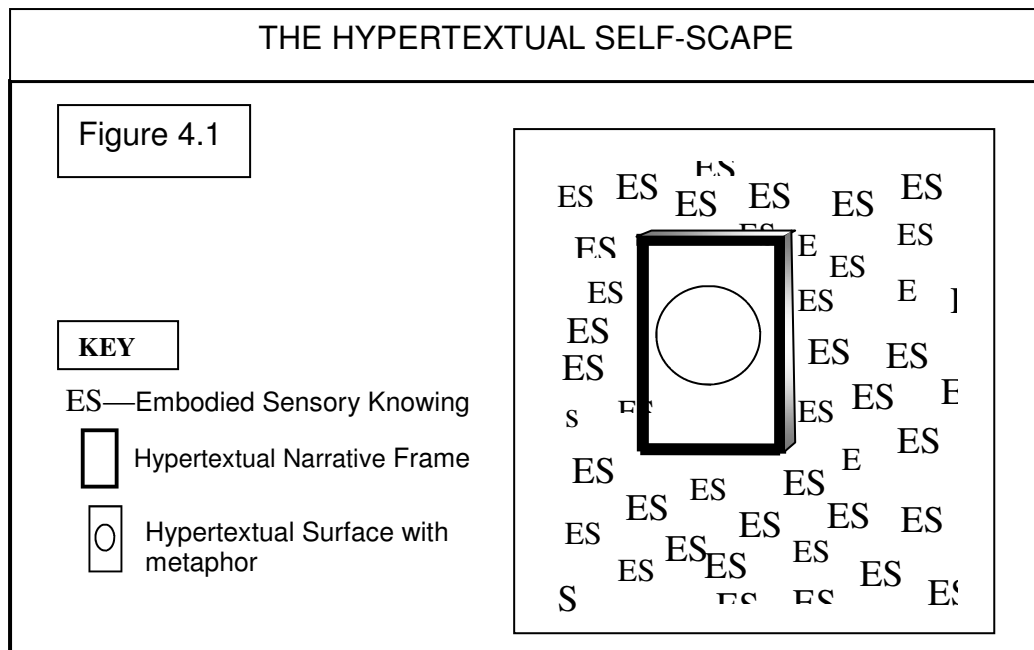
in a non-sequential way<sup>15</sup>. Here I am using it because hypertext enables an individual choice about how they will engage with information. Hypertext enables users to move backwards and forwards through information and data. It is based on linking images, text, audio and video in any way the user chooses and allows for options of looking, from an overview to exploring the depths of the information being offered. In using a model of a hypertextual self-scape it enables another way of viewing, moving away from the simplistic mirror model, to multiple reflexive hypertextual metaphoric surfaces within hypertextual narrative frames. These allow the viewer and the participant to step into and out of the various manifestations of self, thereby expanding the potential symbolic images of self and revealing the possibility of numerous representations of chronic illness experience. Hypertextual self-scapes allow for multiple levels of visibility to present a hidden experience.

The hypertextual self-scape is made up of embodied sensory experience, a narrative frame and a reflexive surface. The frame and surface are created when a person looks at their life and decides what experiences to represent and narrate. The sensory embodied experience is framed by narrative and held within its frame is a permeable surface where the object chosen by the participant as a representation of experience is held. The reflexive surface is created out of different experiences, memories and representations of the self (Figure 4.1 following page).

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<sup>15</sup> <http://dictionary.reference.com/browse/hypertext>

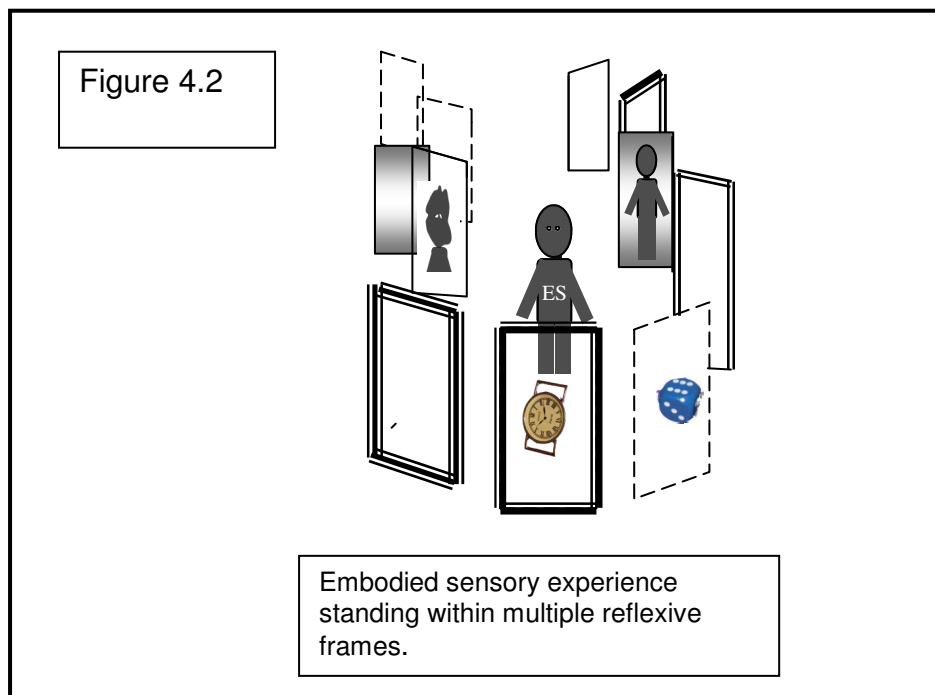




The hypertextual self-scape enables several layers of story telling. It begins from embodied sensory experience, it is represented through metaphor and framed in narrative. This reflects the process participants went through in choosing their objects. They began by thinking about their experiences, they chose an object to represent one aspect and then framed the object through their narrative. In this chapter I discuss the frame and the object chosen as they create verbal and visual narratives about self.

The hypertextual self-scape allows more than a mirror surface and creates a place of interaction and permeability that Cooley's looking glass self does not<sup>16</sup>. The hypertextual self-scape supports the multiple facets of human experience as places where self is created, examined and experienced. For example the frames and surfaces can develop from examining symptomology of chronic illness, moments of joy or grief, life defining events such as births and deaths as well as relationships can all become reflexive surfaces (Figure 4.2 following page).

<sup>16</sup> People with chronic illness often limit their interaction with other people due to the symptomology they experience or as a way to manage the illness experience.



Through the creation of multiple frames a web of the chronic illness experience is created. There are different types of surface are created which represent body, mind, spirit and soul etc. Some may contain perfect physical replications of the body or distortions of physical appearance, some contain an object as representation or are a frame of dialogue but all include parts of the personal and public lived experience. In looking in a mirror the hard reflective surface can reflect images which challenge a person's understanding of themselves. The Hypertextual self-scape represents an internal space permeable and reachable, holding experiences on multiple layers, including time and space which allows sensory embodied knowledge to be contemplated and communicated. The hypertextual self-scape has several levels of connection which will be discussed here and in the following two chapters. It is a format for expressing and holding a person's lived experience, sensory memories, personal meaning and personal discourse.

At the first interview as participants began reflecting on their experiences, individual situations, struggles and symptoms of chronic

illness. These created the surface and frame in which the objects were given meaning. Each individual frame contained a single visual representation of the participants embodied sensory experience. At the second interview objects were grouped. The result of changing to the group photographs of chronic illness was an extended representation of experience. Increasing its hypertextual visibility to a viewer. 'Instead of visibility as a defining property of the traditional object, it is the practises of looking invested in any object that constitutes the objects domain: its historicity, its social anchoring and its openness to the analysis of its synaesthetics' (Bal 2003:11). Participants chose what parts of the embodied sensory self-scape to gather together when looking at specific topics. This known experience flows outward into representation by assigning hidden experiences visual representations.

The importance of the hypertextual self-scape is that it allows an expression of a subject within a narrative boundary that it fluidly holds with consideration for what is represented. This is not a mirror which is a unforgiving metallic surface. The hypertextual reflexive plane holds characteristics of the self expanding beyond the external representation of the body. Through the choice of looking the reflexive surface allows the self to be contemplated through any means, not just the external body. This is shown with the objects in the "MeBoxes" and the participants' masks. In doing this a depth of meaning and understanding of the lived chronic illness experience is created.

The objects selected depended on how participants chose to visualise their experiences and were influenced by how participants chose to narrate their lives. The choice came from the self not the choice of "others". In the method of the "MeBoxes", looking into the reflexive surface of chronic illness resulted in images which encompass a variety of different representations of the experience. Through the boxes and the masks the reflexive surface is made visible using visual metaphors. 'Because of their embodied nature, metaphors create meaning not only through representation but through enactment or presentation' (Kirmayer

1992:337). In this situation the hypertextual frames and surfaces created by the chronically ill body reveals itself in the reflections it creates. In the hypertextual frames metaphors for chronic illness become visible.

#### “MeBOXES”: HYPERTEXTUAL SELF-SCAPE

The collection of the objects into the “MeBoxes”, as I stated in the previous chapter, often began slowly as participants became familiar with the objects and chose the items that reflected their experiences and had meaning and relevance to them. Their different choices showed how ‘intrinsically hidden in an object are multiple experiences waiting to be told’ (Paskow 2004:101). Here I will discuss the process in greater detail, along with the objects chosen and the narrative that accompanied them. The selection of objects I took with me was only to be the beginning of the creation of the boxes and participants added to them before and during the photographing of the objects.

The objects began by reflecting one particular aspect of the chronic illness experience, and the one I will be discussing here is time. The participants reacted to their “MeBoxes” in different ways and people were selective with what they wanted to add. Participants also struggled with how they wanted their boxes to look and one of these was Beth. She struggled with some of the items that she put in the box. On one occasion she picked up the wide weave fabric and stated:

I like it and I don't like it. I don't like that it's disorganised. I like my space organised. It stresses me to put it in my box, it represents tired. But maybe the box needs to have the negatives, they can't be ignored.

The box became an extension of her personal space and on several occasions she questioned whether she wanted items in her box. Beth was not the only participant who struggled with this. Many participants spoke to objects but chose not to put them in their boxes. There was on average one or two items that did not go into the “MeBox” and they all

related to negative experiences of chronic illness. For example Katrina chose not to add a piece of fabric that she had spoken about in relation to her bed. She did not want to acknowledge that she collapses on her bed on her day off and stated 'that doesn't need to be in there.'

This did not mean that nothing representing the difficulties of chronic illness was added. Everyone included items that did reflect the difficulties of living with chronic illness. For many participants when asked about excluding objects from their boxes they explained that they didn't want them to be a part of defining who they are. In creating their hypertextual representations they chose which frames to focus on and how they acknowledged their experiences. The dialogue between the objects and the chronic illness experience assigned meaning to the objects whether they were placed in the box or not. The meaning assigned to the objects was not foreordained but gained significance and history as participants examined their embodied sensory experience (Paskow 2004:106).

The way in which participants related to objects gave them meaning and a reason for placing them in their "MeBoxes". Participants embedded the objects in the reflexive hypertextual surface and with their narrative created a visual hypertextual frame of their experiences. One reflexive surface which all participants used related to embodied sensory experiences of time. Reflections on time resulted in different visual and representations and narratives. An example of this was the image of a clock which took on different embodied sensory meanings as participants reflected on its place in their experience.

## REFLECTIONS ON TIME

As I stated earlier the initial process for the participants was to choose objects which reflected a single element of embodied sensory chronic illness experience. I will begin by discussing one of the representations participants created, the hypertextual frame and surface of time. Experiences relating to time were the most important and consistently

represented image placed in participant's boxes. When contemplating the embodied sensory impact of chronic illness to scheduling, commitments and desires many participants saw these reflected in a clock. The clock reflected many aspects of time which is difficult to negotiate for people with chronic illness (Moss and Dyck 2003:116). Charmaz in writing on time, illness and disability discovered that 'temporal incongruence develops when time perspectives are incompatible and inconsistent with time structures' (Charmaz 1997:171). This was true of the hypertextual narratives and surfaces which represented time. To begin linking visually the hypertextual self-scape a black and white image of the object, chosen by the participant to represent time, has been placed as a watermark behind the dialogue that accompanied it. This is done to create the first level of visibility of a hidden chronic illness experience.

For Beth<sup>17</sup> time related to understanding her energy levels and the awareness of time caused by medical treatments. When I met with her she was at the end of her weekly B12 injection and was due to have another one in a couple of days. This meant that her energy was waning and that her ability to cope with the everyday was diminished. Time also related to her struggle with rushing and to need to do things at a measured pace.

Its interesting that I like that it's got the old fashioned numbers. It doesn't feel so in my face, in basically what I see time as. It's about time management and what I do with that time not how much time I spend on something or what activity I actually do. Rushing is one of my worst things, we've learned I need to take time rather than rush out. He likes to just leave to do things like go on holiday but I need more time. The word time for me also brings up the fact that it's that time of week when I'm running out

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<sup>17</sup> All names have been changed.

of time with my B12 injection. Time is quite a complex one really.

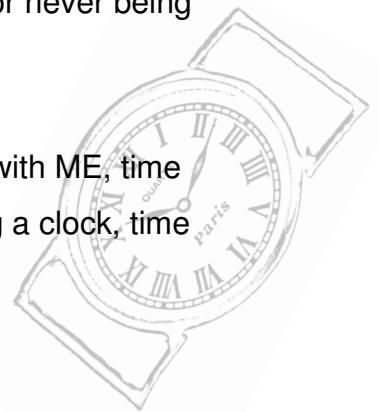
Beth

In speaking about the clock face Beth also remarked that of all the objects she had chosen it was the one that caused the most 'feeling response in relation to the body and emotionally speaking to it'. In holding the clock and speaking about the significance of the embodied sensory experience it became part of her description. I had noticed as I watched her talk about rushing, she began to breathe more quickly and became tense. When she recognised herself what was happening she slowed her breathing and relaxed her body.

Esther also chose the clock face which related to time and her symptoms. She described the disparity between well times and chronic times finding that when she was feeling well the time always went faster. She spoke about how ME/CFS does not have a treatment plan so full recovery is not something she expects to happen, but she tries to manage her symptoms. The long term time frame of the illness has resulted in completely changing her lifestyle and planning for never being 100% well.

The clocks not working, but I'm drawn to it because with ME, time just doesn't end, it just keeps going. It's like watching a clock, time can go so slowly and other times really fast.

Esther



Katrina was still working part time and for her time was dictated not only by her health but also by her boss and job. Time placed multiple expectations on her and she struggled to meet all of her commitments. Time was connected to who she felt she should be as due to her health, her loyalty and commitment to people was questioned. She began by looking at the difference between time before and after the onset of her illness describing how structured her time used to be. Picking up the clock she began:

I used to have to travel a lot to visit clients and then when I was back I had rehab clinics I ran. My time was very structured, but then when I was getting sick I had to finish the day early, go home and have a rest and then go back to work after hours to finish paper work. Time to me was not spent in bed feeling sick and not being able to do anything. Then when I was worse and could only manage an hour to do something. Then there were the better days but I'd not manage to get everything done. Time was wasted by resting in my thinking. I wasn't being productive like I was used to.

Katrina

The clock Katrina chose was a sticker which she attached to a luggage label that was also in the large plastic box. This visually reinforced the connection between time and when she received a diagnoses for her symptoms or as Katrina put it 'I finally got a label.' For Katrina her hypertextual narrative and surface revealed how time had moved from being structured and controllable to unbalanced and unstable.

The kaleidoscopic illness experience challenges the understanding of the self and can place doubts into the body and mind about its own abilities. For Karl, who also chose a clock face, time related to loss of consistency in his brain caused by Fibromyalgia. This resulted in a loss of confidence in his own abilities and frustration at his body for not being able to perform as he once had.

Your self confidence starts to go. I think I'm nowhere near as confident as I used to be. Even though I have a strong personality, that confidence level has gone. You start questioning your ability to be able to do things, y'know? That in itself then creates a downward spiral, because its almost self destructive to a degree. You don't know how to change it and then you may have a day you really feel like that and you're questioning everything



and then the following day everything goes so well, everything you've planned and thought about that you were going to do happens and you think that's the way I did it five or ten years ago. Then you think, maybe it is a head thing, and you start putting doubts into your own mind and you start questioning yourself.

Karl

Mark did not choose a clock face to represent time but a piece of wide weave fabric. For Mark time had changed and his expectations of what he could do and he and his wife could do as a couple was often dictated by Esther's good and bad days. Time for Mark was out of his hands by association with chronic illness, not by having it himself.

ME's like the fibres. It's a little bit unpredictable and you don't know where it's going to go, and ME is like that. You don't know when you're going to feel okay or not. When we first started dealing with it together, it was difficult. I had my lifestyle that I was used to. I had to adapt it to a safe lifestyle, not going out and having to have a structure and getting some awareness that if we do have to go out then the next day it's going to be difficult to do anything.

Mark

Amy the youngest participant used an alarm clock to represent time in a very concrete way. Time was something which controlled her waking but not her sleeping as sleeping was not consistent at night. The alarm clock reflected a body which didn't fit into circadian rhythms and the frustration of not being able to sleep at the right times.

The alarm clock does it because I use to have long sleeping and it was hard to wake me and at night I had no sleep and when I did it was difficult to wake me up.

Amy



Sleep patterns were also reflected in Amy's mother, Claire's, discussions about time. Amy's mother, spoke of how time changes with ME/CFS and spoke of the alterations she had made in trying to help with the problems relating to fatigue. Claire's hypertextual narrative showed how standard time frames for daily activities needed to be adjusted for Amy's ME/CFS. As with Mark's experience of chronic illness and time Claire was also a spectator of the chronically ill body. Her time was frequently spent waiting for the ill body. Time was spent in waiting for the body to achieve an activity, waiting at doctor's appointments and waiting for a diagnosis, time had become something unstable. Mark and Claire, rather than rebelling against the chronically ill body, have learned by experience, like their wife and daughter, to manage with the chronically ill body.

What I did learn very early was if she didn't want to get out of bed I didn't make her. There was no point in pushing it. Before hand I'd get her out of bed, put her clothes on her, sit her in front of her breakfast and get her organised but when she got sick we'd just have to wait. If you waited then you might get to work and school for a half day, but if you got her out of bed she would just collapse and the whole day would be gone.

Claire

The objects and their hypertextual narrative tells of the self in chronic illness. Time becomes dictated by chronic illness symptomology and that in turn impacts on the person's ability to cope with daily activities. People with chronic illness negotiate time through the fluctuating severity of symptoms. Time was carefully managed to gain the most possible out of both good and bad days and took precedence over external societal timeframes. In creating the hypertextual frame and narrative, emotions and physical sensations were the start point in visually creating representations of the embodied experience of time in chronic illness.

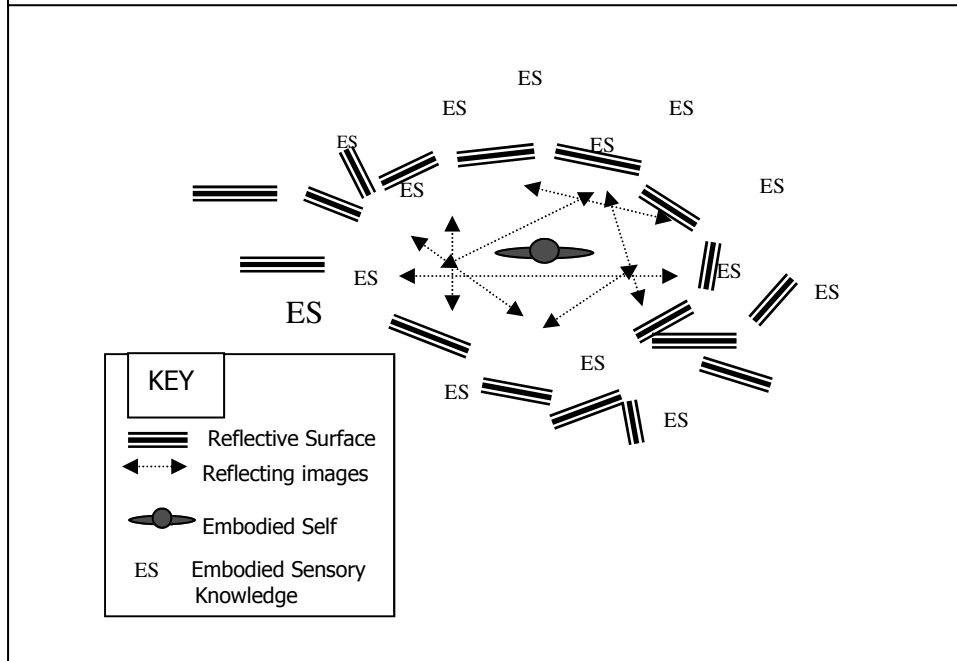
Charmaz describes the different relationship to time as 'one day at a time' mode, 'existing day to day' and 'recapturing the past' (Charmaz

1997:180,186, 194). Through these mechanisms, time and symptomology is divided into long and short term coping mechanisms. Awareness of the body and listening to the body redefines daily, weekly and long term timeframes. However for many of my participants there was not the expectation of recapturing the past, it was recognised as gone and this may have been due to the lack of medical understanding about the causal factors of ME/CFS and Fibromyalgia. Participants chose hypertextual surfaces of time wrapped in hypertextual narrative to relate their stories. At the second interview objects and narratives were grouped. These photographs and comments showed multiple hypertextual frames in a single photographic frame creating depth, time and space.

#### MULTIPLE FRAMES OF REFLECTION

The representations of time chosen during the first interview were included in a variety of photographs which expanded their initial meaning. At the second interview I chose four themes which approached different aspects of chronic illness. The initial question for choosing the objects had been sufficiently general to allow participants to choose how they represented their experiences. The topics for the photographs were more specific and arose from themes which evolved during the first interviews. In re-envisioning more information was created about the object and the experiences applied to the objects (Paskow 2004:97). By changing the format the previous hypertext around time encouraged flexibility between the various types and layers of representation. Through linking time with other hypertextual self-scapes depth of experiential knowing is explored. In drawing from the embodied sensory experience the self-scapes reveal another level of lived experience through their multiple hypertextual frames and hypertextual surfaces. The single frames and surfaces when gathered together show how issues like loss have multiple facets (Figure 4.3 following page).

