

**THE INSIDE STORY OF LIVING WITH CHRONIC INTRACTABLE  
NONMALIGNANT BACK PAIN. AN AUTOETHNOGRAPHY.**

**Submitted by**

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**A thesis submitted in total fulfillment of the requirements of the degree of  
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**May 2007**

## **Statement of Sources**

The work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text.

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

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This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in this thesis received the approval of the relevant Ethics/Safety Committees (where required).

Signed:

Date:

## **ACKNOWLEDGEMENTS**

Firstly I would like to thank my supervisor, Dr Carmel Seibold, who gave me the initial encouragement to pursue this degree when I did not have the same belief in myself. I thank Carmel for her constructive criticism and patience during the writing and many editing phases of this thesis, and particularly for her support and encouragement in regard to using autoethnography as my methodology. I would also like to thank Carmel on a personal note, for her never ending support and friendship at times when I thought it may be impossible for me to finish. Carmel always acknowledged my health difficulties, yet at the same time urged me to continue at my own pace, for which I am extremely grateful.

I would also like to thank my family for their continued support and encouragement and special thanks to my mother and sister for help with final corrections.

My thanks go to the university's disability officers, who have assisted me with tape transcriptions.

Finally, I would like to thank the five women who participated and contributed to this study. They spoke so openly and honestly about subjects that were often sensitive and at times, traumatic and I am deeply grateful for their trust.

## ABSTRACT

The aim of this study was to uncover and understand the reality of living with chronic, intractable nonmalignant back pain, as it is understood by sufferers themselves. A narrative autoethnographic research design was chosen, enabling me to interact with participants during the interview process, as well as have the opportunity to further explore my own experiences, as a long time sufferer of chronic, intractable nonmalignant back pain. Thematic analysis of participant interviews, and a deep, introspective scrutiny of my own journey, resulted in four stories being written. These stories illustrate the startlingly similar experiences we share. Although each story is written around one central character, they are in fact composite characters, representing the participants' experiences as well as my own. The stories are: 'The merry-go-round: Searching for a cure', describing the endless visits to various specialists, in search of the elusive 'cure'. 'Mourning the loss', illustrating the grief-like process we must go through when it becomes apparent that a cure is not possible and pain will be with us for the rest of our lives. 'Walk a mile in my shoes', giving a snapshot of issues facing us in our daily lives, and 'Here we go again', a description of a 'typical' pain management hospital stay. A fifth story, 'We're not in Kansas anymore', was added following a bizarre emergency admission I was forced to endure during the course of my research. It is therefore a story where I am the central character. These stories illustrate the impact chronic back pain has on a sufferer's life, ranging from loss of mobility to an altered body image. They also illustrate the struggle to maintain normality, including masking the pain and facing labelling and stigma. These stories identify and demonstrate the often hidden aspects of chronic intractable back pain, and have the power to inform practicing nurses, students, teachers and the community of the 'lived experience'.

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## **CHAPTER ONE INTRODUCTION**

My research topic chose me! Having personally lived with severe chronic pain for over 15 years, I have developed an extensive insight into the dynamics of hospitalisation, and of chronic pain itself. The following brief history will attempt to set the scene of how I came to be as I am now, and how this has influenced my choice of topic.

As a nurse, I have always been professionally interested in my patients' different approaches and reactions to being hospitalised, and in particular the pain experience and its treatment. I saw that acute pain was the primary focus for most nurses in large, inner city tertiary hospitals. When patients were admitted for chronic pain, they were expected to exhibit the same pain symptoms and behaviours as the acute pain patient, which is not the way chronic pain manifests.

My knowledge of chronic pain did not end, unfortunately, with professional interest. I sustained two major injuries at work, the first in 1987, which left me unable to maintain employment for 6 years. On return to part time employment in 1993, I sustained a second major injury at work in 1995, and I have been unable to work since that time.

My experiences as a nurse in the 1980s contributed to my subsequent injuries. In the past nurses have had to assume an enormous physical burden, constantly lifting and bending to accommodate patients' needs. Patient health was considered before the nurse's own health. At the time of my general nurse training, which was hospital based, occupational health and safety was in its infancy, and nurses were expected to lift all patients, no matter their weight or dependence. I remember being instructed by a physiotherapist to assist a totally dependent 146 kilogram (23 stone) woman to get out of bed and stand. This was good for her health, but was certainly not good for mine! The unfortunate consequence of these demands has meant that nurses were constantly doing incremental damage to their backs. It was unusual to find a nurse who did not have a backache at the end of her shift. Continuous pressure on nurses' backs increases the likelihood of sustaining a major injury in an incident. Hopefully now,



with 'no lifting' policies in place, young nurses will not be faced with the trauma of injury, as I was.

Following my first injury, a series of seemingly unending hospitalisations began, both for diagnostic and pain management purposes. As a nurse, it saddens me to say that many hospitalisations were extremely traumatic. I felt an extreme loss of control as a patient. I entered the hospital as an articulate, intelligent, self-assured woman, but as soon as I became a 'patient' I was suddenly cast in a role that characterised me as someone whose knowledge and opinions about her own body were dismissed outright.

As a person, we rely on our roles in the world to give us our sense of self and personhood (Goffman, 1971). The thoughts and opinions of the medical and nursing staff were more important than what I was trying to communicate to them. I felt powerless and totally out of control, which was extremely frustrating and scary and left me feeling invalidated, isolated and alone. These experiences have been echoed in the accounts of other chronic pain sufferers.

I have ended up avoiding hospitalisations, even when I desperately need them, because the psychological trauma far exceeds any improvement I can make physically. Unfortunately many, if not most of the nurses, still hold stereotypical beliefs and label chronic pain patients as malingerers or exaggerators (Burckhardt, 1990). Nurses sometimes treat chronic back pain sufferers with derision, and sometimes even contempt, and usually respond to our requests, such as for analgesia, extremely slowly. I challenge these stereotypes and debunk many of the myths that surround chronic pain in the next chapter, where I review the literature and contextualise my study.

My own experiences and accounts of others reinforce the belief that chronic pain sufferers, as a group, are often stigmatised. Because the injury itself is not visible and is sometimes difficult to definitively diagnose, it is thought that back pain is an easy injury to imitate. This leaves back pain sufferers being viewed as frauds, which incidentally is how we are often portrayed in the media. Apart from the stigma of being viewed as a fraud, many chronic pain sufferers require narcotic

analgesia to manage their pain, and endure stigma because they are considered to be 'addicted' to opioids. There is widespread misuse of the term addiction. While most chronic pain sufferers may be dependent on opioids, it is unusual for them to be addicted (Portenoy, 1993). I cover this point in greater detail within the review of the literature.

There is also stigma associated with the way in which the injury occurred, if the person's injury is compensatable; either an injury that occurred at work or in a motor vehicle accident. Having sustained my injuries at work, I am therefore a WorkCover (worker's compensation) recipient. I have experienced stigma because of this, and this is illustrated in my story and the stories of the participants.

I have found, as already noted, that my story is not at all dissimilar to other severe chronic pain sufferers. I wanted to tell their stories as well as my own, to illustrate the greater need for understanding and empathy on the part of the nurses, other healthcare professionals, and the general public, as they interact with people living with chronic pain. I acknowledge that chronic pain patients have a responsibility within this relationship as well, but it is the nurses' and healthcare professionals' responsibility, as the professional in the relationship, to enter each therapeutic relationship with an open mind and to treat each new patient as an individual.