Figure 4.3 Multiple Hypertextual frames and Surfaces



### SELF-SCAPES OF COPING

The previous section looked at a specific individual hypertextual surface. The next sections look at the combining of objects around a broader theme of experience. I will begin by looking at images which represent coping in which the clock image often appeared. This visual theme was unique in that many of the participants went on to collect objects in use from around their houses to be included in the photographs. This reflected the personal involvement of the participant. Many participants after the first interview had very few objects that were representative of coping strategies in their box and this may have been due to the fact that they were already being used. Anne began collecting objects that reflected coping at the end of the first interview by collecting an empty medicine container and several pages of writing. She continued adding objects at the second interview by including a photograph and a piece of fabric. Anne spoke about one of her coping strategies which was to realize that she was unwell and couldn't do everything she had wanted to do. Coping in the photograph was shown through her quilting, a blue fish and feather to represent her cat, butterflies which represented acceptance and shells that were about choosing new things to enjoy in

the loss of previous pleasures. These hypertextual narratives link to create depth of experience. (Image 4.1 included below).

Other people help, other interests help, they help a lot, the cat helps. Having medical or naturopathic medicine helps, and this is about introspection and reassessing. It all helps. The quilt helps to give me a sense of purpose. Planning ahead before having to leave work definitely helped. It depends on how you're feeling at the time too. I'm lucky in that I am well enough to have a life. Some people are bed ridden or house bound and surely being able to get out and do things and appear normal for a short amount of time must make a huge difference.

Anne



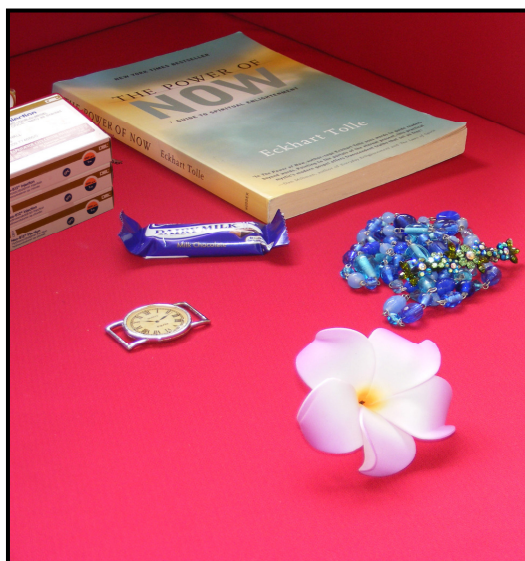
Image 4.1  
Anne's images represent how she copes with living with chronic illness. The objects represent her changed hobby, her focus on acceptance and her cat.

At the first interview Anne spoke about being mostly at home and that she needed to add a sense of purpose to her day. She did this through her quilting and enrolled in a course which would begin when she had to stop working. The feathers and the blue glass fish represent her cat and how important that relationship is to her. She explained Queenie was companionship and also meant that when her husband came home she

had something to talk with him about. 'He sometimes does the funniest things and I can tell my husband and I've got something to talk about rather than the illness.'

Beth also collected her medications, as well as other lifestyle reflections to show how she coped. One of the items she described as important was a book which she felt had given her the permission to live the way she needed to. Beth's hypertextual narrative reflected managing the body and feeding the mind and spirit. Within this photograph there are also images about playing and finding joy in moments as part of caring for herself.(Image 4.2 this page)

The biggest way of coping is acceptance and not feeling I should do the things I'm not able to do anymore. Acceptance encapsulates everything. With the *Power Of Now* it just shows how I just live absolutely in the moment. I can't plan things so I don't even try. I can't change what's happened so I don't let that be a distress so that it won't take away from my energy now. Like we're here talking now and this is my life in this moment and that's huge and I really like that. It makes it easier. So if I live this moment well and take care of myself and enjoy it hopefully that can extend to the next moment. Sometime physiologically things happen but generally I pay attention.



Beth

Image 4.2  
Beth's objects represent her focus on making the most of her life whilst living with chronic illness. Included are her B12 vials, chocolate, necklace, flower and a book that she has found valuable.

Both Anne and Beth have lived with ME/CFS for more than 7 years which may account for their focus on accepting their bodies as they are and not trying to fight against them. They have experienced pushing the body to meet societal expectations and have lived with the exacerbation of symptoms which were the outcome. Through their coping mechanisms Anne and Beth have shown how important it is to understand the needs of the self.

Coping with chronic illness takes on a new form when you do not personally have chronic illness. People with ME/CFS, Fibromyalgia or both have the ability to “check in” with their body and evaluate what is possible within a given day. The person without this embodied knowledge becomes reliant on a body outside their own to dictate the day’s possibilities. In Claire’s situation coping reflected support networks she has gathered around her from Amy’s school and her own work to enable the flexibility she needs to meet Amy’s requirements. In photographing the things that helped her cope Claire included her business card and her daughter’s school jumper which had not been in the box. (Image 4.3 following page)

You learn to value kindness in people. My work is really fantastic and gives me time off and Amy’s school has just understood her learning problem and have never pushed her too hard and have given her extra tuition in the things she needed. They’ve done the best for her.

Claire





Image 4.3 Claire's objects represent her family through the three turtles, money to cover the costs of medical bills. The heart was drawn by her daughter and represents their relationship. The final two objects are Amy's school jumper and Claire's business card to represent the support she receives outside of the family. The card and jumper have been distorted to remove identifying details.

Esther's coping strategies related to her faith and her friendships. She focussed on people that accepted her where she was, supported her rather than being a burden and didn't drain her low energy reserves. Empathy in her relationships was important for Esther and this was reflected in the beads she chose to represent her friends at the first interview. At the second interview one of them fell out of the box and we were unable to find it. When Esther realised the two letters H.E. spelt HE she was happy to do the photograph with just these two beads as they represented her friends but also her faith. She included the lyrics to an important song and her journal, as her poetry was an outlet to her experiences. (Image 4.4 following page)

I don't know if you know this song but it's called I look to you. It's about when you can't cope any more and you can't do it alone. It's about looking up to God and just turning to him. Here is my poetry book and of course my creative outlet. There's the H. E. too which represent my friends. I guess the H. E. is like HE which would be God.

Esther

Coping strategies reflected in hypertextual frames and surfaces show the variety of ways in which people approach managing chronic illness. The



ability to cope with chronic illness depends on both the individual, those in community and relationships with them. Through the multiple frames of representation shown in the individual photographs the depth and variety of coping strategies are explored.



Image 4.4 Esther's objects which reflect how she copes through her faith, friendships, creativity and singing

### SELF-SCAPES OF LOSS

The redefining to a new “normal” can be painful during the onset and management of chronic illness (Moss and Dyck 2003:134). Many participants had a large number of objects which reflected aspects of things lost. Katrina's photograph, like other participants, creates a hypertextual self-scape of loss. Katrina began by describing the losses she experienced at the onset of her illness. She then continued by explaining what objects reflected existing losses and all were placed in the same photograph. Showing the history of losses she had experienced due to her ongoing illness.

A current loss related to her work commitments. At work she struggles to keep up but rather than conceding to her body's needs she collapses on her days off in an attempt to recover from her work commitments. Some of her objects reflected this loss of security in her own body to

achieve daily activities. Katrina's losses related to both the crisis onset of her illness and how she is affected now as she tries to manage her life and her symptoms. During the interview she was surprised when she realised that the onset was approximately 19 years earlier. The losses whilst being pictured as an object often had a history to the story which reflected how long she had lived with chronic illness. She listed the losses in the photograph as follows. (Image 4.5 this page).

The car is loss of independence. Money is loss of income. Loss of continuity. Loss of time. I don't know what could show my loss of memory. The wool is my loss of crafts and the cross stitch, this ones got mistakes on it, it can be loss of concentration and creativity.

Katrina



Image 4.5 Katrina's image includes loss of ability to do craft work through the wool and cross stitch. Her loss of mobility and financial stability are shown through the car, purse and coin. The image of the clock also appears here to represent loss of stability and structure as the body now dictates what can be achieved in a day.

The car at the beginning of the list was associated with the onset of her illness as well as her current status. The car initially was talked about in relation to not being able to drive (which is no longer the case) to the present where she can not drive the distances she used to and often

asks other people to drive some of the way. Time which was discussed in an earlier hypertextual frame interacts with the objects in the image to create a complete experience of loss of embodied stability.

Anne spoke about loss as something that had taken place and that can continue to take place due to limitations put on the body in chronic illness, but she was determined that loss would not define her. Earlier in the interview she spoke of many people having health problems and that meant that being ill was not unique. This informs her philosophy to life and shows up in her discussions about loss. (Image 4.6 this page).

You have to find something instead of grieving all the time for what you can't do. You do grieve you have to grieve and all the stages of grief but it's about being a whole person and being able to feel happy and be kind to yourself because it is something you really like doing. People don't really prepare themselves for illness because it isn't going to happen to them. So in addition to feeling lousy, because you're ill, you have to give up all sorts of other things as well. It's really hard.

Anne



Image 4.6 Anne's image represents the loss of careers, her music and finances. The globe, fabric people and written sheets all refer to loss of ability to plan and control her environment and dreams.

In Anne's image about loss there are also the written pages she added to her box at the end of the first interview. In the pages she wrote about letting go of things being perfect and finding acceptance of her current situation. Anne's losses related to her previous lifestyle that had been full with work, an income, social life and her musical interests.

Beth in her journal spoke of loss and listed many of the things she had lost during the onset of her illness. Like Anne she had also had to give up her previous lifestyle including her career, her competitive sports and many social relationships. Many of the things that Beth lost were not represented in her image but she spoke about her chef's coat and her racket and that she would have like to have something to represent them. In the image is a small cat which represented the recent death of her feline companion. The losses were not all negative and Beth spoke about the blank mask and that whilst it represents not being fully involved in society it was also something she treasured as it gave her privacy. For Beth her image of loss was not all related to grief. The wide weave fabric and the dumb bell both refer to her loss of moving easily through the world. (Image 5.7 following page)

There's loss of social interaction and loss of lightness in self. As much as I like going through life with an optimistic accepting attitude sometimes things feel heavier than they need to be just purely because the energy's not there to manage it sometimes. I've lost the person I used to be prior to the ME but in saying that it is not so much of a loss, because I've reclaimed a part of me before I went into a life of responsibility.

Beth



Image 4.7 Beth's image includes losses of ability to move freely by image of the car and the piece of fabric. The money represents the loss of her job which is connected with loss of relationships shown by the felt people. Time is shown in the image as loss of previous timeframes is shown.

Loss of the familiar self is one of the many difficulties in adjusting to a chronic illness lifestyle (Charmaz 1997:49). All of the images have included representations of money which relate to lost careers and financial stability. The images also reflect the loss of mobility through the environment, which both Beth and Katrina chose to represent in a car. Loss and grief are part of the chronic illness experience and Katrina, Beth and Anne show how grief can also give way to finding a new way to enjoy life. Unfortunately the images even when part of a hypertextual narrative do not allow the viewer through the permeable surface of the hypertextual self-scape into a sensory knowing of the experience of loss described by the participants.

### SELF-SCAPES AND EMBODIED EXPERIENCE

The hypertextual narratives and surfaces on the physical aspects of illness are made both by people who physically have chronic illness as well as those who participate in it, such as Mark and Claire who live with people who have ME/CFS. Earlier I discussed Mark's use of a piece of fabric to describe time. At the second interview when we photographed objects that reflected the physical experience of chronic illness Mark



used the fabric to create a large wave and made pegs and paper money into a boat and added an anchor into the image.

The complete image was about the variability's of illness and his place in trying to anchor them in amongst the chaos. The fabric in this new format was still connected with Mark's descriptions at the first interview. It refers to the changeability of ME/CFS, but with the addition of the pegs he had previously chosen to represent himself and his wife and the money to represent the financial struggles they have, a more complex image is created. It is interesting to note that the image he created with the wave is still fluid and flexible and relates to the way he held and moved the fabric the first time he picked it up. Mark created a fluid, sensory hypertextual surface through the creation of this image. (Image 4.8 this page)

The pegs are fairly complex and the money is financial. Together they're like a sail boat and in the waves you're controlled by the wind and nature. There's a little bit of control but you have to go where the wind takes you. I'd better put the anchor on there too.

Mark



Image 4.8 Mark's image shows himself as the large peg that is holding a small blue peg which represents his wife. The money which is the sail refers to the small amount they have because Esther can not work. The boat has an anchor and sits on a swelling wave of fabric.

Marie's embodied sensory awareness impacted on the ways she described her experience. Comments around feeling that everything was out of control featured strongly in her objects about how it physically feels to have chronic illness. Marie explained at the first interview that she has both ME/CFS and Fibromyalgia which may also have impacted on the way she described her experiences. Many of the objects had similar roles to play in explaining her illness. Marie viewed the illness as taking away her whole self. She began by collecting the beads she had chosen at the first interview and spelled the word crazy. (Image 4.9 following page)

I like the crazy because not only do I feel crazy most of the time, people think I'm crazy most of the time because they don't understand what I live with or why I live the way I live or why I behave the way I behave and I can imagine a lot of people in my position being labelled as crazy. The mirror is kind of a distorted sense of self, because I know I'm not living my authentic life. I'm not the person I want to be or was meant to be.

The dice are how I am a victim of circumstance at the whims of the universe and I never know if I'm going to be sick as a dog or okay. I can't plan anything, I can't commit to anything but I know that the likelihood of not being able to deliver is high and it's just a roll of the dice whether I'm going to be okay.

Time is a totally different time concept to me ... I view clocks and watches as torture devices reminding me that I can't get my shit together. I'd like to be, I should be but it depends on the dice. The eggs are broken potential but we spoke about that. The nails are pain and also that thing that's in knots, that's pain and also confusion. I don't know how to put it into words. It's feeling like nothing makes sense, feeling overwhelmed.

The rocks are the rocks, some of us get more than others I guess. The tortoise is a creature that has to live in a shell. I've had to learn to develop a shell against other people and their condemnation, also against myself too because I beat myself up too for not being as together as I should be.

Marie



Image 4.9 Marie has multiple objects which reflect the physical experience of chronic illness and for her they reflected loss. Loss of a stable body is represented by the hand sanitizer the cat, pot, turtle, dice, knots of wood, lichen, clock and wire. The illness had taken away who she believes she should be and are represented by the feathers, door handle, stones, key, egg shells and beads.

Other objects spoke to the practicalities of living with chronic illness with a damaged immune system represented by hand sanitizer. The cat was a collapsible toy and she said that it represented not knowing when she would collapse and that the toy, like her, collapsed easily. Marie's experiences speak of somebody trapped in an unending spiral without any sense of it finishing. Marie also returned to an image she had spoken of earlier in relation to the feathers. Her hypertextual narrative of physically living with her illness predominately focused on loss as she felt that was the primary physical experience of chronic illness.



The feathers are a combination of colours. They're like Icarus's lost feathers, I've been robbed of light. .. they have something to do with lost potential. I can't fly, my feathers have melted like Icarus.

Marie

The despair of the illness experience is clear in Marie's description of how she sees physically living with chronic illness.

Amy related to the physical feeling of ME/CFS through her school experience and curbing of her activities because of an inability to do the same things as other children her age. The alarm clock initially chosen because of sleep and fatigue problems became part of this image along with the turtles and the object she chose to represent Dr. R.Vallings who had helped her with diagnosis and practical medical support. (Image 4.10 this page)

I chose the alphabet bead because before I got the illness I was nearly in all the top groups at school and I just went backwards. I get stopped from doing things like I want to win at cross country, but my body says stop.

Amy



Image 4.10 The physical experience of illness for Amy was represented by managing illness and losses. The losses are represented by the turtle, the shoe and the C bead. The managing strategies are represented by the alarm clock, chocolate and the blue glass bead to represent her doctor. The key represents her diagnosis.

Claire described having ME/CFS from a carer's perspective. She chose two objects, one large green outline of a person and a smaller blue outline of a girl. She then positioned the blue figure on the green placing it in different points on the green body. The different positions represented different levels of reliance on her by her daughter. The levels of care were caused by the severity of her daughter's symptoms and their circumstances. As the main carer a lot of the day to day care as well as pressures from outside their immediate relationship were dealt with by Claire. Claire later in the interview spoke of the support she received from her work place through flexibility in being able to work from home when necessary. There is also support from the school through extra programmes e.g. understanding Amy may not always be able to attend school and perform in the manner that would be expected of a child her age. But ultimately it was Claire and Amy who experienced chronic illness together. (Image 4.11 this page)

Both the figures have to be quite close in understanding, and Amy is a bit less independent with her needs. It's physically carrying her sometimes up the stairs if she's too tired to make it or if we're walking somewhere and she suddenly gets tired. Also, metaphorically, it's a bit of a burden the whole illness.



Image 4.11 These are three pictures put together to express Claire's experience of chronic illness. The large green outline represents herself and the smaller blue one her daughter. The different positions represent the level of care Amy needs and the difficulties of having a daughter who is chronically ill.

Chronic illness is an embodied sensory experience whether the body carries the diagnosis of chronic illness or not. Through relationships the chronically ill body impacts on those living with the person who carries it. This translates chronic illness experience into the unaffected body. Mark and Claire both live with the tensions of chronic illness connected with their relationships to the affected body. Their physical bodies are affected by the illnesses of their wife or daughter placing pressures and burdens on them. Carrying illness in the body is not the only physical experience of chronic illness.

### SUMMARY

The hypertextual self-scape through its framing of embodied sensory knowing reveals experiences of chronic illness. The frames hold multiple features which include time, space and sensory knowledge allowing each component to reveal information about chronic illness. The embodied sensory experiences and memories become part of the hypertextual frame and surface communicating the body and self's images of loss, time, and changed physical status. In amongst the changes to a chronically ill body coping strategies are created showing through the hypertextual self-scapes the resilience of participants and grief for the lost "well" lifestyle. The individual hypertextual frames and surfaces when connected showed representations of how it physically felt to have chronic illness, experiences of loss, the physical symptomology and coping strategies. The hypertextual self-scape is created through the mind, body, spirit, and self allowing reflection on experiences. The objects reflected, initially, have meaning for participants and through a hypertextual narrative they are explained. In looking at the objects and reading their narratives we are invited to share in the meaning of the image reflected and share in the hypertextual self scape which expanded and developed during the photographing of the objects. In the next chapter I will be discussing the masks and the hypertextual surface they create.

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## CHAPTER 5

### MASKS AS REFLEXIVE HYPERTEXTUAL SELF-SCAPES

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In this chapter I will be discussing the masks created by participants. I will also begin to examine the concept of how we interact with images and using Paskow's three levels of viewing, examine how images can translate experience. Masks in this research have become places which expose myths about chronic illness and reveal the complexities of living with a hidden illness experience. A central theme of the front of many of the masks is the judgements to which everyone is subject and relates to how the body's lack of visible display of illness is read and interpreted. The inside of the masks show the contradictions between the external observed body and the embodied internal illness experience. The masks enable a connection to the participants embodied chronic illness through their representation. Scarry in writing about pain describes how pain is effortlessly felt by the person in pain but the same information can not be transferred to the body not in pain (Scarry 2005:324). I will show that with the use of Paskow's spectatoral consciousness and using the hypertextual self-scape a greater communication to the person who does not have chronic illness becomes possible.

#### HYPertextual MASKS

Through these masks and the way in which the viewer chooses to interact with them, this transference or communication of a body in chronic illness can become more accessible; the outcome being a greater level of understanding through visibility. The hypertextual self-scape allows for more than its creation from experience but can also become a doorway into a deeper level of understanding for external viewers. The hypertextual surfaces through their permeability invite the viewer to decide the depth of understanding of the experience of chronic

illness they will interact with. The “MeBoxes” through the hypertextual surfaces represented by the objects and narratives, reveal a limited representation of chronic illness. Through entering the narrative frame and reflexive surface represented by the “skin” of the mask it becomes possible to engage with participant’s embodied knowledge.

The participants have gathered embodied sensory knowledge and framed it with a representation as shown in figure 4.1, moving from embodied experience to external metaphor (Pg 50). Viewers begin with the single metaphor, for example the clock, and the narrative frame. By moving into the surface and frame through a choice to connect with the story teller entry into another level of understanding about chronic illness experience becomes possible. The masks more directly reference the body due to their design resulting in participants treating the mask as if it were the boundary of the skin which made it possible to show both the external and internal experiences of illness.

This method allows both the hidden and external aspects of illness to be visible within the context of the mask, directly addressing the differences between the internal and external experiences of chronic illness. The Looking-glass self as described by Charmaz is relevant to how participants have chosen to paint the outside of their masks. However the internal experience as depicted on the inside of the masks differs dramatically from the outside. In contrast to the outside the inside, in many of the masks, is where experience overwhelms societal assumptions and the person in pain and dis-ease is revealed. However these masks are more than simply the outside or the inside but also reveal a hypertextual space where the skin both absorbs the external and holds the internal experience of chronic illness. This space is true of the actual body as the skin is a living breathing entity which surrounds the internal self and is subjected to the elements.

#### ON THE OUTSIDE NOT LOOKING IN – HIDDENNESS

These masks reveal the Gaze of “others” who judge the body for its right to experience the fatigue and pain which exist within it. Charmaz and Rosenfeld state ‘embodiment complicates self and identity’ but these masks show that multiple and single aspects of identity are all present in the one body (Charmaz and Rosenfeld 2006:37). Illness challenges self but it does not necessarily complicate the issue of identity if identity is looked upon as being multilayered or as a hypertextual self-scape where reflections interconnect, overlap and exist in experience, space and time. Where a person with chronic illness can choose, to some extent, where and how they represent their identity of chronic illness. Many of the masks show the clash between society’s reading *on* the body and the owners experience *in* the body. Again the body is more than its physical representation and is made up of mind, being, spirit, body, experience.

The masks reveal three selves; the “me”, “them” and “we” identities. The “me” is the internal experience of illness, the “them” are the assumptions of the external mask and the “we” are where both sides of the mask create a whole illness identity. This whole identity can be seen in the multiple conversations about looking so well and feeling so ill that are part of the literature of ME/CFS, Fibromyalgia and Multiple Chemical Sensitivity illnesses (Ware 1992:349, Bell 1995:9, Berne 2002:6, Moss and Dyck 2003:110, Charmaz 1997:36). These groups are by no means set but fluid as communication across the internal and external develops, melds and changes. This can be seen through the experiences of Mark and Esther who were newly married at the beginning of the year and had just moved in together. Both Mark and Esther are negotiating communication of the illness experience for themselves and for each other, as they try to understand each others point of view. Through the masks they were able to discuss their views of chronic illness using visual and verbal communication. The hypertextual frame and surface helps to inform participants and onlookers about experience.