Like others I have experienced the highs and lows of looking for a cure, undergoing unsuccessful surgery, and of suffering iatrogenic conditions. In my case, diabetes, chronic fatigue syndrome, arthralgia and open heart surgery, were all side effects resulting from treatments for pain. At the same time I, like others, have undergone the ups and downs of denial, self doubt, acceptance and coming to terms with limited mobility, whilst not taking on the role of the invalid. As a result, I wanted to conduct research within this area, and give back to nursing, through providing nurses and healthcare professionals with the knowledge required to provide optimal care in this specialised field of nursing. The focus of this study is on the experiences of severe chronic nonmalignant back pain sufferers treated with long term opioids, including their experiences of hospitalisation, so much a part of the life of a chronic pain sufferer.

The next chapter, Chapter 2, reviews the literature related to chronic nonmalignant pain and suffering and nurses' understanding, knowledge, beliefs and attitudes regarding chronic nonmalignant back pain sufferers. Theoretical understandings of labelling theory, stigma, caring, ethical decision making and body image disruption are also examined, as a way of placing this study in context of existing research, and as a way of setting the scene.

Chapter 3 describes the process of choosing and developing methodology, as I interacted with the data and further examined my chosen methodology, finally settling on autoethnography, seen as best suited to exploring the experiences of people living with severe chronic, nonmalignant back pain while also incorporating my own experiences. In describing this process, I further explore my own personal journey and the process of recruiting participants and conducting interviews. I also describe my experience of story writing within the chosen autoethnographic approach.

Chapter 4, titled: 'This is your life: Coming to terms with loss and disability', in keeping with the chosen methodology, autoethnography, is written as a series of three stories that illustrate the experiences of the participants and myself, from the time of an acute injury progressing into a chronic, lifelong condition. The first story, titled 'The merry go round: Searching for a cure', describes the seemingly endless visits to specialists, looking for the elusive 'cure', whilst often being told by doctors that the pain is "all in your head".

The second story, titled 'Mourning the loss' explores the process of coming to terms with the fact that a cure is not possible, and severe chronic back pain will now be a lifelong condition. The other issue to be faced is that the pain can only be managed as it is extremely unlikely that any specialist will be able to treat you so that you are pain free.

The third story in this chapter is titled 'Walk a mile in my shoes'. This is written in the form of a letter. The letter is addressed to the next nurse who is to look after us in hospital; to doctors both past, present and future, who question the validity of our pain; to student nurses: our future carers, learning about the pain experience; to

medical students: our future doctors. In 'Walk a mile in my shoes', I ask the reader to imagine themselves to *be* a chronic intractable back pain sufferer: To literally walk in our shoes.

Chapter 4 illustrates that chronic back pain affects every facet of a person's life. These stories are important because they demonstrate the issues and experiences that 'patients' bring with them to a hospitalisation, so that nurses and healthcare professionals can have some insight into their patients' every day lives.

Chapter 5, 'Hospitalisation: An inevitable part of life', consists of two hospitalisation stories. The first story is titled 'Here we go again' and describes a 'typical' hospitalisation for pain management, usually when the patient is in a 'pain crisis'. The second story in this chapter is titled 'We're not in Kansas anymore'. It is a story about an acute emergency admission that I experienced and I am the central character. I have chosen to use my own name to identify this fact.

Chapter 6 reviews the research process and reflects on the choice of methodology and narrative or stories as a way of writing up data. Also considered is how stories may impact on healthcare professionals. I conclude with some personal reflections.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **Introduction**

*“Disease can destroy the body, but pain can destroy the soul”* (Lisson, 1987, p.649).

Chronic pain is an increasingly widespread health issue, with substantial economic and social costs (Gardner, 2003). Chronic pain is among the major health issues confronting Western societies. According to the 2004-2005 Australian National Health Survey (Australian Institute of Health and Welfare, 2005) 31% (6 million) of the population (33% of females and 29% of males) reported having a long-term disease of the musculoskeletal system and connective tissue, 15% of which were back problems. Back problems refer to back pain and problems and disc disorders that have lasted, or are expected to last, for six months or more. Nearly one third of those persons reporting a disease of the musculoskeletal system or connective tissue as the main underlying condition (28%) had either a profound or severe core activity limitation in mobility, self care or communication (Australian Bureau of Statistics, 2005). In 2000-2001, 9.2% of total allocated health expenditure (\$4.6 billion) was spent on musculoskeletal conditions, only slightly less than cardiovascular diseases (10.9%) and diseases of the nervous system (9.9%) (Australian Bureau of Statistics, 2005).