As stated in chapter three not everyone used the surfaces of their masks. One of the participants who chose not to do this was Beth. Beth

did look at her internal and external experience of chronic illness but chose not to transfer this on to the mask. This was a conscious decision as Beth felt that putting something on the mask limited its potential. As the mask symbolize her experiences, painting, writing or drawing on it would have limited her representation of herself. (Image 5.1<sup>18</sup> this page)

I've lost the self I used to be prior to having ME but in saying that it's not so much of a loss. I've reclaimed a part of me before I went into the life of responsibility. Now I accept that my responsibility is to take care of myself and be a decent human being in the world. It's quite liberating. The mask is a neutral space, I'm still becoming. It's easy to have it blank because there are new experiences coming everyday.

Beth



Image 5.1 Beth's Blank mask which held possibilities.

She did write in the book she chose at the first interview and wrote about both the internal and external experience of ME/CFS. Beth's writing about the outside of her mask reflected how she managed her illness and to what extent she revealed her experiences.

Because I manage my energy and only do things when I have saved my energy and planned for them. I feel people often don't see my struggle with fatigue and brain fog – let alone my physical limitations.

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<sup>18</sup> Larger images of the masks appear later in this chapter.

Some people who I spend more time with do see the fatigue, and I have at times tried to explain some of my other limitations. I don't feel they comprehend to what extent it effects my everyday life.

Beth

In creating the outside of her mask Esther chose to represent how she presents herself to the world and what she allows people to see. 'To a certain degree, people can control the impact of their illness and disabilities on their surface appearance' (Charmaz 2006:40). The outside is beautifully crafted and she has chosen to leave the white unpainted. Her choice to leave the mask white and uncluttered reflects a common theme with the participants of control of environment in amongst the chaos of the chronic illness experience. The flowers represent how she crafts her external appearance but always her chronic illness is there, shown by the use of a veil, even when she chooses not to share her experiences. In amongst this carefully crafted person is a freedom to cry in public. Esther added pearls to represent tears that she is no longer afraid to cry and alters her public behaviour to match how she is feeling, crossing unspoken boundaries between public and private behaviour. (Image 5.2 below)



Image 5.2 The outside of Esther's mask



When you first look at it it's well presented and well balanced and everything is kind of perfect. I've got the red lips because although body doesn't feel like it's doing what it should be doing I can always speak the right words at the right time because my brain is still working the way it always used to. Even when I'm feeling really, really rubbish I can still keep a conversation going. My mouth is the way I cope because it's the one thing that never changes no matter how low I'm feeling I can still sing, I can still string a couple of words together in a conversation. The pearls are because I'm not afraid to cry in public. Now I think I am learning to be honest with my feelings.

The left hand side has a sheer cover because I feel 24/7 there's probably part of me that's veiled from the world it's sort of a protection, and unless you've been through it you can't understand. There's that meshing between you that's not letting things flow freely. The big ribbon flower is because I still like to be well presented. If I'm going to leave this house I'll look perfect, it's not often that I won't go the extra mile to look just right. The other flower is on the veil and it gives a sense of togetherness and beauty and I always try to keep that up. I left the mask white because with my ME I try to keep everything pristine, even myself. The side that's not veiled has eyelashes to show that I've become an observer of other people and I always keep my eyes wide open and I notice what is going on with other people. There's not much that can be hidden from me now. I was always pretty aware but now I feel like I'm more aware of people's inner being

Esther

In looking at the mask the first area the eye is drawn to is the mouth. Its colour stands out amongst the pale flowers and pearls. Esther has chosen to represent how she copes and how she remains a part of community as the initial connection with the viewer. It is after this that the rest of the mask can be seen. In this sense the hypertextual surface

is used to present who Esther chooses to disclose and reveals the boundaries between the visible surface and embodied sensory experience. Esther through visual representation has carried on her main ability to communicate verbally into a visual communication still connected with the mouth. This is true of the outside representations for both Beth and Esther as they negotiate what to share of their experiences with family and friends.

Other participants chose to write on their masks. Anne wrote about what people see describing herself through behaviours which represent “well” societal activities. The external body is still seen to function without obvious visual clues about its changed status. The only clues to the internal nature of her body are comments about her skin colour and her eyes (Image 5.3 this page). She explained that these can be misinterpreted along with the behaviours and activities she wrote about. Anne felt that she wasn’t a very creative person and wasn’t sure about doing this activity. Unlike Katrina or Marie the choice of black and white was not specifically done but was about what pen worked well on the masks surface. Anne, like Beth, used her mask during the second interview as part of the photographs of things lost and objects that reflected the physical experience of chronic illness.

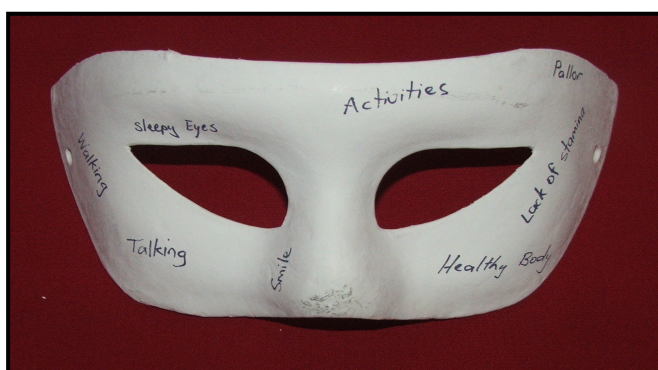


Image 5.3 The outside of Anne's mask

Marie and Katrina used words to describe the external impression of chronic illness and have included quotes of comments made to them by other people. The outside includes assumptions made on the external appearance of the body and Marie and Katrina's inability to perform certain social activities. Where Marie chose to use black pen on a white

background Katrina chose to write in different colours. For both Marie and Katrina the hypertextual surface contain judgements on their internal embodied sensory knowledge. Katrina explained that it was all so negative she wanted to make it look happier (Image 5.4 below).

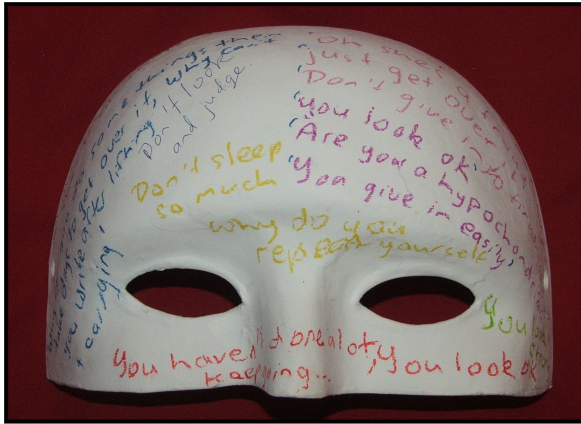


Image 5.4 The outside of Katrina's mask.

It felt pretty negative writing it up but I put it in different colours so it's a little bit more colourful and wasn't all black.

Katrina

Katrina did this for herself but also because she 'didn't want to depress people.' In Katrina's case many of the comments had been made by friends and family. Marie's were from neighbours and strangers and she specifically chose to use black and white because she felt that it was how people saw her (Image 5.5 below).

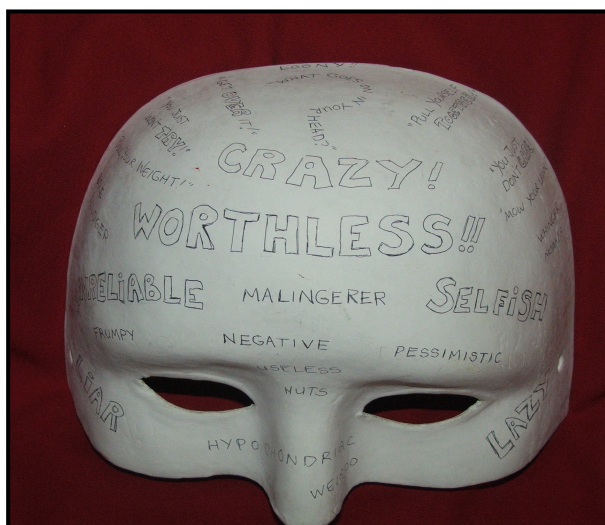


Image 5.5 The outside of Marie's mask.

To others it seems black & white. They have such simplistic opinions etc about my "problems" and what's "wrong" with me. I've even experienced this from my doctor

Amy's mask related to school and included the comments made to her 'try harder' and 'you're late'. At the top of the mask Amy focuses on not being able to keep up with other people. She shows a race with a turtle crossing the finishing line before she does. There are also girls chanting and holding a sign. When she described this part of the mask she sang the song she had made up for the girls which repeated the words 'Amy is slow.' Amy's mask also shows more external markers of illness on the body than the other participants in the research. The bags under her eyes, her snotty nose and the bruise on her nose all point to signs that exist on her body because of chronic illness. However the outside markers on the body do not help in people's understanding of chronic illness and like Katrina, Amy said 'the outside is about not understanding me'. (Image 5.6 below).

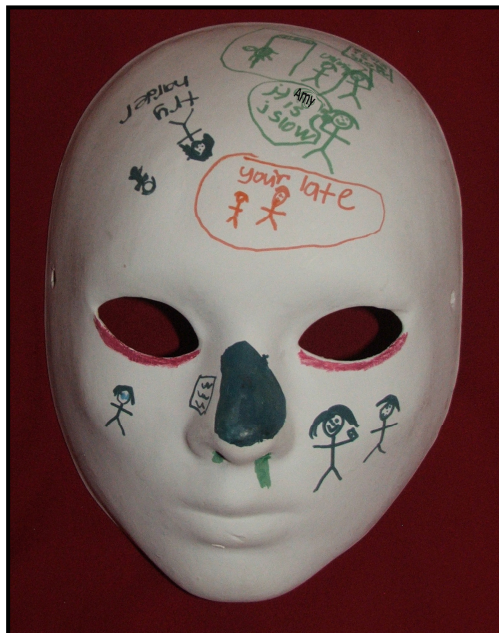


Image 5.6 The outside of Amy's mask.

This is the outside. The top green part is about being slow, this person is holding a sign saying Amy is slow and this is the turtle beating me. It's a race between me and the turtle and I lost. This here is trying to learn harder to ride my bike and this is me with

Irlen syndrome in my blue glasses. This is what I look like, I have bags under my eyes and that's a bruise because I keep hurting myself somehow and that's snot coming out of my nose because I've always got a cold.

Amy

The outside of the masks in representing the societal assumptions about the body whether managed or not reveal a societal narrative about expectations of an ill body. Whether wanted or unsolicited this discourse around the body and its place in community adds to the difficulties of living with chronic illness. The hypertextual self-scape of the masks contains embodied sensory knowing which engages the self as well as social and cultural expectations in defining chronic illness experience. In the next section the inside of the masks show the differences between society's discourse and the internal embodied sensory experience.

### ON THE INSIDE

In each of the masks there is a distinct difference between the words and images used to explain the internal and external experience of chronic illness. In the masks by Marie, Katrina and Amy the outside is created by the comments and assumptions of "others" to the symptomology and experience of chronic illness. Through the masks it is possible to see these external opinions do not necessarily correlate with the internal experiences or understanding of self. In Marie's mask she contrasts the external black and white negative assumptions with internal bright fluid colours. Marie is challenging the external voices rebelling against their assumptions about her self.

In chapter four Marie spoke about her difficulties with the illness but here on the inside of the mask she chose to contrast negative assumptions with beauty. Her internal mask focused on who she believed herself to be, even though she lives with chronic illness. The inability to be creative was one of Marie's greatest struggles with her chronic illness and she stated on several occasions 'I'm a painter who can't paint.' Choosing to

make the inside full of colour reflects her creativity but also one of her greatest losses. Marie also said she was somewhat unhappy with the final product as she wanted the interior 'to be more magical and intricate.' (Image 5.5a this page)



Image 5.5a The inside of Marie's mask.

To others it seems black and white. They have such simplistic opinions about my problems. The colours represent the amazing world inside that no one ever sees or acknowledges. The rainbow colours represent creative energy, the creative self, the magical mind and inner world. They emanate from a spiritual centre, some might call it the third eye. They have a swirling movement, energy in motion.

Marie

The brightly painted interior reflects loss caused by her symptoms and finances as she is unable to buy art supplies on a benefit. The pattern of the colours in a wave represented movement, creativity in motion, but for Marie's lack of energy represented lack of creativity. The hypertextual frame and surface allows colour, fluidity, reflexiveness, and creativity to blend, meld and reform across the whole hypertextual self-scape.

Mark's mask also addresses the inconsistency between the external and internal representation of illness. The outside of his mask is covered with faces undistinguished from each other. In taking a deeper look into the eyes of the mask the body is revealed to be imprisoned in its



experience of chronic illness. Mark represented the limiting effects of chronic illness and the control it exerts on the body (Image 5.7 this page).



Image 5.7 Mark's mask.

On the outside the mask is what everyone else sees, there are so many different people in the world, yes there are European, Maori and different cultures but they kind of look the same. You can't tell what's going on inside from their outward appearance. You can't tell who's got it. For someone like me who doesn't experience it from the inside outward but I guess from the outward in, you have to look closer and then you can sometimes see what most people are feeling like their body is a bit like a prison. They want to be outside doing things but their body restricts them.

Mark

Mark's mask differs from the other masks in that he has created it as someone who doesn't have the illness, as an onlooker to his wife's experience. His experience of not knowing by looking at the outside of a person covers the outer hypertextual layer. His collage of faces are all different but being placed on the outside of the mask shows that they are only the outer representation of the person. He painted bars on the inside of the mask and then placed a piece of cardboard covered in polished tin foil over the back. He did this so that it was possible to only see the reflection of the prison bars as a reflection of how a person with

chronic illness lived. This mask shows through its design how hypertextual self-scape creates a permeable surface inviting the viewer to look more deeply. Mark's image of the body as a prison is experienced by the person with chronic illness which is represented through the bars he painted that line the inside "skin" of the mask. As an observer he shows that only through looking with intention is the captive body revealed.

Esther's mask is significantly different on the inside. It changes from white, cream, pale pink and red to simple black and white. For Esther this was how she lived her life, she lived in the shadows and due to her fatigue and pain everything had to be black and white. The white highlights the lips and has been created to echo the red lips on the outside. The lips represent speech but from a different place, the white represents the internal known experience of ME/CFS which is held back and the red, the external representation of the self. For Esther the lips represent how speech regulates the information she shares with friends and family. A white pulse line travels through the black forehead of the mask. There is one place where it flatlines and this shows the days which Esther described as her worst days. (Image 5.2a this page)



Image 5.2a The inside of Esther's mask

The inside is just a lot of shadow. The mouth is there and it's white because the things I speak are pure in the sense that I don't



tell a lot of people what's really going on because I still have this sense of not wanting to bring other people down. I'm just trying to get through it alright. Apart from the mouth the only thing I have is the pulse line because I feel like it's just one breath after another and sometimes I feel like I'm flat lining and that everything is over, but it always starts again and you keep breathing and you keep taking each day as it comes. Inside there's not much going on there's just me and the ME taking each day as it comes. Inside it's a lot less complicated than what people see on the outside. The other reason for the black and white, my husband will be testimony to this, is black and white is all I am I don't do shades of grey. The outside of the mask is white, pristine and positive but inside, it's just black

Esther

At the top of Amy's mask is her brain. She describes the problems she has by using a filing cabinet where the files have all fallen out and she can't work out where they go. Amy depicts her brain as being like an office and the worker inside does not know what to do. The second most dominant feature of the mask is the eyes which have been coloured yellow. The yellow around the eyes represents a cross over between the outside world and her body through sun light. Amy had recently been diagnosed with Irlen syndrome which is a light disorder where the visual pathways can not regulate light and it affects a person's ability to read and write. There is initial research that shows that this could be a common problem for people with ME/CFS (Robinson, Sparkes, Roberts and Dunstan 2004). One image that appears on both the front and back of the same cheek is chocolate. Amy frequently referred to chocolate and every comment was made with a huge grin. (Image 5.6a following page)

This is my office and the wind has blown the files away and there are no labels on the files or on the drawers where the files go and the worker's going, I don't know what to do.

Amy



Image 5.6a The inside of Amy's mask.

Amy's mask more than any of the others has links between the front and back. Her important chocolate is seen on the outside but the girl watching her is confused about why she is eating it. On the inside it becomes a coping mechanism and a positive thing to look forward to each day. The other cross over between the two sides is Irlen syndrome. Like her ME/CFS Irlen syndrome is not visible from looking at the outside of the body. The only possible sign is squinting eyes whilst reading or reading and writing in a darker environment. Through the wearing of her glasses Amy translates her internal experience to coloured lenses which correct her light problems. On the inside the yellow light is bright and dominates the eye, on the outside a girl with a small pair of glasses smiles.

The inside of both Anne and Katrina's masks continue using words but the content of the words changes. For Anne the words are symptoms of her illness experience which exist alongside the word 'isolation' which is the consequence of the symptoms she describes. Again the hypertextual skin of the mask gives a much greater depth of understanding beyond the perceived surface of the external body.

The choices of descriptive symptoms are predominately around the brain and this may be due to the shape of her mask as she had described

other symptoms and experiences during the interviews. In this situation writing on a body mask may have elicited greater detail, as in the interviews Anne spoke about how the whole body was impacted by chronic illness. (Image 5.3a this page).

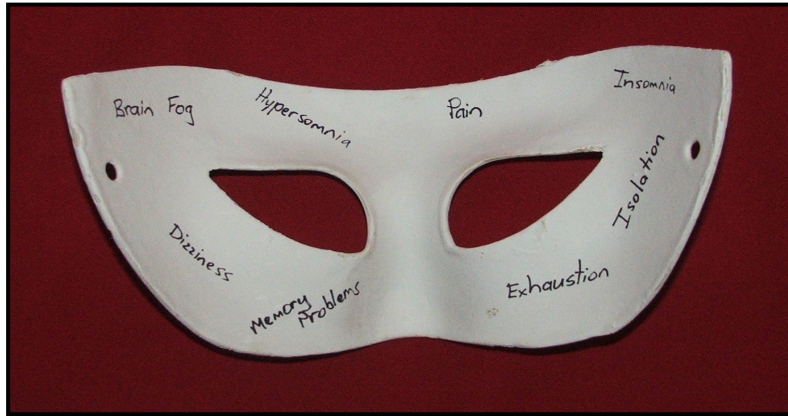


Image 5.3a  
The inside of  
Anne's mask.

Katrina chose to use the inside of the mask as representative of the whole body and it is covered with words describing her symptoms. Like the outside the inside is in colour so that it is not too depressing. When we discussed her mask she was concerned that I couldn't read it and read out all of the internal comments to make sure that I had clearly understood. After reading it out I asked her about the process of creating the mask and she said. (Image 5.4a below)

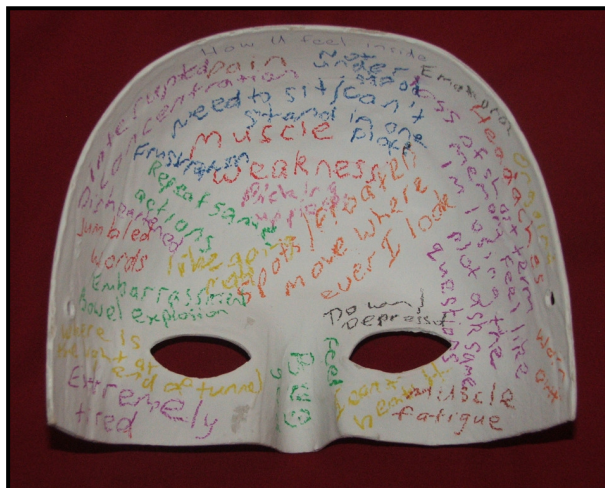


Image 5.4a The inside of Katrina's mask.

I know I live with it but when you look at it like this you think oh shit that's a lot of stuff.

Katrina

Beth explained her illness through the use of journal dialogue by asking herself questions and answering them. Through Beth's writing it is possible to see some of the more difficult things she experiences with chronic illness which did not come up during the creation of the "MeBox". This has further shown the value of using different visual techniques during the interview process.

How does one explain the complexities of the many subtle and not so subtle stresses I feel now especially in the brain? Only a person with ME can understand some of the bizarrer feelings you describe as part of your everyday life. It's like trying to describe a headache or migraine to the lucky people who never get them.

Headache? Well they can last for days and can be painful and can make me feel sensitive to light, pain, temperature, which is part of ME anyway but add a headache and one just can't function in any useful or enjoyable way. They just suck the joy right out of your day – days.

Beth

The masks show the complexity of chronic illness and how the body and self can be misjudged. The masks were created with the purpose of showing the differences between internal and external experiences becoming representations of the hypertextual self-scape of chronic illness. Through the development of the masks an understanding of the greater level of experiential meaning and self knowledge brought up awareness of the permeability of the skin. The masks hypertextual reflexive surface or skin extends into the self and through visual metaphor supports and enhances an understanding of participants own embodied experience. In the next section I discuss how viewing affects our ability to engage with the hypertextual self-scape. Viewing contains complex issues which are a thesis in their own but I would briefly like to look at Paskow's work on engaging with images and the act of looking. I

am doing this because in making chronic illness visible it implies their will be a viewer.

### VIEWING IMAGES

In creating the masks participants were aware of two levels of visibility that were taking place. In choosing to do the masks participants revealed their hidden experience, creating them for themselves and for people who will be viewing them, enabling a hypertextual crossover between participants known embodied experience and the unknown viewer. Through the collaborative process between the creator and the viewer the surface of the hypertextual frame becomes porous and a pathway to the sensory experience of illness is made. The Masks, like a painting, become an object which represents a reality and as with painting connecting with an image is more than deciphering a visual puzzle (Paskow 2004:161). It is a place where the metaphor of the hypertextual frame and surface brings in a reflexive framework to inform both the understanding of the participant and the desire to reach the uninformed observer.