Chronic pain can have devastating and dehumanising effects, and can destroy quality of life (Burckhardt, 1990). Chronic pain affects every facet of a person’s life including mobility, work, personal relationships, sexual relationships, and roles within the family. Living with chronic pain means engaging in a constant struggle to remain in control of one’s mind, body, pain and life and thus sufferers tend to perceive and evaluate their pain in terms of their entire life situation (Pellino & Oberst, 1992), which includes the impact on their family (Burckhardt, 1990).

This chapter is arranged in two sections, the first presenting an overview of chronic pain, how it affects the individual and the family and experiences related to

hospitalisation, together with nursing theories and studies relevant to caring and decision making. The second section addresses theories such as labelling, stigma and the body associated with illness and disability.

### **THE CHRONIC PAIN EXPERIENCE**

In order to appreciate the significant impact chronic pain has on individuals and their families, it is necessary to first review the way in which pain and suffering have been defined and described.

#### **Pain and Suffering**

Pain and suffering have been closely linked in the literature. Pain has been variously described in the literature. Pain has been defined by Sternbach (1968, p.396) as “an abstract concept which refers to a personal, private sensation of hurt; a harmful stimulus which signals current or impending tissue damage; a pattern of responses which operate to protect the organism from harm.” Strevy (1998) also describes pain as an intensely personal and subjective experience, which Leder (1990, p.73) notes sets it off from other sensory experiences: “namely it *hurts*”.

The first definition is in keeping with a physiological understanding of pain. Pain theories have evolved over time, as researchers have begun to understand more about the phenomenon. Specificity theory and pattern theories were earlier theories, now rarely referred to, however they formed the basis of later theories. The gate control theory is now the widely accepted theory (Melzack, 1993). I do not propose to outline the concepts behind these theories in this review, as there is a copious amount of published material available and an understanding of these concepts is not necessary when exploring chronic pain as experienced by individuals.

Unlike acute pain, usually temporary and often with a sudden onset, chronic pain is considered to be so if it persists over 6 months. It is not only the duration of pain that distinguishes acute from chronic pain but, more importantly, the inability of the body to restore its physiological functions to normal homeostatic levels (Loeser & Melzack, 1999). Chronic pain can be episodic, changing in its nature, such as

intensity and character, often in response to changes in activity and position, with “pain receptors ... adapt[ing] either little or not at all” (Leder, 1990, p.72). Scarry (1985, p.35) explains that “pain is experienced spatially as either the contraction of the universe down to the immediate vicinity of the body or as the body swelling to fill the entire universe.”

### **Pain as a personal, subjective experience**

Ultimately pain is defined by each individual introspectively, in terms of one’s own personal experience. In this way pain is an isolating experience, as “pain strikes one alone .... Pain is marked by an interiority that another cannot share” (Leder, 1990, p.74), and is an alienating experience, particularly if it is ongoing.

People almost universally describe their pain as ‘it’, separate from the ‘I’. The painful body is often experienced as something foreign to the self. With chronic suffering a painless past is all but forgotten. ... While knowing intellectually that we were once not in pain we have lost the bodily memory of how this felt. Similarly, a painless future may be unimaginable (Leder, 1990, p.76).

Leder (1990, p.77) emphasises that “to experience the painful body as merely an ‘it’, that which is separate from the essential self, yields some relief and re-establishes one’s integrity in the face of overwhelming threat.”

Pain can also cause, or be experienced, as disability, with consequential effects. Previous abilities, performed without thinking, have been lost.