Paskow forwards three different levels of viewing and engaging with an image which are relevant to the viewing of the masks and the images which appear in the next chapter. These are 1. The unreflexive and affective experience of the initial recognition of an image, 2 Reflexive effort in which we try to understand what the creator means by the image, and 3. Evaluative effort which investigates a piece of work in the light of its techniques, style and theorising about images (Paskow 2004:159, 205). Paskow's aim in examining the first two levels of spectatoral consciousness is 'to indicate a way of dwelling with or inhabiting the subject matter of painting to allow them to speak to us more clearly than they otherwise might' (Paskow 2004 158-159). This is also relevant for other visual methods used like those in this chapter and chapter six.

Paskow describes these levels of viewing as taking place in the order he mentioned but did not consider the context in which images are presented. Because of the academic nature of this thesis the images are not shown to a receptive, prepared audience as a painting in an art gallery would be. They connect with the viewer at the second level where reflexive effort involves analysis of the meaning behind the images created. Wollheim put forward the theory of the first and second spectator, the first is the scholar and the second creates a “virtual reality” inspired by the image they are viewing, creating participation through the internal experience of the image (Paskow 2004:165-166). Wollheim’s first and second spectator and Paskow’s spectatoral consciousness challenge how pictures are viewed and give different places from which an image can be viewed. These different places of viewing enable a sensory connection with the images and a theoretical place from which to interpret the art work. However, Paskow states that ‘to experience a painting appropriately, one must live in its world, to experience it as an incommensurable, existential event’ (Paskow 2004:191). In looking at a painting it is possible to connect with its “world”. The chronic illness experience expressed in these masks and the images in chapter six invite this spectatoral view through the viewing platform of the hypertextual frame and surface which invites observers to enter in.

Masks have the ability to translate both the internal and external experience of illness taking the viewer to a different experience or space, creating Paskow’s ‘existential event’. In many cultures wearing a mask means taking on a new persona and embodying that being, god or object (Levi-Strauss 1979:10). Connecting with a mask or an image requires the viewer becomes personally involved removing distance between the viewer and the creator. Paskow writes about stepping into an image as if stepping into a dream but in this situation a nightmare may be a more accurate description. He challenges viewers to enter ‘into its world, visually and quasi-corporeally, and with our imagination and uninhibited emotions, gradually allowing its content and implied issues to be blended with those of our own world, just as we might do when listening to a

family member's or dear friend's complex personal problems' (Paskow 2004:175). Each mask is a personal representation and reveals something different about the person's illness experience. In entering into its world, by wearing the mask, the words and art touch the skin and can pass through that barrier to inform on the self-hood of the viewer. I would now like to challenge the reader to re-look at the masks with the thought of placing the masks on themselves, to embody the illness experience, to feel the experiences on the outside informing your body of its external identity. To then look at the internal mask and imagine physically putting on the mask and in doing so touching the skin would be the reality of the internal experience.

REVIEWING THE MASKS – In the next twelve pages the masks have been enlarged and show more detail. This has been done to enable entering into the mask creating a hypertextual “virtual reality” to connect with the experience of chronic illness. The connection with participants through the masks reveals the permeability of the hypertextual self-scape.



Image 5.1b Enlarged view of the outside of Beth's mask.





Image 5.1c Enlarged view of the inside of Beth's mask.



Image 5.2b Enlarged view of the outside of Esther's mask.





Image 5.2c Enlarged view of the outside of Esther's mask.



Image 5.3b Enlarged view of Anne's mask.

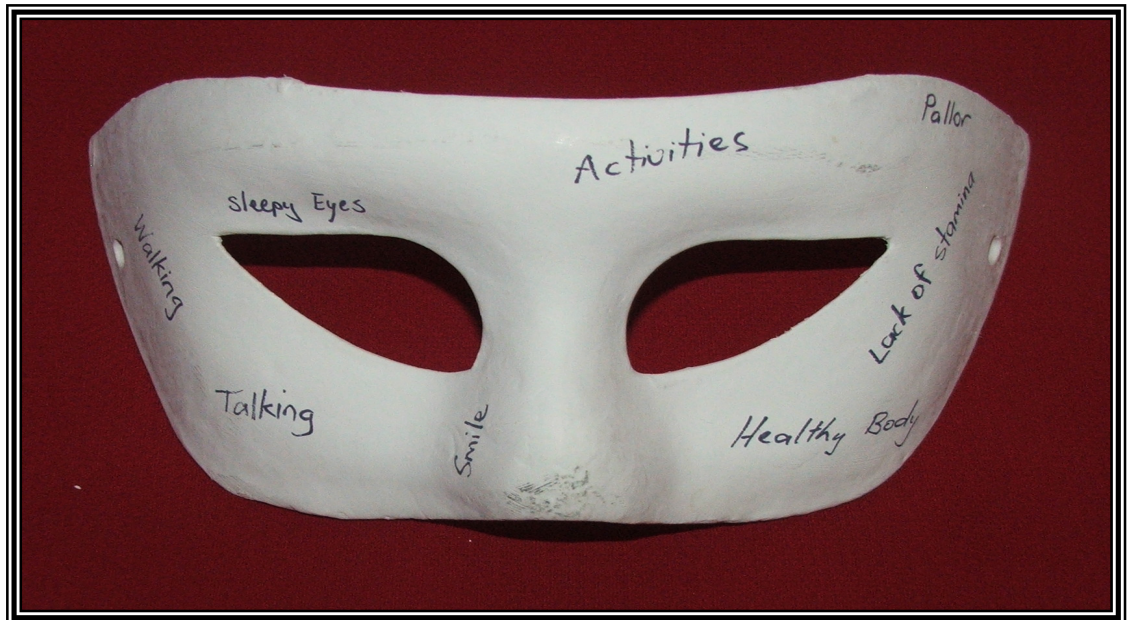


Image 5.3c Enlarged view of the inside of Anne's mask.

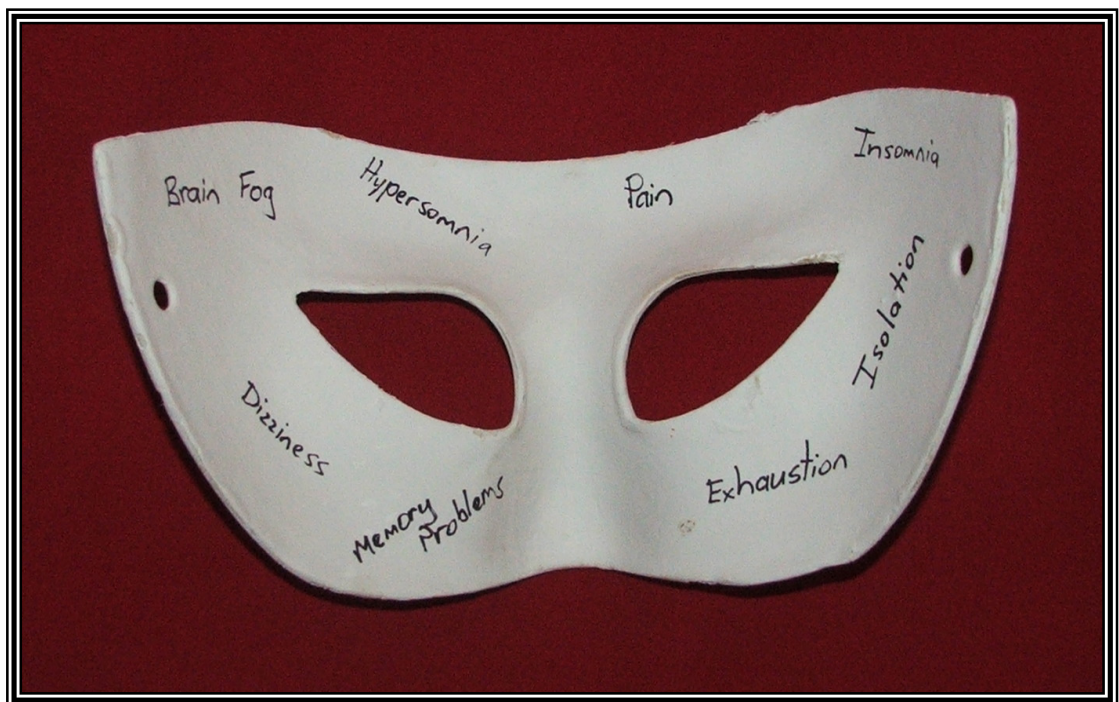




Image 5.4b Enlarged view of the outside of Katrina's mask.  
Including photographs of the sides.

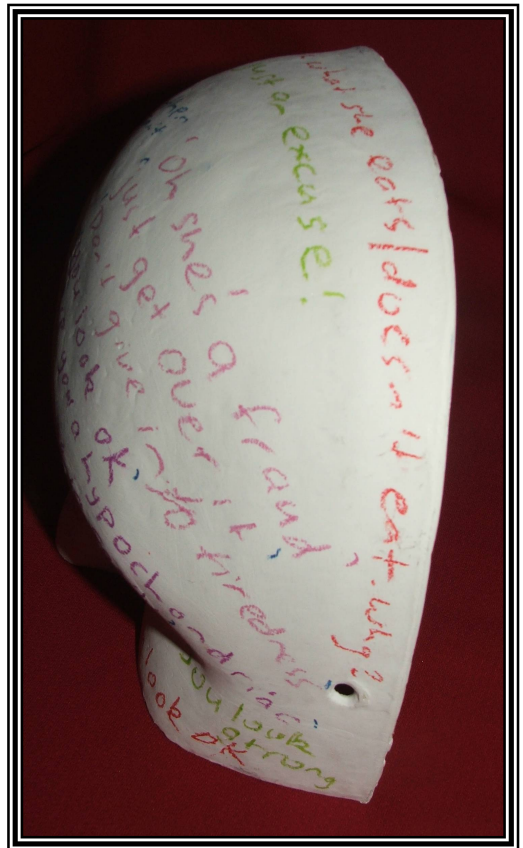
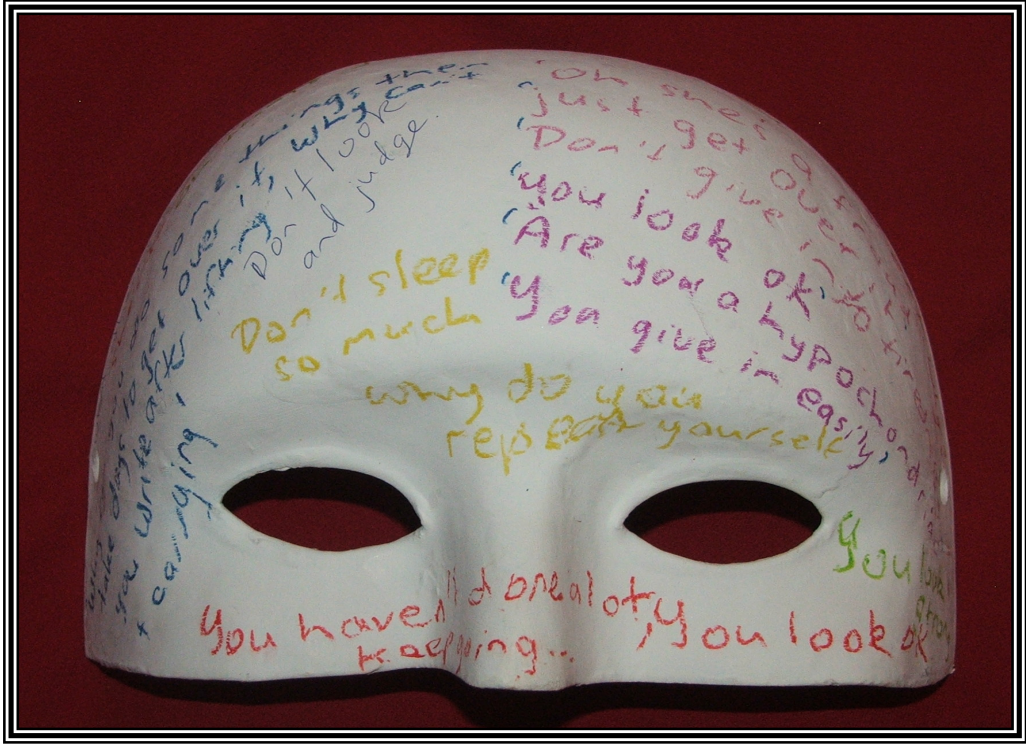


Image 5.4c Enlarged view of the inside of Katrina's mask. Including photographs of the sides.

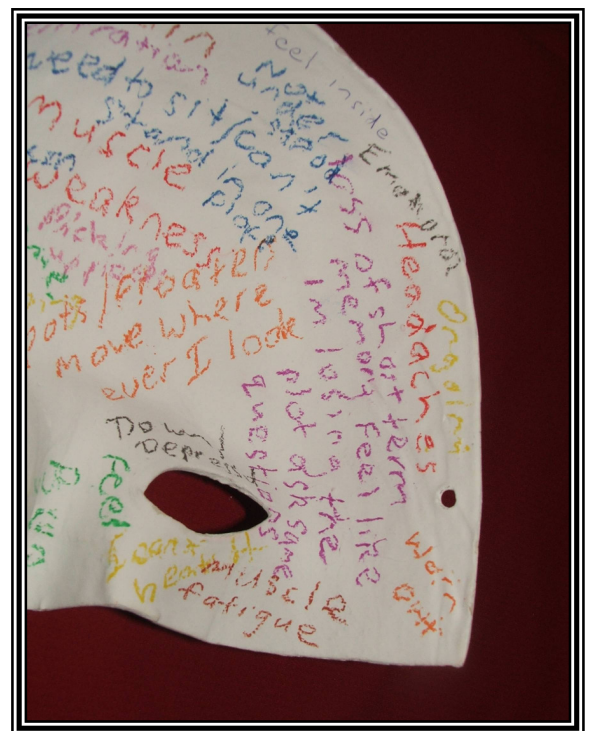
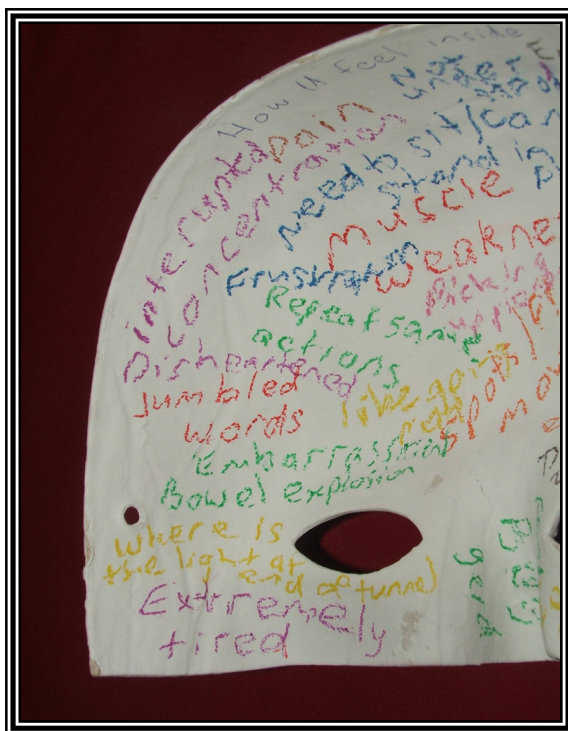
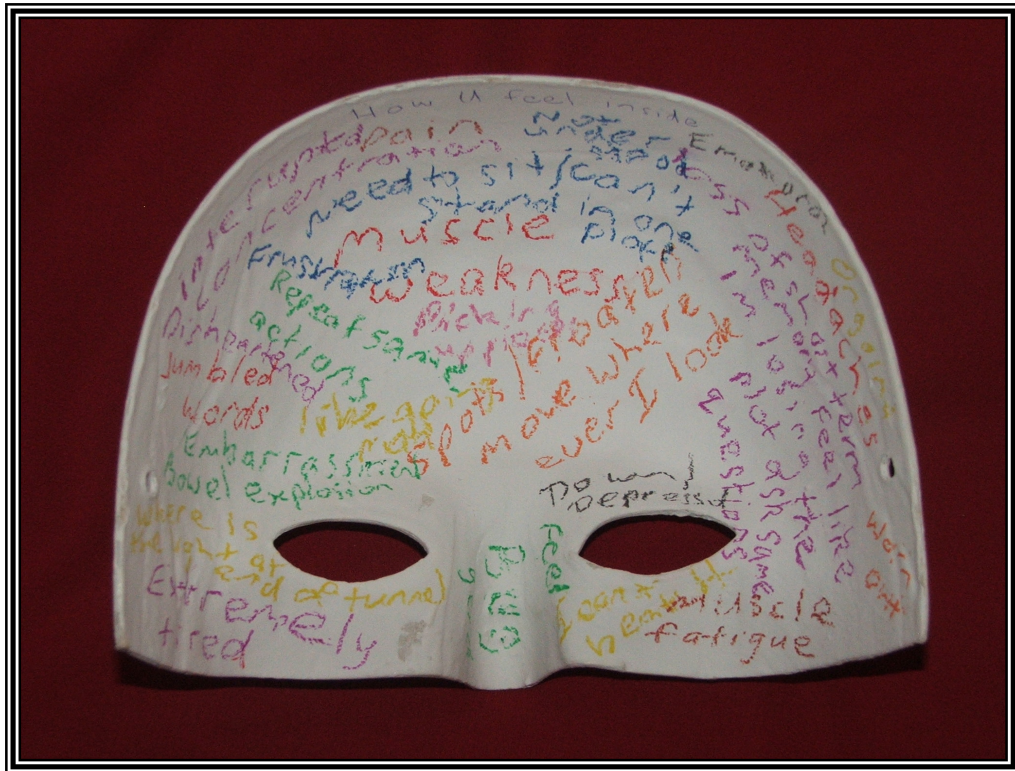




Image 5.5b Enlarged view of the outside of Marie's mask. Including photographs of the top and sides.

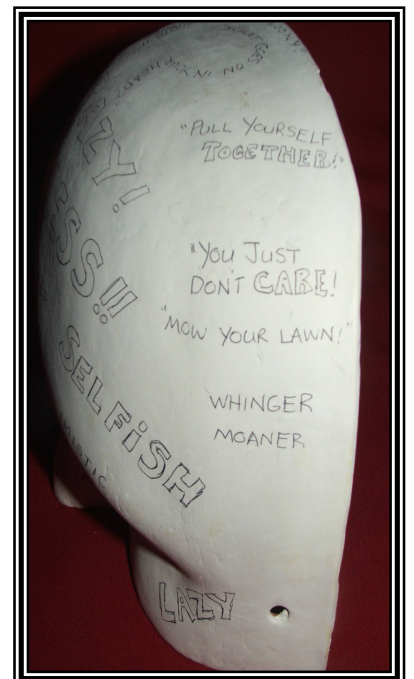
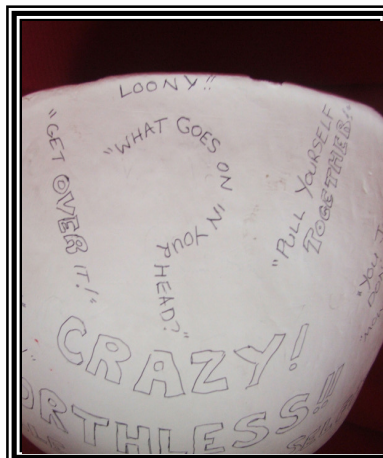
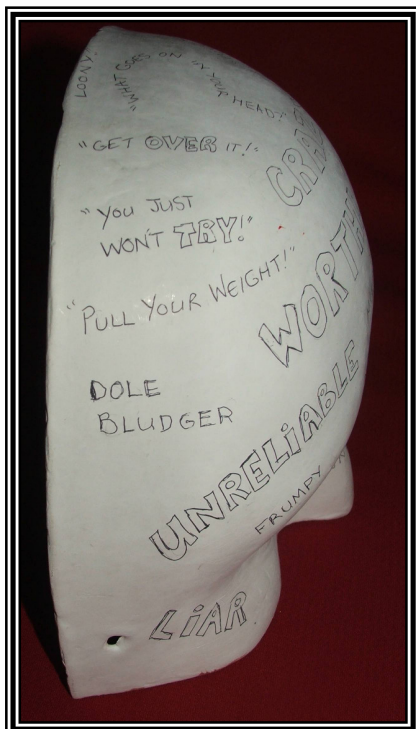
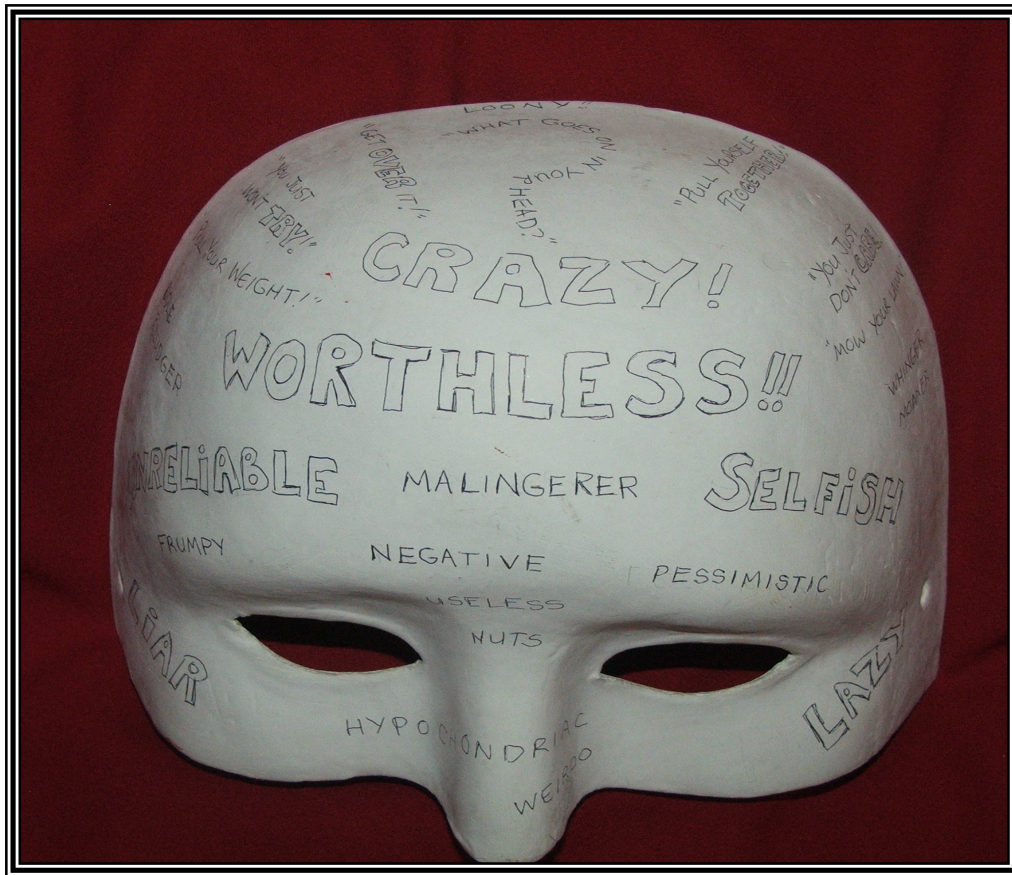


Image 5.4c Enlarged view of the inside of Marie's mask.