This could be termed the phenomenon ‘I no longer can’. When sick, I can no longer engage the world as I once could. There may be nostalgia for lost possibility, hope for its return, fear that disability will spread. One is actively *dis-abled* (Leder, 1990, p.81).

Being a contributing member of society, such as being gainfully employed, contributes enormously to a personal sense of self worth, self esteem and sense of personhood. If one is unable to participate in such activities, self esteem and self worth are likely to be diminished (Goffman, 1971). Inherent in these descriptions is the notion of pain as suffering.

## **Pain experienced as suffering**

Morse (1997) defines suffering as “a highly emotional response to that which was endured, to the changed present, or to anticipating the altered future.” Expanding on this definition, Gardner (2003, p.43) describes suffering as “an anguish that is experienced, not only as a pressure to change, but as a threat to our composure, our integrity, and the fulfilment of our intentions.” Suffering, like pain, is ultimately highly individual and personal (Cassell, 1982) and usually results in a quest for interpretation and meaning (Leder, 1990). Bakan (1971, p.57) writes:

to attempt to understand the nature of pain, to seek to find its meaning, is already to respond to an imperative of pain itself. No experience demands and insists upon interpretation in the same way. Pain forces the question of its meaning, and especially of its cause, insofar as cause is an important part of its meaning. In those instances in which pain is intense and intractable and in which its causes are obscure, its demand for interpretation is most naked, manifesting in the sufferer asking: ‘Why’.

Perceived threats to the future, loss of control, overwhelming pain, or chronic pain, are reported causes of suffering. If the cause of the pain is known, and no threat is perceived, agonising pain may not cause suffering. However, when a person in overwhelming pain feels out of control, suffering is likely to accompany their pain (Cassell, 1982). Suffering is not only confined to physical symptoms. Social isolation, the feeling of no longer being able to communicate, distress and disbelief by others can also contribute to suffering (Smith & Friedemann, 1999). As Vilensky (2002) notes: “*Myth*stakes of inadequate pain management is one of the obvious causes of suffering, but other parameters involve loss of society with family and friends, functionality and employability in addition to significant financial burden.”

Healthcare workers cannot anticipate what individuals will describe as a source of suffering, but must ask the patient. From the patient’s perspective, chronic pain, uncertainty and loss are all forms of suffering, as “illness [is] a transformative experience” (Morse, 1997).



## **Studies of the Chronic Pain Experience**

Explorations of experiences of chronic pain have included young people's perception of their pain and its impact on their lives (Carter, Lambrenos, & Thursfield, 2002), the experiences of pain and the coping strategies employed (Hillevi, 2005) and dimensions of chronic pain and the factors influencing the pain experience (Strong, Ashton, Chant, & Crammond, 1994).

Carter et al. (2002), in a workshop with five young people with chronic pain found that while they acknowledged camaraderie with their fellow sufferers, they emphasised their pain was their own, unlike anyone else's. Similarly to descriptions of pain by Leder (1990), Carter et al.'s participants described their pain as if it were a separate entity from them as well as an intrinsic part of them. All described their pain as agony, but did not exhibit any noticeable (to the researchers) outward signs of pain during the workshop. This was put down to their need to strive for independence, especially when their peers were becoming increasingly independent. They chose to assert control by managing their pain, because if we "sit and mope around and don't do anything it seems to ... make it worse." All of the young people in the group felt that they had had to grow up fast, as they did not like depending on anyone else (Carter et al., 2002).

Hillevi (2005) also found in a qualitative study of 22 chronic pain sufferers that they strove for normality by strenuously managing their pain, not always an adaptive response in the long term. In studying the coping strategies of the 22 participants, all of whom were in full time work or study, she identified what she called "the disregarding defence" as a psychological defence where low back pain was not given any significance, and because pain was not allowed to intervene with daily activities, participants were able to keep up with life in spite of the disorder. This was considered an adaptive mechanism in the short term which might last for months or even years, but could in the long run be harmful. That is, if the person continued to use the disregarding defence for a prolonged period of time it was seen as having the potential to "limit the participants' sense of responsibility for pain and pain management, and, as it increased the likelihood of future relapses, it seemed to interfere with rehabilitation" (Hillevi, 2005).

Participants were seen to undergo a psychological crisis after ceasing to use the disregarding defence. A period of reappraisal usually followed as they took responsibility for the control of their pain and reassessed activity abilities. Most participants then readopted the disregarding defence in temporary situations, as a coping strategy when no other method was available. Thus denial, often seen as a maladaptive coping strategy, can be used selectively as an adaptive coping strategy (Hillevi, 2005).

An Australian study by Strong, Ashton, Chant & Crammond (1994) investigated the dimensions of chronic low back pain from the patient's perspective in order to gain a better understanding of chronic pain and develop more effective assessment and measurement tools for nurses. Strong et al. (1994) found that the most important factors in the experience of pain for the participants were: positive and negative affect/emotions, features and symptoms of pain, mobility, domestic activities and treatment and family/personal relationships. They found most of these contributors to pain intensity were not currently assessed in Australian healthcare practice.

The researchers found that the patients' positive and negative affect and emotions, while possibly observed by the nurse, were often misunderstood. Because chronic pain sufferers have learnt to cope with their pain over time, they do not behave in the same manner as acute patients and will often minimise the outward signs of the effect their pain is having, by putting on a façade, or mask. Strong et al. (1994) also found that, while overall mobility and the ability or inability to perform domestic activities is important in the overall assessment of a chronic pain patient, these indicators were not usually assessed, unless the patient was referred to an occupational therapist. Likewise, while pain symptoms, usually using a 1-10 analogue scale, and type and location of pain experienced were assessed, efficacy of treatment was not regularly assessed by nurses, for example by asking how the patient's pain intensity was affected after administering analgesics. Family relationships were also found to be inadequately explored in terms of support, as were family members' knowledge of their relative's pain and pain cues, in both the home and the hospital (Strong et al, 1994).

## **Chronic pain sufferers and family members**

Chronic pain affects not only the sufferer, but all those within their close environment. Depending on the level of disability, spouses or partners may become unofficial carers, resulting in both physical and psychological stress. Family roles may need to be renegotiated, as a parent may no longer be able to maintain the same level of physical involvement with their children. Families often feel isolated and unsupported and children are greatly affected (Miller & Timson, 2004).

In the study by Miller & Timson (2004), partners of chronic pain sufferers reported that they felt their lives revolved around the partner in pain, experiencing “levels of disruption on an emotional and functional level which are similar to those of the back pain sufferer.” Partners also experienced tiredness, agitation, resentment and verbal abuse from their partner, leading to psychological distress. The unofficial carers, who often referred to themselves as ‘helping hands’ felt helpless and frustrated as they watched their partner in pain and could do very little about it. Miller & Timson found that participants do not usually ask their partners directly about how they are feeling, but rather attempt to predict how much pain their partner is experiencing and, if they misread their partner’s cues and respond inappropriately, confusion and disharmony often results. They concluded that the partner’s chronic back pain “is an obstacle in their lives that has to be negotiated rather than directly confronted.” Similarly in Carter et al.’s (2002) study, previously referred to, the young people acknowledged that their chronic pain had a “difficult impact” on their families and that time was required to reassess relationships and needs, or a period of negotiation. All of the young people currently identified their family as an integral part of their support system. It is worth noting that being a parent of a young person with chronic pain can be very different to being a partner.