Image 5.6b Enlarged view of the outside of Amy's mask with close up of top.

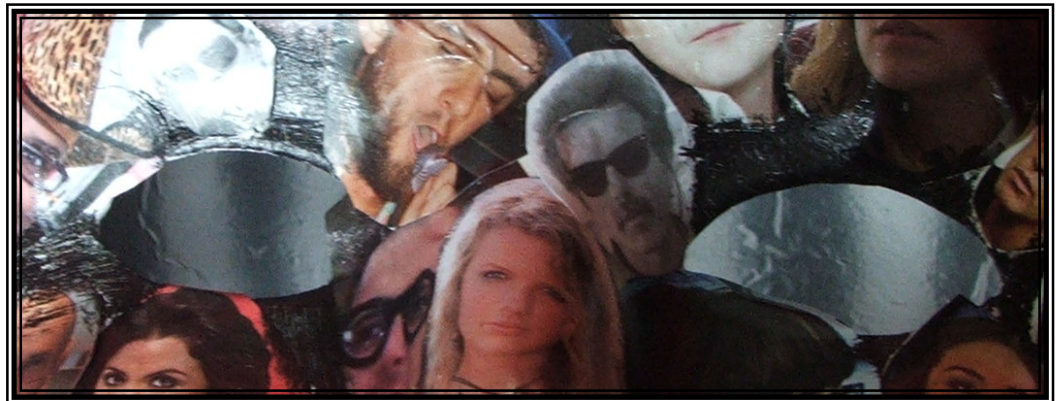


Image 5.6c Enlarged view of the inside of Amy's mask.





Image 5.7a Enlarged view of the outside of Mark's mask. Including a close up of the eyes and a view of the bars.



## SPECTATORSHIP

Engaging in levels of spectatorship through the hypertextual self-scape different depths of meaning are assigned to the image being viewed. By figuratively wearing the masks the relationship with the masks and therefore the people who created them is altered. In changing our view from the external observer to the internal participator the relationship to the chronic illness experience changes through the porous nature of hypertextual spectatorship. The viewer is invited in to an alternate reality as the body, mind, spirit and self, interacts with the image to create meaning and understanding. This does not mean that no interpretation of what is being seen takes place, as seeing is invested with cultural customs, aesthetics and training in how we interpret images (Paskow 2004:159,187). However in looking from different perspectives and engaging with the masks as hypertextual spaces alternate levels of spectatorial consciousness, embodied sensory knowledge and representation of chronic illness inform the body, mind and spirit of the viewer.

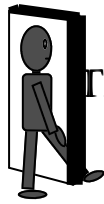
The use of imagination in presentation is debated through out various fields. The ability to think and create is part of the human condition and has the ability to help us interact, creating a knowing which is different from theoretical knowledge. The use of hypertextual self-scapes create knowing of sensory knowledge in the body which does not transcend the mind but engages the body, mind and spirit in deliberate perception. The masks enable the spectator to visually stand alongside the personal chronic illness experience. The masks have not been created as abstract artworks but reflect real experiences of real people, they are not to be judged and separated into scientific pieces but reflect a real known experience of chronic illness. The hypertextual self-scape challenges Cooley's belief in the looking glass self where our understandings of who we are is created through the reflections of how "others" see us.

## SUMMARY

In this chapter I have discussed the concept of hypertextual self-scapes in connection with masks and its potential to reflect parts of our selves. The reflections of the self through the objects in the boxes and the masks reveal any part of our selves can be reflected in hypertextual frames and surfaces. Experience is not static nor is it absent of sensory experience. As Paskow argues in looking at images it is necessary to give 'much more encouragement to our "naive" often discredited inclinations' (Paskow 2004:159). This challenge to relate to images reflects the value of sensory experience as a way to imagine the self-scape presented through the masks and objects in the "MeBoxes".

The world of perceived objects is already and always felt on the plane of co-being to be bound up with the overall direction or significance, the "at-stake" dimension, of our being-in-the-world and, I now wish to assert, paintings themselves proffer us image-meanings – artfully modified re-presentings of objects – of everyday co-being experiences' (Paskow 2004:164).

The distortion of the everyday through the application of different meanings is part of the following chapter where the hypertextual frame is explored as a doorway into a level of sensory experience of the chronically ill body. The ability to create a collaborative hypertextual framework enables the viewer access to the sensory experiences associated with objects and narratives. In the next chapter I will expand on engaging with images by walking into the hypertextual frame through composite hypertextual self-scape images.



## CHAPTER 6

# THE HYPERTEXTUAL SELF-SCAPE

### **Beyond The Surface**

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In this chapter I will be examining how to visually represent the embodied sensory chronic illness experience of the participants. The visual is integral to the ways in which we communicate about ourselves and illnesses which are visually hidden miss out on this form of communication. Illness is a whole body experience that affects mind, body, senses, spirit, relationships and here I examine a different way to communicate the knowledge of the holistic self with chronic illness, progressing through the boundaries of the hypertextual surface and frame to the felt embodied sensory experience. In the previous chapters I wrote about the choice of objects and the creation of the masks. In this chapter I endeavour to connect the narratives, objects and masks in a composite hypertextual self-scape metaphor which engages with sensory illness in an embodied sensory portrait. The composite metaphor enables a viewer to step through the hypertextual frame and surface into an awareness of the sensory experience of chronic illness.

I will begin with a discussion about representation and some of the literature about photographic techniques including recent developments in digital imaging. Accompanying this literature is a discussion about artistic methods and their ability to create a sensory dialogue through an image. In the second section of this chapter I will continue by discussing sensory dialogue. This is followed with each individual composite metaphor, the process behind why and how it was created and comments made by participants.

Throughout the research process a collaborative approach has been taken especially when creating the composite images to ensure that

they were accurate visual representations of participant's experiences with chronic illness. The reason for creating these images is multiple but I would like to begin by stating that illness is a sensory experience and therefore it is necessary in looking at hidden chronic illness to have a level of experience of the body in dis-ease to develop understanding, to engage with the embodied sensory level of the hypertextual self-scape. The composite images have the ability to do this. Whilst I will be explaining the components of the composite metaphors and the reasoning behind each of the images, the words can only tell part of the realities of chronic illness. The composite metaphors challenge the limitations of analysis in communicating sensory knowledge and encourage spectators to engage with the chronically ill self.

#### HYPERTEXTUAL SELF-SCAPE: Through the Surface

Chapter four figure 4.1 (page 63) showed how starting from a sensory experience forms of embodied metaphor develop. This system is reversed for a viewer, the viewer begins with the embodied metaphor of a single representation, into the embodied practice where multiple metaphors exist to the core, embodied sensory knowledge triggered by the composite hypertextual self-scape images. Each stage challenges the concept of taking representations at face value.

If visibility is no longer a quality or feature of things, nor just a physiological phenomenon (what the eye can perceive), then it entails questioning modes of looking and privileging of looking itself, as well as the idea that looking is based on one sense only (vision is not visual perception) (Bal 2003:17).

For participants a greater awareness of the body and its needs marked their experience of chronic illness, therefore in viewing these images the audience, in the way they look at the images need to increase their awareness of the body. Acknowledging that in looking an 'untameable mixture of the senses is involved, but also the inextricable knot of affect and cognition that every perceptual act constitutes' (Bal 2003:11).

## WHY ART? WHY THE VISUAL.

Through art, photography and film it is possible to connect with experience through empathy or a sensory dialogue with the body in disease. This offers a new dynamic to representation as 'conventional scholarly practise is limited in its capacity to communicate the directness of the sensory and affective elements of emplaced experience' (Pink 2009:132). Whilst I hesitate to use the term art as it may misrepresent the images later in this chapter it is important to look at art as a visual form of communication.

Art communicates experience and envisions emotion. Pain, emotion and sensory experience are represented throughout art history. In the early renaissance art of Giotto's *Deposition* (1304 -1306) to Picasso's representation of the suffering caused by war in his mural *Guernica* (1937) sensory experience and emotion is captured and communicated. The styles differ but the ability to create a connection with the spectator is relevant to both images. As stated in the second chapter images such as Edvard Munch's *The Scream* (Appendix ii) conjure up strong responses in the viewer in both the body and mind. Munch composed this image because he sensed a scream passing through nature and wanted to capture it, he recorded the moment in his journal in 1892.

I went along the road with two friends – The sun set. Suddenly the sky became blood. I stopped, and leaned against the fence, deathly tired – Clouds over the fjord of blood dripped reeking blood. My friends walked on but I stood trembling with an open wound in my breast trembling with anxiety. And I heard an extraordinary scream pass through nature. (Munch in Prideaux 2005:151, a slightly different translation is at <http://www.edvardmunch.info/munch-paintings/munch-paintings/The-Scream-1893-2.asp>)



The figure in the foreground was 'developed to personify the state of anxiety' (Wood:1992:98). The image is strong but it is also important to consider that he heard the scream, that he was himself aware of it. Munch connected with the anxiety and frequently repainted and reworked this image as it also reflected his own feelings. Art historians connect these images with his nervous breakdown in 1908 (Prideaux 2005:229, Wood 1992:185). Munch's images after his rehabilitation altered and no longer reflected the anxiety and pain of his earlier artworks<sup>19</sup>. The distortion of particular elements of the image, the paint strokes, the colour palette and the movement in the image all convey the scream that Munch was trying to communicate. Anxiety and pain becomes a visible construct in the art of Munch<sup>20</sup>. Munch's work and that of other artists show art has the ability to communicate embodied experience through visual methods and can capture the imagination<sup>21</sup>. 'In artistic form we can access a richer understanding of the complexities of lived experience which can throw light on broader social structures and processes' (O'Neil 2002:70 in Pink 2007:14). Art has always conveyed meaning and told something of the people who created it and those it was created for. The artworks *Guernica* and *The Scream* become a reflexive hypertextual scape in which the viewer is invited to engage with the embodied sensory experience the artist has endeavoured to capture.

Of relevance to the images created here are those of digital artists who use multiple images and ideas which evolve into a single image. Artists use pigment, brushes, precious metals and other physical materials to create their art. Digital artists use virtual materials with the computer as their canvas. The digitized image along with accompanying software allows 'a photograph [to] become infinitely malleable ... and expands our notion of what a "photograph" can be' (Lipkin 2005:15,17). Digital artists

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<sup>19</sup> <http://www.getty.edu/art/gettyguide/artMakerDetails?maker=356>

<sup>20</sup> <http://www.getty.edu/art/gettyguide/artMakerDetails?maker=356>

<sup>21</sup> Pain as a visible construct in art is an interesting area for more information and images created by people around the world please see <http://www.painexhibit.com>

challenge our understanding of the world and raise questions about how we live our lives. Where paint's and brushes are familiar artistic tools digital imaging is new so I will continue by giving an overview of digital imaging.

### DIGITAL TECHNOLOGY

Digital photography and its technique of recording an image through the use of data methods enable the photographer and digital artist greater flexibility and therefore greater responsibility for the final image produced. 'The digital image can be conceived of as a Meta image, a map of squares, each capable of being individually modified and, on screen, able to serve as a pathway elsewhere' (Ritchin 2009:141). Image manipulation is not a new technique as photographs and negatives could be cut, receive multiple exposures, be re-coloured and undergo various other methods to enable the photographer to create the image they saw in their mind (Tagg 2009:181).

The film based systems of photography required acquiring light onto light sensitive film to capture an image, and controlling light to continue to alter the images. This was done using a variety of darkroom techniques and it was possible to create an image, and in so doing expand its meaning, beyond the direct representation of a given object, person or scene. With digital imaging this has continued to develop and amplify what a photograph can represent. The opportunities presented to researchers through digital technologies could allow researchers to find innovative ways to present gathered data. As researchers examine digital representation its potential will 'expand and harness an evolving medium that can respond to some of photography's frailties, its lies and limitations, with new methodologies' (Ritchin 2009:146).

With the development of digital technology the image is captured using strings of data which are stored as files, changing the dynamic of photography from capturing light to making a photograph another form of computer data. 'Digital photography is a process of creating, storing and

manipulating numbers in a computer, and then rendering them into visual images.’ (Lipkin 2005:13). Changing images to a data form has altered the way in which it is possible to interact with an image. Through redefining images into computer speak the access to the photo files results in greater access for manipulation or creation. Where once a photograph needed to be processed in stages from the development of the film to the exposure of photosensitive paper before an image could be recovered, the digital format creates instant access to the image created. The film based photographer processed their images in a darkroom away from “others” in a light limited and chemical environment. The computer has altered this to the dim room, so called because of the lower level of light to see the computer screen, making the images more accessible to both researcher and participant (Lipkin 2005:20). So ‘it stands to reason that any change in photography will have a significant effect on the way we live our lives, the way we remember the past, the way we understand the world’ (Lipkin 2005:1).

#### PHOTOSHOP 4.0

The digital camera has resulted in a variety of different programmes for loading on the computer to use with the image data. In the past I had used various techniques in the conventional darkroom but I had never used digital imaging to alter photographs. I had not used *Photoshop 4.0* before and had not had any training on the programme. I approached the programme with the focus of making the static images I had collected more accurate to the sensory narratives that accompanied them, to create representations of the chronically ill hypertextual self-scape and expand on the type of information given in written and verbal formats. It was mostly about trial and error but I have found this valuable because I did not have preconceived ideas about what the programme was capable of. I instead ran through the various filters and techniques until I found an appropriate visual representation for the participant’s experiences. I did this by constantly referring to their descriptions of the objects, took notice of how the information was conveyed in speech patterns and checked my notes for any particular handling of the objects

e.g. the way in which they were placed in the box or on display for photographing. Because of this method the images have been a melding of photographs and narratives enabling a viewer to step through into the embodied sensory hypertextual self-scape described by participants.

### DIGITAL IMAGINING

With the development of digital technologies the opportunities to create and represent new images is helping to create new artistic forms and I believe new ways of communicating knowledge. Photography as a medium of representation has been accessible for over a century and has become a part of western memory creation.

Photographs have been used by artists for visual expression, by journalists to record events, by scientists to gather data about the physical universe, and by nearly everyone else drawn by photography's ability to faithfully record the world, it's low cost, and it's ease of use (Lipkin 2005:1).

Photography can therefore be an accessible way to represent events and experiences. However the framework in which an image is created defines the way it is formed and communicated. Visual methods are integrally linked with representation as an image is captured with a purpose and part of that purpose involves its future audience (Pink 2007:43). The list of uses of photography Lipkin gives above results in specific visual outcomes because of their context and focus.

### IMAGES IN CONTEXT

In *Lost Voices* the photographs of people with ME/CFS, the images, stories and poetry have been created within the context of communicating the illness experience to "others". The photographs are of the acutely ill alongside images of the person before they became ill making the suffering of the individual clearly visible. The images are a mix of created and casual images, with several photographs using

computer software (InvestinME 2008:50,60,62,66,67,95). The images often have a portrait quality with the person with ME/CFS as the central focus and any digital imaging additions placed around the central figure. InvestinME was set up to communicate what ME/CFS is, to gain support and to lobby for strategic biomedical research (InvestinME 2008:6). The images in the book reflect this goal. Many of the images in *Lost Voices* show medical symbols of severe illness such as oxygen masks and wheel chairs which help to visually categorise the people photographed as seriously ill. These external symbols reflect the internal suffering and aid the onlooker in understanding that the person photographed is suffering. For many of my participants taking portrait style photographs like those in this book would not reflect their experience so I have developed a more abstract approach to represent their hidden experience.

#### PARTICIPANT, RESEARCHER, VIEWER = Reflexive process

In the creation of these images there are three different components, the compiler or researcher, the creator or participant and the viewer or audience. Each brings their own experiences and knowledge into the creation and understanding of the image. However these are not equal relationships which align like 'successive lenses in an optical instrument through which a single sight line passes' (Bryson in Bal 2001:14). In using this simile a single Gaze is created which assumes that all involved align in their viewing. It also enables domination of the object or image. However an image has multiple visual relationships which create seeing and generate meaning (Paskow 2004:159-160). I will briefly discuss the participant as I have covered this area in the previous two chapters. Then the researcher and the viewer.

#### PARTICIPANT

If we begin with the participant they had multiple objects, images and words to choose from in describing their experiences and compiling their "MeBox". They have the initial and primary seeing which is drawn out of embodied sensory knowing. The objects gained meaning through the

participants as they chose to move from the central known experience into metaphorical representations as a way to communicate the sensory knowledge. Access creates potential.

## RESEARCHER

As the researcher I was informed of their experiences in a visible, verbal, sensory discourse of the illness experience. I put together the initial box of objects, and asked the initial questions but the participant's choices and descriptions were and are the primary focus. This is reflected in the collaborative approach with the composite images. These images when completed were returned to participants for further discussion adding to the depth of their visual dialogue. In creating the images I found that I have spent a great deal of time with the images and the interviews, more than would normally have been the case when including photographs in a thesis. I have been very aware of my own journey with chronic illness as I did not want my own experiences to impinge on those of my participants. Being aware of an editorial status I have been careful to ensure that what is visually represented is accurate to participants' experiences (Ritchin 2009:101-102). However I believe that my insider status did enable me a level of understanding on a sensory level which I could draw on in asking for sensory clarification, enabling a more collaborative approach in listening to participant's descriptions of the embodied illness experience.

As the editor I consider presentation, formatting and production which most accurately represent the initial meaning given by participants in a way that is visually accessible to the audience. For example many of the images have been created to specifically evoke a sensory response compatible with the experience assigned to the objects. In the case of Katrina's image, the words, which interact with the other objects in the image have been purposefully distorted along with the chair to create discomfort for the viewer so that in reading the words the discomfort described by them can in some small way be echoed in the body of the viewer. The unaltered objects before each of the composite hypertextual

self-scape metaphors do not evoke this response, except perhaps that they are a group of recognised objects such as a chair and a mask. As time is taken to look at the composite images the essential experiences of participants narratives are exposed where these are visually missing in the original images.

## VIEWER

The third component of the visual is the viewer, the person who comes into contact with the image without being involved in its initial creation. This viewer brings with them experiences and knowing of their own as 'looking, as an act, is already invested in what has since been called *reading*' (Bal 2003:13 original emphasis). Each of these three elements interacts and creates relationships through the image. This creates multivocality within the photographs, with the outcome of making the invisible experience visible through the complex interrelationships between presenter, creator and audience. The outcome is a reflection of the hypertextual self scape.

In viewing the image the audience interacts with the participant and the researcher collaborating in giving the image meaning. The third contributor to the image, the audience, brings more than a blank body awaiting a sensory experience. The audience brings with them pre-existing knowledge which impacts on the way in which the image can be interpreted. For example photographs have taught us a way of seeing and my deliberate revisioning of the known creates a point of disquiet.

Photographs in their ambiguity can provoke, motivating the reader to interrogate their meanings. The photograph may create enough confusion and curiosity to stimulate the reader to solicit alternate voices, to peruse the accompanying text' (Ritchin 2009:97).

## REPRESENTATION: WRITTEN AND VISUAL

In discussing a sensory experience and communicating in a sensory method different levels of experience are created. This comes easiest to the participant as it their illness experience. As the researcher I stand between and beside the participant and the viewer aware of both, which informs my research method and praxis. With the writing process it is necessary to analyse the information gained in the field and from existing literature (Kirby and McKenna 1989:150). My writing style and the way I phrase the data gathered, shapes and forms the written product (Rountree and Laing 1996:186). The structure of the writing and the selection of data to be included influences the narration of participant's experiences, it is also necessary to do the same with the visual. How the objects are photographed and communicated will invest them with meaning with the potential to add or subtract from the original purpose created by the participant (Ritchin 2009:146).

The composite hypertextual self-scape metaphors challenge preconceived ideas of the illness experience through the visual representation of chronic illness that can not be seen on the body. 'The visual technologies ethnographers use, like the images they produce and view, will be invested with meanings, [and] inspire responses (Pink 2007:48).

In one way the composite images can be ascribed to art in that art can convey mood, emotion and memory. However their presentation is in academic research about people with chronic illness and they therefore are subject to scholarly anthropological analysis. Art differs from life in that it is often a thought-out reflection on existence and is therefore representational of lived life (Hinchman 2001:135,168). In the creation of the images and initially the collection of the objects it gave the opportunity to reflect into the experience of illness from the created narratives of the participants (Kleinman 1988:49). Through the objects and masks the beginning of connecting with the embodied sensory experience of chronic illness starts to develop. Through the composite



images it is possible to step through the hypertextual frame and surface into the experiences that created the reflection of the objects.

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## PART 2 - SENSORY DIALOGUE

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The use of visual methods brings 'researchers and their audiences close to other people's multi-sensory experiences, knowing, practise, memories and imaginations' (Pink 2009:132). Therefore to see is to engage the senses and create a sensory encounter. In shifting the act of seeing from the purely theoretical to the visually created it alters our perception of the person being represented (Paskow 2004:101). The visual becomes 'a critical reflexive voice and a means of communicating understandings that are accessible only by non-verbal means' (MacDougall in Pink, Kurti and Afonso 2004:1). The change in representation enables the viewer to change their perspective in looking and engaging with the images but the object's original meaning remains unchanged. The presentation of these images is done with the specific aim of connecting a viewer to sensory experiences of illness. This interaction results in the ability to collaborate with the images and change from theoretical knowing to a level of physical knowing about the chronic illness experience (Pink 2009:25). However the choice of how to interact remains with the viewer and it is their choice to move through the porous barriers of the hypertextual self-scape.

The images whilst using artistic techniques are not created for an artistic audience. They have been created as a form of communication of the embodied chronic illness experience. Each image is created for only one individual and is dominated by their narrative, expressions and discursive style. To begin looking at a sensory dialogue challenges the scientific privileging of objectivity, as human interpretations and understandings can complicate how an image is interpreted (Paskow 2004:9). The

result of using the body as a means of communication, is a dialogue beyond the boundaries and confines of scholarly understanding and the dichotomy of the mind and body. This is not to say that words cannot evoke a reaction from the body but that art often requires an initial letting go of the dualism of mind and body. To engage with the image through the senses requires the viewer to leave theoretical analysis and engage with this visual communication. In a visual metaphor 'the interactional nature of metaphor ensures that thoughts may be felt immediately in the body' (Kirmayer 1992:336). Moving from sensory connection, to theoretical analysis rather than the other way around removes distance between the chronic illness experience and the viewer.

The images like all forms of communication can not fully communicate the experience of living with chronic illness. The hypertextual self-scape is about finding ways to communicate more and thereby create understanding that further corrodes the inclusion and exclusion dichotomy (Pink 2009:134, Bal and Bryson 1991:84). As stated earlier in the images the viewer is challenged with an alternate reality, through the use of a hypertextual self-scape, where the objects photographed in the previous chapter look familiar but the differences appear through looking intentionally at the image. The composite images redefine the physical objects into meaning images, representing through the grouping of objects, the colour palette, filters and effects the sensory narratives of the illness experience. With more traditional photographic ethnographic methods the photograph is an actual representation of a person or event rather than an image created to show a hidden experience. However 'the ethnographicness of any image or representation is contingent on how it is situated, interpreted and used to invoke meanings and knowledge that are of ethnographic interest' (Pink 2007:23). Here this relates to the composite hypertextual self-scape images which create ethnographic representations of dis-ease challenging preconceived ideas about the sensory experience of illness.

To create digital representations of an experience or group of experiences enables the researcher a new method of communicating the narratives of the people they are working with. This research came out of the frustration I found in my research project in 2008 with communicating the lived experience of illness through a purely written format. For me without these visual methods the research and thesis would lack in its ability to communicate sensory information of chronic illness and struggle with representation of the experiences of participants. To communicate in words the experiences of my participants would be insufficient to express the way they live as illness is an embodied experience. This is where the hypertextual self-scape enables exploration of the embodied sensory experience.

In the following pages you will see the composite images created with the express purpose of a response in the viewer to enable a connection with the chronically ill body using the embodied sensory dichotomy to access the hypertextual self-scape imagining. Digital photography and its ability to manipulate images have been much maligned but here I have found the malleability of the images enabled a greater connection to the true meanings of the photographed objects (Lipkin 2005:9). Due to its malleability the opportunity to accurately represent the narratives assigned to the objects becomes possible. These digitally altered images add life to the meaning of the photographed objects when compared with those earlier in the thesis giving a greater permeability to otherwise surface images. Without the alterations the objects are missing the link to the narrative which assigns them meaning and significance. Simply adding descriptive text to the photographed objects conveys a limited low-sensory meaning. To give the objects their hypertextual meaning is to connect the viewer with the experience of the participant. Technology allows for new representational methods for the researcher which makes the experience of the participant accessible in non verbal ways and gives metaphor performance a more immediate power.

## COMPOSITE HYPERTEXTUAL SELF-SCAPE METAPHORS

As I mentioned earlier in some images I have purposefully created some of the discomfort narrated by participants but other images are more passive in the way they impact on the senses. They all challenge the viewer to understand illness on a different level and encourage the audience to enter into the embodied sensory experience within the hypertextual self-scape. The images were created from the objects chosen by each participant and composited in association with the conversations about the objects. One of the techniques I found useful in creating the images was alteration of a recognized object or artistic style e.g.: using a still life method to represent the value of being still for Beth but with objects chosen by her (Images 6.23, 6.24, 6.25, 6.26). Taking an image out of a recognized format is also a common technique in writing. The images like Alice's journey through the looking glass take the traveller to an alternate experience where things are recognisable but have a different life.

Like Alice's mirror, the hypertextual photograph can lead to the other side, whether to explore a social situation or to create an image poem. The photograph is no longer a tangible object, a rectangle resembling a painting, but an ephemeral image (Ritchin 2009:70).

In viewing we are invited like Alice into the frame and find that the familiar is disconcertingly unfamiliar as the images reflect the body in disease (Foucault in Campbell 1999). This then leads through to the greater awareness and deeper reading of sensory embodiment found through the hypertextual self-scape. In looking at these images it is about taking a step into the framework of the hypertextual self-scape to look beyond the face of the object and gain a glimpse of the embodied sensory experiences of participants on the other side.

In the next section of this chapter I describe the images and the processes involved in creating each of the composite metaphors which

create the possibility of walking through the hypertextual framework. This section is clearly set out with a description of each of the composite self-scape metaphors with comments made by participants, the unaltered photographs and the composite metaphors. I begin with the unaltered images, this is followed by the image that was created in collaboration with participants, and then the explanation of the image. This has been done to enable the viewer to first engage with Paskow's 'unreflexive and affective' spectatoral consciousness, before moving through to the meaning behind the image and its theoretical analysis (Paskow 2004:159).

To enter into its world, visually and quasi-corporeally, and with our imagination and uninhibited emotions, gradually allowing its content and implied issues to be blended with those of our own world, just as we might do when listening to a family member's or dear friend's complex personal problems (Paskow 2004:175).

Each participant's image is individually discussed and shown with verbal as well as visual metaphors combining to make many of the images, developing into the multi layered depths and fluidity of meaning that is the hypertextual self-scape. The images are collaborative and comments made on their composition by participants resulted in alterations to the image that was initially created. The composite image is a representation of the hypertextual self-scape of each person. I will begin with Anne's composite metaphor.

**ANNE**



Image 6.1 objects which reflected Anne's experience of living with chronic illness



Image 6.2 Anne's scales





Image 6.3 Anne's composite hypertextual self-scape image



## ANNE

Scales: At the first interview Anne spoke of trying to find balance and calculating the energy required with the energy necessary to do various daily activities. During the interview as she chose various objects she discussed trying to balance energy expenditure with the energy she had available. I didn't have a set of scales or a calculator at the time to add to her box but the verbal metaphor was important. The comments about finding balance related to all aspects of her life including her activities, finances and relationships.

I've had to learn to prioritise and do what I need to do then, even if that's rest because I'm not going to be very effective if I don't do it and the things will just have to wait. It's about analysing what I can do and when I've got the right amount of energy. If somebody asks you to do something or invites you to come and do something I always calculate it all out, I have to. So you change what normal feels like day to day. You learn to accept but in a way its give in but don't give up. So you give in to how you're feeling and you live with that and although you know you get upset or frustrated or whatever, you can't feel like that all the time. Because who wants to live frustrated all the time or angry all the time its not good for you and causes its own problems and so you learn to adjust to it but I'm always constantly trying to look after myself and find that balance to maximise how I am.

Anne

At the second interview I spoke about the use of this metaphor and we took photographs of her calculator and scales (Image 6.3). After consideration I did not use either of these items as it was difficult to translate them in the image to correspond with the whole visual narrative. In this situation the words spoken took precedence over the photographs and I took another picture of an older style of scale which would be more

visually accessible to the viewer and relate to Anne's descriptions and objects.

Butterflies: At the first interview Anne spoke about finding acceptance and patience and chose butterflies to represent this. She specifically spoke about Monarch butterflies, and the fact that once they become butterflies their lives change dramatically. The butterflies were also spoken about in connection with having to find patience with the illness even though Anne said it was sometimes very difficult as it would stop her from doing the things she enjoyed. One of the ways her acceptance was outworked was through Anne being very conscious of having an illness and making the decision to live within her capacity or limitations. She considered her body's needs rather than pushing herself beyond her abilities to meet somebody else's expectations.

Sometimes the perfectionist says it has to be better, and it doesn't when you really come down to it. Some things are okay slap dash and other things they have to be better. Everyone probably has there own opinions on which is which, and sometimes its not very kind to yourself to think that things have to be better all the time. We can accept that their not as good as you'd like them to be and so what would be acceptance? .....so acceptance ... the monarch butterfly.'

Anne

I have used a large number of butterflies flying around and above the scales to accent this as this hypertextual surface was a recurring theme throughout both of the sessions. For Anne her approach to chronic illness was to accept what can and can't be achieved in a given day and the need to find patience and acceptance of her whole self. Anne did not claim that this was easy but an ongoing deliberate choice. At the first interview Anne chose a large number of butterflies which reflect

acceptance as an ongoing process. This lead to hypertextual self-scapes as can be seen on the composite image.

The phrase: In each image I have included a phrase which added to and affirmed the visual image. This was done to show that words and images can be combined to make a visually communicative image of the hypertextual self-scape. The use of the phrase also aids in connecting the visual and verbal meanings. This direct quote from the interviews helps to give grounding to the images present drawing the hypertextual frame and hypertextual surface together. The phrase has been purposefully placed on the scales at a place where they are part of the grounding mechanism for the object as well as the image.

The Colours: The colour quadrants represent two visual themes. Anne spoke of the variability in her experience of chronic illness. The choice of the muted colours has been done to represent this change and to show that change exists not in extremes but often as subtle modifications. The colours are not bright and shining because the presence of the illness impacts on connection with loved ones and lifestyle, making this the colour in the hypertextual frame reflecting the metaphor of illness. Secondly Anne made a conscious decision when she knew she would have to give up work, to find something else to add into her life, this was quilting. Anne spoke of how this gave her something to achieve during the day which she could pick up or put down as her energy levels allowed.

You need to find a new hobby when your old hobbies are too strenuous. That's why I do quilting. I don't go diving any more, I rarely go out in the boat fishing. I don't go cycling all over the place and I don't go tramping. I like to do all sorts of things but I am unable to do those. Now but I enjoy my quilting.

Anne

People: Family and friendships are important to the lived experience of ME/CFS for both positive and negative reasons and this was also true of Anne's experience. The people outlines which Anne chose related to her difficulties in being able to help her family with a recent crisis in the way she had wanted to. She has a very supportive family and found that they worried about her not overdoing it. Therefore in the image I have used the objects she chose as symbols of these relationships on both sides of the scale. Thereby showing that these relationships also need to be kept in balance, families can be a place of strength and at times also a place of stress.

Globe: The globe also appears on both sides as Anne chose this object to speak about the difficulties in balancing her desires for a well future with the concern that she may be missing out on smaller dreams because of a hope that the big one will be possible. The main image which was associated with this was the globe representing the travel she wanted to do and the concern it may never happen.

Goals still have to be there. I still want them to be there. I plan for being better, but we've got to have a life. We can't just keep planning waiting for when I'm feeling better because that may not happen. Do we live waiting for me to be well so we can do these big trips or do we do smaller things now?

Anne

Weights: The weights represent the influences on the body and self. This image was not one initially chosen by Anne but it was part of the metaphor around balance. I have placed the weights at the bottom right hand side of the scale. They represent the fatigue and exhaustion of ME/CFS. These weights play a part in how the whole scale mechanism works and have the ability to throw everything out of balance. They relate to the changeability of the symptomology and that at any time everything can be thrown out of balance. At the first interview Anne was going through one of those times and spoke about how her husband was

helping her more as a way of balancing her energy. During the second interview Anne felt that some things were improving so I have balanced the scale to represent this.

To create the hypertextual self-scape image I began with the scales and then using the “magic brush” tool I copied objects from the original photographs. The final stage after placement of all of the objects was to use a filter called quadrant which flattened all of the different layers of images into one and applied this effect. I then used the colouring tool to adjust the colours of the various quadrants. The colours were chosen which reflected the photograph of a quilt Anne had made and added to her “MeBox”.

Anne’s response to the image was as follows.

I can see how all the symbols have been chosen and interact. You've managed to tie in a number of things, both positive and negative, about how ME affects my life and decisions. The overall picture represents emotions, practicality, growth and support systems.

Images: 6.1, 6.2, 6.3 Pages 129-130

**KATRINA**

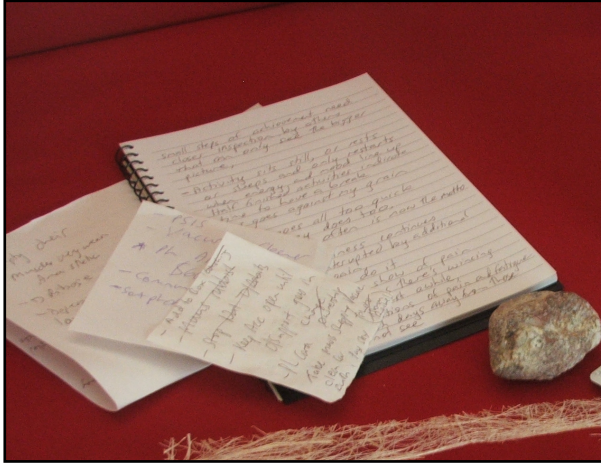


Image 6.4 Journal



Image 6.6  
Traffic lights



Image 6.5 Chair





Image 6.7 Katrina's hypertextual self-scape image



## KATRINA

Chair: For Katrina the chair represented a loss of ability to move freely in and outside her home. At both interviews Katrina explained that when she sat on the floor she needed a chair to help her to get up. At the first interview she spoke of how sometimes when she sat down it felt like she kept on falling through the chair like falling down the rabbit hole.

There's one thing for you, an empty chair because I can't stand for long, that for me is the most important thing my muscle problems. If I can't stand I can't stand. If I'm sitting on the floor then I climb up my legs or use the chair because I don't have the muscle strength but I've found it very hard to accept a wheel chair or anything like that. Sometimes you feel like you just keep going through the floor you just can't rest.

Katrina

The chair therefore has two visual experiences that it is communicating about embodied sensory experience through the hypertextual self-scape. The distortion at the back of the chair reflects the discomfort associated with sitting down and feeling she wasn't sitting still. The front of the chair remains solid because it was often the only way for Katrina to get up off of the floor, due to her muscle weakness. This draws the viewer through the hypertextual framework into her embodied sensory knowledge.

Words: The words which cover the image are taken from journaling Katrina did during the months between the first and second interview. I have then put a digital muslin filter over the words to make them slightly harder to read. This has been done for two reasons. Firstly to make them more difficult to read so that it is uncomfortable for the reader. By the end of the page the repetition of the words, which tell of Katrina's difficulties with chronic illness, and eye strain in reading them creates a physical sense of frustration. This discomfort is created to reflect the pain and frustration Katrina spoke about. Secondly Katrina is severely

hearing impaired and she has said that communicating visually is easier for her. In choosing to use words through the journal and on her mask she wants to make sure she is understood (Roots 1999:15).

Mask: In the upper right corner of the image situated on the chair is Katrina's mask. The mask is looking out from the distorted part of the chair to emphasise the distress the mask represents.

Traffic Lights: One image which I struggled with was the foam person with the traffic lights on it. This was an image created by the participant at the first interview and was important at the second. When I added it at various sizes and varied its position it took away from the other components of the image and did not honour the participant's desire to have words a central part of the communication of her illness. In our discussions about the composite image Katrina mentioned the traffic lights and she suggested using the red and orange lights to emphasise that she feels her body is always saying stop or wait. I revisited the image and added a different representation of the traffic lights.

Katrina's response and comments on the image.

Chair, I cannot stand for long so have to sit a lot of the time, even sitting on the ground and crawling to a chair or something solid to aid me getting up. I don't want to resort to a wheelchair even though I could move around while seated, due to my own and other peoples' perceptions or distorted view of what they think is a healthy person who can walk, or view that person as playing on a disability or illness. Visually it works well to describe the ME experience. Yes it looked ok. for me, a future addition or footnote could be the stop go man or traffic lights stuck on 2 colours or not knowing when to go...or stop or get ready or keep going, only an afterthought. Doing things differently is life's journey.



**MARIE**



Image 6.8 Unaltered Nest with  
Egg Shells





A nest is supposed to be safe  
but mine has a hole in it.

Lost potential

Lost chances

Broken

Spoiled



## MARIE

With many of the participants I began by starting several images before deciding which to complete and send to them for comments. The criteria for the choice of image and alterations related to the way objects and concepts were talked about and how often they were discussed. This was done to ensure the image was a close reflection of that person's hypertextual self-scape. This was also true for Marie and the original image I sent out was based on an image she had created during the first interview which involved a bear in a cow costume and a cocoon made out of a piece of wide weave fabric, which was added to with rusty nails to hold the fabric in place at the second session (Image 6.10 this page).



Image 6.10 Unaltered Bear image created by Marie

I altered the colours to visually heighten the discomfort and grief she spoke about and aligned the description of the nails with the visual image. I enhanced the nails with an effect called 'torn paper' to reflect the pain she described as feeling like it was trying to tear her body apart. The words which framed the image were from the second interview when she summed up the object saying 'The bear is disguised, wrapped in a cocoon and held in place with the rusty nails of pain'. That it's 'in



disguise wrapped in a cocoon between a rock and a hard place and backed into a corner. That pretty much sums it up'.

Marie did not like the image and felt that for her of all of the objects she collected it was not the most relevant to her experience of illness. The object she felt that was more representative was one she collected for the second interview and was a bird's nest with a hole in it. This was an image which I had initially started working with but had stopped as the other image was one she had created during the first interview and was still significant in the second giving it more apparent significance. Though it appeared contradictory to our discussions I chose to follow her lead and therefore changed the image. My focus was a collaborative image rather than dictating what I believed was appropriate. After making contact with Marie I went back to the birds nest and completed the adjustments to it and re-sent the image. This image was one she felt better represented her illness experience. She did mention that she felt that the nest itself looked too tidy to represent her home. On receiving the image she sent back the following comment '

Yeah, the nest (any nest) is supposed to represent safety, a nurturing safe place. Mine (my life, existence, house, body, etc) are anything but that.

Marie

The Nest: The alterations to the image of the nest have all been done to visually represent Marie's feelings of loss of safety and stability. Thus ensuring the image of her hypertextual self-scape reflected her perception of her embodied sensory knowledge. This has been done by altering the colour palette to a cooler colour scheme rather than the red background on which it was originally photographed. Around the edges of the nest the back ground swirls, through the use of a liquefying tool, showing constant movement that challenges the eye. It is difficult to view as the eye's either get stuck or move restlessly over the image, showing Marie's discomfort and sense of loss of safety. The swirling

hypertextual framework is tugging at the edges of the nest dragging it into the void but not yet succeeding. The hole in the centre of the nest sees these same external forces coming into the nest and distorting it. Around the bottom of the nest are twigs and mud that have fallen off as the nest slowly disintegrates. The image draws the viewer through the hypertextual frame into the reflexive surface.

The nest has a hole in it and it's supposed to be empty. The thing with the nest is a nest is supposed to be a place of safety and comfort and warmth but my nest has got a hole in it, it isn't any of those things and it's also empty, like life.

Marie

Egg: This image for Marie was about loss and brokenness. The words around the egg shells are the things which have burst out of the egg and are direct quotes from our conversation about them.

The little eggs, I don't know whether they should go in the nest because they belong together but they are separate as well. Although they go with the nest what the eggs actually represent is potential but they actually represent lost potential. Some people would look at them and say you've hatched and flown away but this is a little broken egg, broken potential. The egg is well and truly spoiled it represents grief.

Marie

For Marie the hypertextual self-scape shows a metaphor of loss to access the true experiences it is necessary to go beyond the hypertextual frame, through the surface, and connect with the multi-faceted layers lying beneath.

Images 6.8, 6.9, 6.10 Pages 143-145

**MARK**



Image 6.11 Life-Saving Flag and Anchor.



Image 6.12 Wide weave fabric with  
peg boat and money sail.

Image 5.10 Fabric Wave with Peg Boat  
and Money Sail.



Image 6.13 Mark's hypertextual self-scape image



### MARK

Mark was one of the participants who did not have chronic illness but lived with it as his wife has ME/CFS. The objects he chose reflected his

care for his wife and what his experience of living with chronic illness represented. The strongest of images represented by the objects were those of protection and the variability of the illness. His hypertextual self-scape incorporates images of protective care as well as loss of dreams and timeframes.

**Anchor and Lifesaving Flag:** At the first interview Mark spoke about needing to be aware of his wife's needs and helping her and protecting her. I have used these two images and lifted them using the magic brush selection tool from their original photograph and made multiple copies and shaped them into hands, which support his wife's mask to enhance the protective and anchoring qualities he spoke of. On the thumbs is a quote from our second interview which reflected changes that they were making to their lives as they learned what it means to live with chronic illness (they had only been married a few months). The anchor represented needing to remain constant and keep his wife centred in amongst the chaos of the illness experience. The flags related to the experience of the emotional and physical ups and downs and trying to contain those experiences so that they didn't have to deal with the extreme highs and lows.

With the anchor I make the analogy of living with someone with ME/CFS being a little bit like drifting, you're not sure where the wind is going to make you drift or the current is going to make you drift of to next. For someone who doesn't have it there's a longing there for things to be stable so life can be a bit the way you want it to be.

Life saver flag not so much that it means that there are lifesavers around but that it's a way of communicating when you're getting into a dangerous area so it's a sign for me to learn signs of when Esther is getting tired etc and for her to communicate it to me when I don't see it so we can avoid her crashing.



Mask: I used Mark's wife Esther's mask within the hands to represent the person who he feels he needs to protect. The hands and mask also represent the insider and outsider status of Mark and Esther's chronic illness experience. However they are both at the mercy of the vagaries of the illness. Mark and Esther spoke about the differences in their health status and how Mark found it difficult to understand as he had never had the same experiences. The hand's in the image care for the mask representing Mark's connection with his wife and her place in his hypertextual self-scape.

Esther: Because I had been sick and got overtired for the first time Mark was actually there when I couldn't get out of bed. I don't know how you felt but for me hard as it was I was actually really glad that it happened because now the legitimacy is there because he saw it, my mind and body weren't connecting, I was so weak and he had to help me out of bed. Mark how did it make you feel?

Mark: I guess again, you can't see it. You can say I can't get out of bed but from my life I've never experienced anything like that. It reminds me of that Bruce Willis Movie 'Unbreakable'. It's about how he has never been sick or injured and there's another guy Mr Glass who is born with a condition where he easily breaks his bones. They are on the two ends of the continuum like were at different ends. It's hard for me to comprehend it because I've never experienced it.

Background: At the first interview the fabric was chosen because of its unpredictability and at the second interview it developed into the sea in an image he created using the anchor and pegs for a boat to show how they were both at the mercy of this illness. I have adjusted the colour by removing the red hue and increasing the blue to re-colour the fabric to represent the sea and the hands and mask are placed on it. The hands

are not anchored to anything but exist within the tides and changes of the illness experience. This was done to show how Mark is also experiencing ME/CFS and the unpredictability of living with chronic illness, showing how the hypertextual self-scape embodies the self knowledge of participants.

There are a couple of things with this. It's like a whole lot of fibres but unpredictable where they go. There a little bit all over the place and I guess ME is like that because you don't know where it's going to go. It also reminded me of the fibres that are used in fibre-glassing the resin that gives it the strength.

Mark was unfortunately in the middle of study commitments and wasn't able to respond directly but he sent the following message through Esther.

Mark's picture really sums him up. He is definitely protector in the relationship which is indeed like the 'stormy sea' in the background.

The way you have created the hands from lifesaving flag and anchor, which hold my mask (or me) really does show how he so gently but firmly has to hold and guide me (and our entire relationship) through the good and bad (sometimes very bad) states of my being.

On the flip side of me, the bright colours are very much him, he always uses colour and he agrees totally with the balance of colour that you have used in his picture.

Images 6.11, 6.12, 6.13 Pages 135 -136

## ESTHER



Image 6.14 photograph of objects in Esther's "MeBox"



Image 6.15 Sock Monkey and Journal

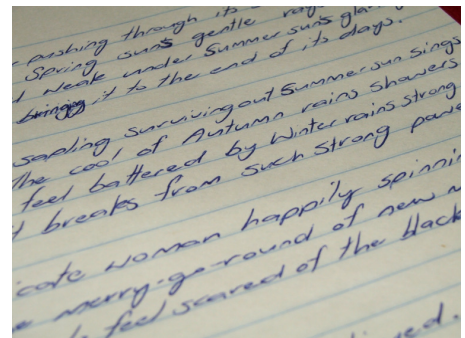


Image 6.16 Journal Page





Image 6.17 Esther's hypertextual self-scape image

## ESTHER

Monkey: This image was very important to Esther and comes from our second interview but also reflects the first interview because in spite of her difficulties Esther always referred back to finding hope. When Esther spoke of the monkey he also represented contributing financially in a way that was possible whilst still living with ME/CFS. For Esther she wanted her marriage to represent a partnership and she viewed contributing financially to be part of this process. The hypertextual self-scape enables participants to interact with self in a positive light which enables new viewing of embodied sensory knowledge.

I saw a sock monkey and thought that's something I can do. So I have friends that meet every second Friday and we meet and have lunch together and just hang out and I said let's make sock monkeys because I was intrigued to see how long it took and whether I could do it as I enjoy doing creative things. So we made these monkeys. He's brought a whole new aspect of life to me because he's something that I can do no matter how I'm feeling because you just sit in the same spot and sew. It's so rewarding and he's so cute. So I've been getting into my creativity again and I'm feeling more positive now and it's opened opportunities. I can make sock monkeys and I can sell sock monkeys. So I can start contributing financially too. It's made me feel like I have a purpose again, even though it's such a small thing but I'm thinking of getting together some materials and making a lot of sock monkeys and selling them.

Written pages: These are from the photographs taken during the second interview. I have added the effects torn paper, emboss and chrome to them to support the meanings of the words. The words were taken from a book of poems that Esther had been writing for several years. She chose these poems as they were ones she had written about her ME/CFS.

Clock: This clock lies over the monkey's arm and represents how time becomes warped. Using the liquefy filter I was able to click and drag the image using the blur function. The clock holds the arm down to reflect the distortion of time caused by fatigue and pain. The clock and the weight of it holding Esther down leads the viewer through the hypertextual surface into Esther's lived experience.

Time just doesn't end, if you're watching a clock it can go so slowly and other times really fast and I guess ME/CFS is the same. Sometimes some days go so slow and there so hard and you just want time to speed up until you're better again, and then sometimes when you're good the good times can go to fast and you want them to slow down. There's lots of aspects to time for me and how I see my illness.

Dice: The dice have been broken up and reflect Esther's concerns about the inconsistency of the chronic illness experience. They represent the volatile body, which is common in the experience of chronic illness (Moss and Dyck 2002:146). The original photograph taken of the dice showed only one side of the dice. To show the variability I used multiple copies of the one image and by using the 3D filter altered them to fit Esther's description.

Every day it's like rolling a dice and every day it's a different number. I like that it's red and white instead of black and white because at the end of the day it's the blood and white blood cells at the scientific core of what's going on.

Masks: Esther voiced concern over masks at our first interview as she felt that masks usually represent secrets and not being completely honest. However, as can be seen from comments in the previous chapter, her mask expresses honest experiences of ME/CFS which is why it is present in the composite image expressing her hypertextual



self-scape through her embodied sensory knowledge. I had initially put the mask at the back looking through the other images on the page to look out on the whole experience so that the viewer could be drawn deeper into the hypertextual surface. After consultation on the image with Esther the masks came further forward. The colouring also changed to those of the mask and the clock as she felt that the colour wasn't quite right.

Esther said,

I think the way you have combined our images is so creative and definitely something I never would have thought of.

I personally am not a big fan of bright things so would have composed my own image of sepia (like clock), black, white and greys myself with just the red dice and red lips as colour. I would also not have the writing covering the mask. I love the broken dice and the warped clock. They evoke a very emotive reaction from me that is hard to describe. Sort of like; "oh wow, someone finally gets it!"

Images 6.14, 6.15, 6.16, 6.17 Pages 156-157

**CLAIRE**



Image 6.18  
Unaltered Clock  
Face And Heart.



Image 6.19 Claire's hypertextual self-scape image



## CLAIRE

Claire as Amy's mother was the second participant who was affected by the illness experience as a family member. Chronic Illness is not a purely individual experience but affects everyone in relationship with the diagnosed person. For Claire's image I drew on only two of the objects in the box, a picture of a heart drawn by her daughter and a clock face. The clock face is central in the image and has been through liquefying filters, 3D effects and stretching to change its appearance so that Claire's reflexive viewing of the object can be visible through the hypertextual selfscape. The melting clock face is one attributed to Dali's work (1931) but in this situation it is an eloquent visual representation of the morphing of time with chronic illness. The clock as the main image was chosen as it reflects time and its flexibility and inconsistency. In looking at the finished image Claire wrote:

As a scientist I deal with the measurable, and am forced to be dispassionate in everything I describe. Therefore I am not practiced in delving into the creative side, and find it refreshing when I do. The picture you created for my experience of CFS, eloquently describes the way that time no longer becomes a background thing that feels constant and reliable. You have captured the way that my experience of time becomes stretched and distorted, with having normal life placed on hold in terms of Amy reaching educational and sporting milestones. My always worrying about the energy budget (of which time is the best indicator) for every activity Amy does such as walking to the dairy, going shopping for new shoes, etc. The distortion of the clocks also represents not only the distortion of time-perception but also the distortion of everything about life, the way Amy no longer fits into the normal everyday childhood world. And the sombre colours, with the colourful heart at the centre, tell of CFS years being a dark phase in our lives, but with family love to see us through.

Clocks: Most of the image is connected with the clock and time. I drew on both of the interviews and comments made at both of them. These related to not knowing how long Amy's energy would last, her sleep problems and Claire's being awake with her at night. The clocks were also talked about in relation to loss of time at work and loss of time as a family. The clock faces differ in how they have been changed. Some have been warped and others look like they are melting. I have done this to show that time is not something that can be used to plan life around and because of that there can be a loss of consistency. The hypertextual self-scape of the image shows time is not constant but it demands to be recognised even in its distorted form. Some clock faces are unaltered to reflect the randomness of the illness and that change is the only constant.

Heart: Having been with both Claire and her daughter their love for each other was very visible and obviously central to their relationship and how they cope with ME/CFS.

You need to have a big heart and you value kindness in others. I guess it's changed our relationship but I don't know what it would be like any other way.

Words: This is a quote from the first interview when Claire was speaking about family holidays and needing to get Amy to school. The quote is at the core of the image drawing the viewer through the reflexive surfaces towards the centre of Claire's embodied experience.

Images 6.18, 6.19 Pages 162-163

**AMY**





Image 6.20 Small  
Shoe



Image 6.21  
Clock Face



Image 6.22  
Unopened  
Chocolate





Image 6.23 Amy's hypertextual self-scape image



## AMY

The centre of Amy's image is a pair of shoes. This object was initially chosen by her mother and added to their shared box but Amy liked the image and spoke about it. At the second interview when photographing her objects the shoe was present in a variety of photographs and she spoke about it before her mother. In looking at the composite image Amy, through her mother, said that she liked the image and the story it told.

Shoes: In our interviews Amy spoke about how difficult it was to know her energy levels and be able to judge what could and couldn't be achieved. Amy talked about how she would need her parents help to get to school and sometimes on outings needing her parents to carry her as she could no longer walk for herself. This variability in fatigue levels is common for people with ME/CFS and for a young girl not knowing what she could achieve was very frustrating. To illustrate this variability I have changed the colours on the shoes, used the effects neon nights, sketch tool and the filters angled strokes, chrome asphalt. These have then been blended using the blur tool in the liquefying filter to graduate the levels in to each other. Through colour and shape the hypertextual self-scape is provided with a deeper visual dialogue.

Claire: This brand new shoe is completely unused and all tied up and we get all tied up and can't do the things we planned.

Amy: Like Mummy and Daddy when we are on holiday usually like to go for big walks and when it bad I get tired really easily and couldn't do it so they had to give it up... My friends used to like to go and play outside but I couldn't do it.

Amy

Chocolate: I included the chocolate as Amy saw it as a positive part of the illness as it was one of the ways to get magnesium into her system. This object appeared in photographs about how she coped with her

illness and in things she felt she had gained, which expressed her deeper sensory knowledge (and love of chocolate).

Amy: I Love my chocolate buttons in the morning. Mum you're the one who knows why you gave me chocolate.

Claire: Because I read in Meeting Place that somebody did a study and dark chocolate improved people's mood.

Clocks: The clocks under the shoe have been distorted like her Mother's, using the liquefy filter, to show again that running and playing aren't always possible. This hypertextual metaphor shows childhood timing is different, with issues around difficulty sleeping, energy to play and school attendance as Claire described in chapter four.

Background: The background is created using two effects which have been coloured to look like grass and asphalt to represent the places Amy spoke about in needing to have energy. The grass hypertextual self-scape image refers to a couple of "good" days she spoke about after receiving treatment from Dr. Vallings which helped to improve her sleep patterns.

We went to the park and I ran around and I climbed up the slippery bank and it was good and I learned to grab hold of the trees as I slid down. I liked holding the trees.

Words: The quote in the bottom left hand corner is from the second interview when we collected the objects under various themes and photographed them. These words were associated with the shoes and with fatigue and loss caused by chronic illness, building the link between the hypertextual frame and the different surfaces of the self-scape.

Images 6.20, 6.21, 6.22, 6.23 Pages 167-168



**KARL**

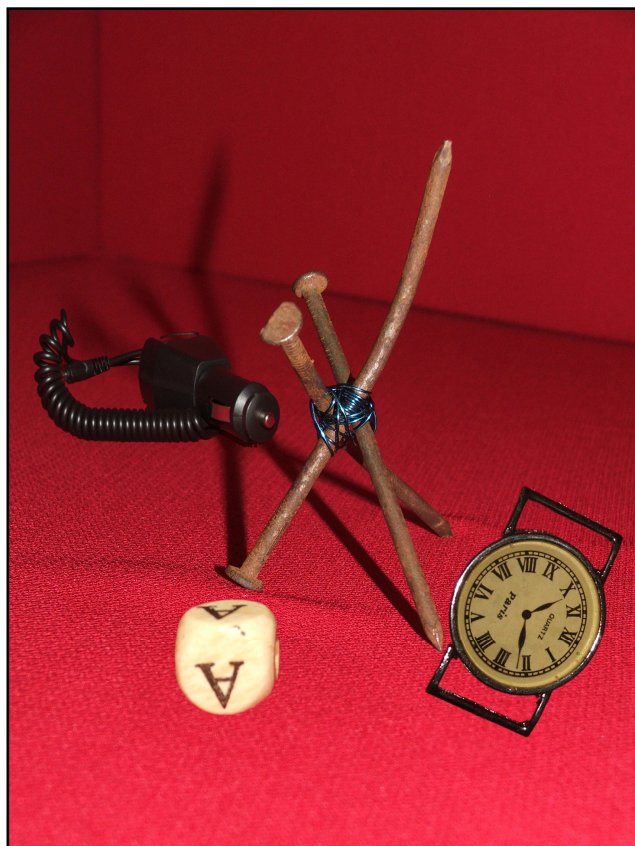


Image 5.24 Objects from  
Karl's Box.





I've got a strong personality and for a time there's probably been quite a lot of denial and as a result of that frustration comes into play because you think to yourself that three years ago it wasn't an issue, why does it have to be an issue now?

Image 6.25 Karl's hypertextual self-scape image

Karl struggled with the process of choosing objects and instead often used verbal metaphors to explain how it felt to live with chronic illness. When the composite image was sent to him, Karl related to the written explanation as well as the visual image. 'I think your explanation and images have captured where I was at quite well, and am happy for you to proceed as is.' The image I created used his metaphors and returned them to visual representations from verbal descriptions. As stated earlier at the second interview we spoke about pottery, it did not go into the box but was very relevant and this has become the main feature of the image.

Clay: This is a dominant hypertextual image on the page and I have added this due the second interview. The clay is multiple layers of the same image with selections removed to enable the appearance of the objects being placed in the clay. When Karl spoke of clay it was in reference to loss of the ability to learn to pot due to the debilitating nature of Fibromyalgia. It was a significant loss as he had had the opportunity when he was younger to develop this skill but didn't have the time. Now he had the time he was unable to handle the physical strain of potting.

My regret is that I didn't take them up on the offer to try and now I don't even have the strength to pull a pot.

Karl

Pottery Shards: Making pots was not something Karl could now do but like Anne he has refocused the things that give him pleasure into something that is manageable with his Fibromyalgia. Karl collects New Zealand pottery often finding treasures that have been forgotten.

It's something I can do that gives me a thrill. I used to ski and for the first time last year I skied up to five slopes and thought I can't do this and went down the easy way. Yeah I guess in some way



the pots do replace that. It's the thrill of finding something important that no one else recognises. It reinvigorates me.

Karl

Nails: The nails and the other objects have all been separately lifted from the original image using the magic brush tool. The nails are from the first interview where Karl chose them to reflect his experiences of pain caused by Fibromyalgia. As we looked through the selection of objects to find something that could represent pain Karl responded to the nails.

At the end of the day for me as far as Fibromyalgia is concerned is always that unexplained pain and of course there are those other things that then get associated with you get sleep deprivation and everything else and it just becomes a snow balling effect. Like you wake up the next day and you feel so exhausted and yet you've got a day to complete in one way or another.

Karl

Battery Charger: This is from the first interview and was connected with comments about just wanting to plug in and turn on again, especially around issues relating to memory. As it was added to the box Karl stated simply 'I know what that is and it's going in.'

Dice: This bead represented a dice as the dice I had Karl felt was too large. The dice as with other participants represented the inconsistency of the symptoms and not knowing how the body would feel during the day.

You never know what's going to come up. You can roll it six different times and get six different answers. You don't know what sort of sleep your going to have. You don't know what you're going to feel when you get up in the morning. So that's why I've chosen the dice, you never know what you're gonna get.

Karl

Clock: This clock, like the clocks in the other images, show's how time is no longer constant and that the body or illness dictates what can be achieved in a day, not the clock. This is a strong hypertextual metaphoric image for most of the research participants. Chronic illness challenges time (Charmaz 1991:171). It show's that while each person's hypertextual self-scape is individual some of the layered surfaces overlap another's experience.

The time thing. There's that fogginess with memory and then there's frustration there's always that frustration. If your going to peel a kiwifruit and you open the draw to find a knife and then you look on the bench and you've already done that action but you gone into repeat mode and then the phone rings and you think fuck off leave me alone and it's like you're trying to deal with something and then there's that interference or you think stuff it why couldn't I remember that I've already done that, moments before hand.

Karl

Background: At the first interview Karl spoke of walls and how they can protect from difficulties but they can also block the good as well. The walls have been created in layers using the effects, bricks, wood, with recolouring asphalt and cold lava. The walls represented protection and the chronically ill body's inability to cope with stressors.

You don't easily allow people into your life either. I suppose as a result of that you're denying yourself the joy that can potentially come out of that. I think we probably put up bigger shields around us. Walls. We don't have one wall we have probably three or four. I don't easily allow people in. Trust comes into it and I don't

know if at the end of the day whether we get hurt more easily.

Because of that subconsciously maybe you try to stay out of that.

Karl

Images 6.24, 6.25 Pages 172-173

**BETH**





Image 6.6 Tea cup.

Image 6.27 Feathers



Image 6.28 Flower, Beads,  
Clock Face and Leaves



Image 6.30  
Pearl beads

Image  
6.29Mask





*I just live absolutely in the moment.  
I can't plan things so I don't even try.  
I can't changes what's happened, so I  
don't let that be a distress so that it  
takes away from my energy now.*



Image 6.31 Beth's hypertextual self-scape image

## BETH

Beth's composite hypertextual self-scape image has focused on her favourite colour and when looking at it initially everything appears to be well proportioned and balanced, following a similar technique to still life painting. However as time is spent looking at the image one begins to see the slight distortions and the difficulties of her experience of chronic illness as imagined through her hypertextual self-scape. Beth has chosen to interact with her chronically ill self by allowing herself the space she needs and balancing her commitments. Whilst her contemplative lifestyle would be something many people would envy, for Beth it has come at a price; not one she resents but one that plays a part in every decision she makes throughout the day. On receiving a copy of the composite hypertextual image Beth wrote.

I guess the best way to explain the impact of the picture is I am a very visual person. Blue is my favourite colour. It brings me peace and it was dominant in the picture. I love balance and the picture was balanced which makes me feel in balance in myself. And of course you made my beautiful cup the centre of the picture and I love my cup and that it represents the time I give to nurturing and honouring myself. It is fabulous you are an amazing listener and have captured the main points very clearly. I feel heard, understood and validated. Thank you.

Beth

Tea cup: One of the ways that Beth takes time for herself is through her cup of tea. It is a ritual she has created. She uses a cup that was gifted her by a friend who passed on due to severe illness. This person was someone who taught her that honouring herself was important. Beth takes a tea pot and the cup on a tray to a special place in her house she has created and takes the time to be still.

It gives lots of time for cups of tea and to be still with myself. My tea time is my quality time with myself. It's a ritual that I have.

Beth

Mask: The mask was given multiple roles during the second interview and in this image I am using it to represent the anonymity that Beth felt she gained because of where and how she lived with ME/CFS. The mask was lifted using the magic brush tool, copied and positioned. The mask also represents a place of growth as Beth felt that the blank mask held potential for the future.

Anonymity brings with it a lot less obligations and expectations and I won't put negative expectations on myself. I just don't engage in all that and that's great.

The mask is a neutral space. I'm still becoming. It's easy to have it blank because there are new experiences coming everyday.

Beth

Flowers and Necklace: Beth spoke about the conscious decision to take pleasure in each moment. The flower came in to the second interview and was accompanied by the necklace. Both of these objects represented something she had chosen to gain within the chronic illness experience. These objects also related to the use of her day to nurture and support herself. This does not lessen the loss of social relationships that Beth also spoke of but they represent her conscious decision about living with joy in amongst the difficulties of chronic illness.

There is time now to do things that are meaningful, that make life meaningful. I take time to smell the roses. I like to go to op shops and I like to take the time to play dress-ups and enjoy those things and to read things that have meaning for me.

Beth

Clocks: Beth's relationship with time and the clock metaphor image was discussed in detail in the previous chapter but here time becomes more visible. In the composite hypertextual self-scape image the clock face has undergone multiple changes to its size and shape with the effects neon nights and chrome and the filters bas relief, torn paper and conte crayon to reflect this. In particular Beth spoke about how her life used to be run by the clock and that time can not dictate as it creates stress. Her body and spirit now determine what can be achieved in a day. Time also represents a loss of the person she was before getting ME/CFS.

Friends ask would you like to do something and you have to think do I have the energy or not, and sometimes it's yes okay lets just go and do it. Sometimes if I'm not well that day I will still go try it and if it's too much I'll come home. It can be something as simple as a walk. That's a big loss for me, I like order and it's humbling for me to be spontaneous.

Pearls: These are from both interviews and were also chosen by Beth during one of the support group meetings. Each time Beth chose the pearls she spoke about wisdom gained along the way. A couple of the pearls have been slightly distorted in the hypertextual self-scape to reflect the wisdoms she said weren't easily learnt and that wisdom is gained through experience and observation. At the support group sessions the pearls were in small strings and Beth choose them all and described breaks between the strands of pearls as gaps in gaining wisdom caused by severity of her illness. At the first interview she chose them and explained:

It's gathering these pearls of wisdom, and gathering the wisdom from when I make wrong choices and when I make right choices and accepting them.

Beth

Words: The quote is from the second interview and reflects Beth's choice in how she manages her illness.

Feathers and Leaves: Beth spoke of the feathers and leaves in relation to feeling lighter and that the choices she had made because of the illness which resulted in gaining a level of freedom from pressures. The feathers in the hypertextual self-scape are also slightly twisted by using the liquefying filter to represent loss of lightness which Beth spoke of in relation to them at the second interview. Reflecting on these objects Beth also spoke about learning from experience as she had with the pearls.

When feathers come into your life it's a tap on the shoulder from an angel. Feathers are also peaceful and light and not a negative, they're possibilities. I like the lightness and the spiritual connection. The feathers are about gaining wisdom about making better choices and understanding myself better. Keeping life not complicated and honouring the self.

I like the delicateness and lightness of the leaf. I collect leaves like this that have the fragility about them and I like to look after them. They are like me as I also look after myself.

Beth

Beth made it clear that she appreciates many aspects of her life but it was also clear that her ME/CFS played a part in how she was able to live this new lifestyle. To reflect this there are some slight distortions on the page to reflect that the body in illness impacts on daily living even when Beth said that the way she now lived, in a quiet environment with less pressures, would have been her choice.

There's a loss of lightness in self. As much as I liked going through life with a fairly optimistic accepting attitude sometimes things feel heavier than they need to be purely because the energy's not there to manage them. I work pretty hard at keeping



life in an even way but sometimes when you get an overload, like two family members in hospital, you have to try to manage your space. You have to listen to your body.

Beth

Images 6.26, 6.27, 6.28, 6.29, 6.30, 6.31 Pages 179-180

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### SUMMARY

The composite hypertextual self-scape images have been created to find another medium in which to communicate the experiences of chronic illness. The term hypertextual self-scape evolved out of the research process. The self-scape represents a condensed self portrait gathered from a vast landscape of experience. The hypertextual term refers to the ability to cross-link multiple layers of information and is taken from its original cyber context to represent the interconnections and complexities of experience. I am not trying to capture the participant's whole life experience in a single metaphoric image but due to artistic forms it is possible to reflect on the cumulative embodied sensory knowledge of the illness experience (Shiff 1978:107). As with the writing process I have edited and framed the hypertextual self-scape images within an academic model, endeavouring to communicate the information that was given during the fieldwork. My process involved working closely with participants, and honouring their understanding of chronic illness through the creation of the hypertextual self-scape images. Without a collaborative approach in the creative process it is not something I would have undertaken.

Communicating experience visually transforms the type of information being communicated and accessibility to the chronic illness experience enabling the viewer to go through the layered surfaces and into the hypertextual self-scape. 'Metaphor confers the properties of one concept on another and all our cognitive, affective, and somatic ways of knowing may be brought to bear to elaborate metaphoric responses' (Kirmayer 1992:332). It removes a level of separation between the participant and the viewer as the viewer is invited into the embodied sensory chronic illness experience. In including the quotes in the explanation of the images I hear the inflections, the laughter and the sadness but in reading them the viewer is denied this knowledge. With the photographs in chapter four this is also true; through the photographs, like the quotes, the viewer is denied the knowledge of their meaning and how the participant physically related to the objects they chose.

In the composite hypertextual self-scape images the viewer and the participant see elements of the initial meaning returned to them as more visual detail about the object and some of its initial meaning is returned to it. The viewer feels the discomfort Maria expresses through the nest, the loss of stability through Claire's clocks and the inconsistency of the illness experience through Esther's dice. The composite hypertextual self-scape images allow the viewer to step through the hypertextual framework and engage with the experiences that the objects reflect. They allow a viewer to stand along side the participant and learn about chronic illness and the body in dis-ease. Through engaging with peoples experiences with the visual it is possible to gain sensory knowledge about living with chronic illness. Privileging the written over the visual denies the importance of the role of the visual in communicating human embodied sensory experience.

The use of the body and self to communicate and interpret experience involves participant, researcher and audience in spectatoral consciousness of the hypertextual self-scape (Paskow 2004:160). As a whole the hypertextual self-scape images represent a group of people

with experience of chronic illness creating a visual community, even though the images tell the story of each individual's experience.

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## CHAPTER 7

### CONCLUSION AND REFLECTIONS

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In researching the sensory experience 'between different projects there will be variations in the types of argument and experience ethnographers seek to represent to different audiences' (Pink 2009:133). Visual and sensory anthropology is more than a system for things that are already visible as it enables "seeing" people's experiences. In this research I have used visual methods to make visible the hidden experiences of chronic illness. This has been possible as photographs are now more able to express the narratives that participants create alongside them. My main focus has been to bring the hiddenness of chronic illness into a visible position and to bring a greater level of understanding to what it means to live with a chronic illness. Chronic illness impacts on the whole person so the interconnectedness, created through visual methods and narrative, is essential and valuable in communicating embodied sensory illness. That written and visual accounts are equally important restores greater depth to research method and representation (Pink 2007:94). Visual methods go beyond simply engaging the sense of sight but connect the whole body. Visual anthropology enables a sensory dialogue through the eyes, mind and between the body's of people who live with chronic illness and those who do not. Anthropology with its capacity to embrace the whole story has the ability to collaborate with this embodied sensory knowledge. In wanting to make the illness experience more visible I have discovered that visibility is a complex interrelationship of senses, history and experience.

Through undertaking this research I have been amazed at the way it has evolved while the focus to make a hidden experience visible has remained at the core of the research. Participants engaged with the

tasks in ways that were unexpected and enlightening and through this method flexibility enabled it to grow as develop as it needed. For participants making chronic illness more visible appears to have been a positive enterprise. Visibility often means authenticity to illness and it is interesting that a visible approach has been taken in the UK in the book *Lost Voices*.

In this thesis I have suggested that visual representations and symbols of illness aid society in deciphering what is chronic illness and how to interact with people impacted by Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical sensitivity. As a society we look for and interpret our world through our relationships and our senses, which often means the less visual are marginalised.

### WHY THE HYPERTEXTUAL SELF-SCAPE

The hypertextual self-scape enables different envisioning of the self in chronic illness by creating meaning for the participant and the viewer. Out of this process of discovery, the concept of hypertextual self-scape became an integrating component of metaphor. The participant's hypertextual self-scape represented gathering embodied sensory knowledge, selecting its visual representation, and attaching the symbols and discourse to make the hidden experience visible. These were placed on a reflexive surface and surrounded in a frame of narrative. Through this creation hypertextual access became possible between the participant and the audience. Due to the permeability of the hypertextual surface and frame the viewer can enter into varying levels of understanding of chronic illness, by reading the narrative, looking at the surface representation or stepping through the hypertextual surface into a sensory experience of chronic illness. In walking through the frame into the composite hypertextual self-scape metaphors the body of the viewer allows some of the sensory experience of chronic illness to cross the barrier of their skin. Images and narrative interact through multiple layers of sensory discourse from the writer or creator to the viewer or reader both having value and enhancing the other. This shows how all

information and representation has value (Pink 2006:17). The outcome is that knowledge can become embodied.

The creation of the “MeBoxes”, the taking of the photographs and the creation of the composite images has involved a collaborative approach between participants, myself, and in the future the audience who will collaborate in the creation of meaning through their viewing. In viewing the masks and the composite hypertextual self-scape images the spectator is asked to become a part of the sensory experience. The masks through their reference to the body create visible hypertextual self-scapes through their “skin”, in a different format the images in chapter six engage the body through their digital surface creating the composite hypertextual self-scape metaphors.

### METHODOLOGICAL ISSUES

The different visual techniques of the masks, “MeBoxes” and hypertextual self-scape images elicited different data which expanded the types of information I could access in talking with participants. This method enabled a variety of different representations and each had the potential to be a thesis in themselves. The main regret I have is that I have been unable to look indepth at the support group meetings I ran. This is unfortunately due to word count and time frames. The meetings showed how people with chronic illness interacted with each other and also resulted in different visual representations to the individual and couple sessions. The method of focusing on a single object often elicited more data about the object as participants sat with it, as was the case with Mavis and the wire. The method I used also impacted on one of these meetings. It has changed how they ran their sessions as it enabled them for the first time in approximately a year to be able to talk about their experiences as a group.

### MASKS

For the masks the only instruction was to paint, write, collage etc... the blank mask on the outside to show what they perceived people see of



chronic illness and on the inside to put the internal experience of illness, as the participant felt was most appropriate to themselves. The type of mask produced depended on the artistic ability of the participant but this method of showing the differences between the internal and external experience was accessible to most of the participants. Not all participants completed a mask and several participants asked for more clarification about what I was asking for. If the masks had been the main method more time could have been spent speaking with participants about them. However, I did not expect the detail and information that I received or the connection that some participants would have with their masks. Many participants have asked for their masks to be sent back to them after they had been photographed and one has become a gift to a friend. One of the participants has since had a portrait taken with the mask she created and placed a photograph of her mask on facebook.

#### “MeBOXES”

Many of the participants during the initial collection of the objects took time to reflect on their embodied experience as they created their visual representations.

The time delay between the two interviews created problems as some participants had forgotten the reasons for choosing objects. It also meant that the boxes were put away to be looked at closer to the second interview which resulted in lost momentum and enthusiasm that had developed for many participants during the first interview. This method also meant that as a researcher I initially turned up at people's homes with a large bag of cardboard boxes and the large (heavy) plastic box full of different items. I startled one of my participants when she answered the door and saw everything I was carrying.

The “MeBoxes” took on different meanings to participants. For some the box was put away, for others it became something that was occasionally referred to but in each of the situations the boxes have been kept predominately intact. Anne, because of her “MeBox”, found a place to put a piece of writing that never had somewhere to belong. Beth placed

her box in her own special space including it with other things she treasured. Karl in moving away from the large box of objects showed his discomfort with the collecting of metaphors but used them verbally. Claire learned more about her daughter's experiences as they put together their box. Mark and Esther in their first year of marriage were able to talk more about their expectations and it was a safe place for Esther to ask questions about how Mark saw her. Katrina at the last interview decided that she wanted to unpack her 'MeBox', some of the images, like the car, were removed as she said they were more about what she used to be. However she has kept several items 'safe in the box' that she felt were important for her to keep and has since added to the box and taken her box to a training programme she is doing to show other people who she is.

## PHOTOGRAPHY

In my early years I remember sending away film and the excitement (and disappointment) of its return. When I got older processing my own film cut back on some of the delay but there was still the concern about whether I had captured the images I wanted. The training I received during those years has helped inform my current practise. Photographic processes have not altered; the camera angles, focusing and cropping required in film systems are still relevant to digital techniques. In the past it was necessary to wait to see what you had captured to see if the image you wanted had worked. However through digital imaging it is now possible to see instantly what is being photographed. Without the advances in photography the composite hypertextual self-scape images would not have been possible and the time commitment by participants and in the field would have increased dramatically.

In taking the photographs I chose to make a screen and cover it in red fabric to visually show the difference between the photographs from the support groups, which had a green background, from the interviews. Choosing the correct colour was a problem and I decided on something that would represent a basic point of connection between participants,

blood. The red was a difficult colour to use as a background as it altered in different lights with some of the images looking like they were on a pink background due to the need to use the flash.

As a student I had learned to take multiple photographs and during the photographing at the second interview it wasn't unusual to take over 70 photographs. Photographing objects meant that the images I had taken were the only ones that could be used. This meant that in creating the composite hypertextual self-scapes images the compositions were in part dictated by the photographic angles. An example of this is Esther's image with the dice where I had to use a dice which only showed two sides as I hadn't thought to get photographs of each side. I had to develop a solution as the object was important and the outcome has been positive as Esther particularly liked the visual image of the dice being broken up.

### COMPOSITE IMAGES

The images that were created whilst needing some artistic ability to help with compiling them were not created for the purpose of artistic appreciation. An artist may choose whether or not to explain the reasoning behind the creation of the image, choosing how they want people to interact with it. As a researcher I am bound by the purpose of the images to translate and communicate information.

Each object was altered in specific ways and in four images the clock appeared in a similar visual form but held a different meaning, for example the clocks in Claire's image and the one in Esther's which holds down the hand of the monkey were associated with different narratives. The images have all been created for a specific person but due to the importance of time and the distortion of time when experiencing chronic illness this became a significant image for many participants.

The visual is an important and complex dimension and has the power to create both a positive and negative gaze. Once an image is created it can become invested with meanings not associated with its first creation

and take on a life of its own. Pink states that this does not indicate that the adding of meaning will necessarily take away from its original significance but that it is important to ensure that the original meaning travels along with it (2007:124). I have begun to address this issue through the quotes included in the images but this is a concern within visual methods. However it should be noted that it is possible to take text out of context as well.

The creation of the composite hypertextual self-scape images involved a great deal of time. Creating them required sitting with tapes, notes and photographs of each individual before and during the process, to ensure I gained a representation that was true to the participant's stated embodied sensory knowledge. The images have always been connected with each of the participants and in sending them out for comments I was more worried about whether I had captured their experience correctly than any comments they would make. The hypertextual self-scape images to my mind are purely connected with the participants and whilst people may relate to them they represent one person.

I would recommend more time spent on the composite hypertextual self-scape images as I would have preferred a third and fourth interview to have more discussions with participants about them. This is not because the hypertextual self-scape images were wrong but because the way in which participants related to them has been fascinating and I would have appreciated the opportunity to discuss this more. I also believe that the composite hypertextual self-scape images had potential to create more scope for collaborative representations.

#### PHOTOSHOP 4.0

The most controversial of the methods of representation I chose was to create composite images. In the field 'the visual technologies ethnographers use, like the images they produce and view will be invested with meanings, inspire responses ....' (Pink 2007:48). This is

not a process I undertook lightly and I discussed my research with other post graduate students at a regular meeting I participated in on the Massey Albany campus. At this meeting concerns were raised about altering the original photographs and the words, 'manipulation of images', were regularly used, and questions were based around whether they represented the truth or were mere manipulations. I was surprised at the level of concern as to me the photographs of the objects did not reflect the actual true experience of the participants and were missing vital details, meaning, narrative and their sensory dialogue. Through this conversation I changed my layout to include photographs of the objects directly before the composites. In creating the images I was very aware of artistic techniques and their meanings and grappled with finding a balance between scholarly representation, and making the images meaningful rather than simply creating pretty pictures.

Existing artwork also influenced how I used *Photoshop 4.0*. In Claire's image with the clocks I did not put in many of the 'melting clocks,' as this image is very connected with Salvador Dali and I didn't want thinking about Dali to become the first reaction to the image. If I had added additional melting clocks it would have become more dominant in the image and may have distracted the viewer from other elements of the image. I still believe that two more clocks needed this technique to fully represent our discussions but due to the visual connection to Dali I did not do this.

As I stated in chapter three I had not used *Photoshop* before and I learned as I went. I personally found this very useful as it was a process of discovering what would best suit the participants sensory narratives. I had not planned to use *Photoshop* at the beginning of my research but had intended to use collage type techniques instead. The use of *Photoshop* opened many more possibilities for representation and without it the images would not be what they are. One of my participants who had received training on *Photoshop* was surprised that I had not had training to use the programme. At times I found the programme

frustrating with the smallest of issues such as changing Esther's image to sepia colours. This was not a simple process and required replacing the original colours and then altering their levels of saturation. As sepia is a photographic colouring I thought it would be easily accessible in creating the image but this was not the case. Another problem with the programme was being unable to blend the different layers of the images. This was a particular frustration with Amy's image as I wanted to make the different colour's and effects blend into each other to make it flow and show how there was no defined warning that her body would not be able to do the things she wanted. Through liquefying the edges of the layers it was possible to achieve something like this but not to my complete satisfaction.

This is not a form of representation that I would recommend everyone undertake as the complexities around art and its forms need to be understood if they are going to enhance the visual representation rather than distract from it. This technique needs to be done using a collaborative method with participants as through visual representation the information transmitted is extremely personal and it is possible to misrepresent a person in ways that a traditional photographic portrait may not.

I don't believe I would have attempted these hypertextual self-scape images on so little contact if I was not an insider researcher. My personal knowledge has been extremely helpful but I have had to be extremely careful not to put my own impressions of living with chronic illness onto the images. In all of the images it is my analysis of participants which has shaped the final product. This is also true for the writing of this thesis. I had to look at the visual metaphors that were being created and ensure that I was not making a complex illness experience more complex through my method. 'In this need to interrogate every image for possible meanings there was a sharper sense of my own distance, as editor, from the events and people being depicted and, concurrently, a heightened desire to understand them'



(Ritchin 2009:102). This reflexive practice continues throughout the research process; before going into the field, during fieldwork and when compiling and organising data and in the writing process. There is an expectation that ethnographers will sift through the information that is gathered in the field and through literature sculpt a thesis, article, book etc... This selection is often difficult but it is an essential and necessary part of the academic process to align with or challenge existing literature.

### XENOTROPIC MURINE LEUKAEMIA VIRUS-RELATED VIRUS

During the year that I have been undertaking this thesis new research into the possible cause of ME/CFS was published (Lombardi et.al 2009). The XMRV<sup>22</sup> virus is being heralded as the possible cause of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. This is being passionately debated in the ME/CFS community, as in the past there have been other claims of finding the causal factor. It will be interesting to see how this develops. It raises questions about the future of the ME/CFS community and possibly Fibromyalgia community as well. If this is found to be causal it could be possible to witness the loss of a culture or a dramatic altering of it. This would remove ME/CFS from being biomedically “invisible” to a simple blood test for a diagnosis. The hypertextual self-scape images created for the participants with that diagnosis may no longer be relevant to the ME/CFS experience of chronic illness and the question I raised at the beginning about hiddenness and visibility may no longer be a core concern. Even the awareness of the body which is central to the images may change in the face of the medicalisation of the body.

### SENSORY ANTHROPOLOGY

The focus of this thesis is to convey the embodied sensory experience of illness in an accessible format. Sensory information can be transmitted in various different forms but the way in which they are received is dependent on the audience. In creating the composite hypertextual self-

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<sup>22</sup> Xenotropic Murine Leukaemia Virus-related virus

scape images I have challenged the viewer to understand on a sensory level the experience of chronic illness.

Picture puzzles that we solve may yield a sense of accomplishment, even delight, they do not move us or provoke us to change; they do not show us, as many do, that our co-being in the world is at stake (Paskow 2004:168).

There can never be a complete knowledge of the experience of living with chronic illness for a spectator but the hypertextual self-scape image expands on literary and verbal information. In this hypertextual self-scape format viewers emotions are engaged creating connection to the person represented by the image. 'Emotions are embodied thoughts, thoughts seeped with the apprehension that "I am involved"' (Kirmayer 1992:330).

### CREATIVITY, MEDICAL ANTHROPOLOGY AND VISUAL ANTHROPOLOGY

In seeking to discover a new way to communicate hidden illness anthropologists need to find new ways of representing the embodied knowledge they gain access to through the method of participant observation. The current availability of hypermedia, PowerPoint, film, photo essays etc... expands the ways in which data can be communicated and the types of information transmitted. 'The photography of the future can explore and delineate universes where multiple principles are at work, and where existence is both solid and illusory' (Rithcin 2009:181). How the image is represented, the way it is compiled or the ways in which the onlooker is asked to interact with the image all impact on the way information can be communicated.

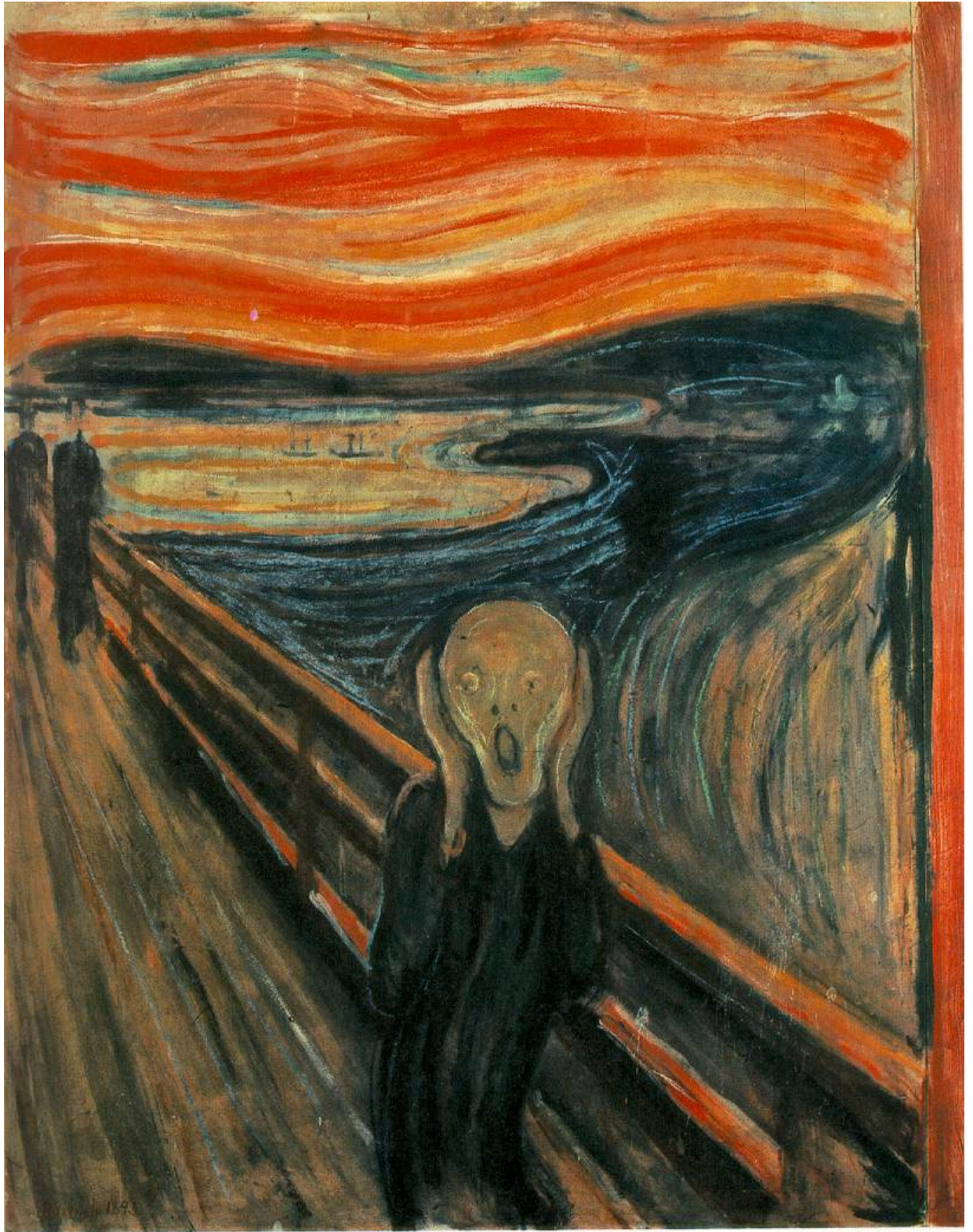
Portraiture from a post-film perspective encourages representation of the self beyond the body's boundaries and through the hypertextual self-scape method I have endeavoured to create sensory embodied experience portraits for all my participants. The altered and composite images challenge 'potential meanings, sustain ambiguities, provoke new

thinking about both the image and the collection of the images as a whole' (Ritchin 2009:102). Through Post Film and Surrealist photographic methods it is possible to expand what a photograph can communicate. The way in which this research is presented needs to become part of the theoretical debate due to the visual nature of the communication (Pink 2007:158,159). Through the use of these techniques the composite hypertextual self-scape metaphors unveil truth about the chronic illness experience in ways that other forms of data can not.



This is the "MeBox" I created in 2005 as an undergraduate.





**The Scream (1893)**

**Edvard Munch**

Tempera and Pastel on Board 91cm x 73.5cm  
Oslo, The National Gallery

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