Silver (2004), in reviewing the effect chronic pain on a couple, notes that the ‘in sickness and in health’ section of the wedding vows are usually said when in good health and as a matter of course, or tradition. When partners’ roles are renegotiated following injury, expectations of the marriage have to be redefined. One aspect is intimacy, with loss of physical intimacy a common result of chronic

back pain, with the sufferer fearing pain and the spouse fearing they may inflict pain. Decreased libido is also possible, due to stress, fatigue, resentment and side effects of medication. Another aspect is the loss of financial security, depending on the level of disability and corresponding ability for employment. Silver observes that the popular image of families being brought closer together through illness is sometimes, but not usually, the case. In any case, most couples experience the emotions of grief and loss. These emotions, described by Elisabeth Kubler-Ross (1969), include denial, anger, bargaining, depression and acceptance. Everyone experiences this process differently and the emotions felt are not necessarily experienced in the given order, with partners experiencing different stages at different times (Kubler-Ross, 1969).

Nurses and healthcare professionals have the potential to assist families to renegotiate roles. However it would appear that health professionals do not necessarily have the skills and, as the research suggests, do not always spend or have enough time getting to know the patient's family.

### **Nurses Interacting with Chronic Back Pain Sufferers**

Nurses interact with patients on a number of levels and the quality of that interaction will influence nurses' attitudes and decision making. Patients experiencing chronic pain are likely to have regular hospital admissions. Many of these patients feel anxious and helpless and are frustrated with these continued re-admissions. The nurse may also feel frustrated and helpless, administering treatments that do not seem effective (Moss, 1988).

As nurses have the greatest opportunity to interact closely with patients and continually make decisions about interventions, they have the potential to provide comfort, support and reassurance to patients. However, evidence suggests that nurses do not always provide support and comfort, but may actually contribute to the patient's anxiety and stress (Moss, 1988). One way in which this can occur is by not validating the patient's pain, thereby increasing patient anxiety, especially at times they are feeling the most vulnerable, such as requesting medication. The

intensity of the patient's pain (and sometimes its existence) is often not believed, and the patient is often thought to be exaggerating (Moss, 1988).

The rapid formation of attitudes towards patients, and groups of patients, is a feature of the nursing profession. If these attitudes are negative, biased or dysfunctional, they may detract from the provision of optimal care (Moss, 1988). Chronic, nonmalignant pain has had a pejorative connotation leading to some patients being labelled "malingerers, hysterical personalities or somatizers" (Burckhardt, 1990). Smith & Friedemann (1999) add hypochondriac to the list of labels and cite "physicians' inadequate recognition and treatment of pain", and nurses' "inadequate physiological assessment techniques" as factors.

Walker (1994), in a study of the nursing needs of the elderly with persistent pain, found that assuming complaints of pain were exaggerated in order to gain attention, led to the dismissal of genuine distress and blaming the patient for the misfortune of being in pain. Moss (1988), reviewing several studies, found that people categorised simply as patients were seen as dependent, and that certain diagnoses, such as alcoholism, affected the way they were viewed and treated by nurses. Moss further suggests that when patients are categorised by a negative label, the nurse reacts to the label and not the individual.

Griep's (1992) Model of Ethical Decision Making identifies 'learned potential inhibitors' of the nurse and how they influence the outcome of decision making. 'Learned potential inhibitors' consist of personal experiences, professional experiences, the culture and the belief system of the nurse and may enlighten or bias the nurse. Care planning and pain management practices are influenced by what the nurse believes to be true about pain and suffering. Griep, in applying her model to decision making and pain management, found that what nurses believe to be true about pain and suffering will affect how they approach care planning and pain management practices. Griep's model identifies 'psychosociocultural variables' (belief system, culture and personal and professional experiences of the nurse) as well as psychosociocultural variables of the patient as influencing the decision making process. Griep notes that existing

attitudes and beliefs about pain cannot be ignored, but emphasises that education can be used to counterbalance or remediate any biases.

Griep (1992) also puts the ethical principles of beneficence, non-maleficence, justice and autonomy into the context of pain management practice; principles that are inherent in the nursing codes of ethics. To be beneficent, nurses must actively seek to relieve clients' pain. Safe and effective client analgesia must be achieved in order to be non-maleficent. Efforts to relieve pain must be ongoing and extended to all clients in order to be just, and nurses must allow clients the right to self-determine when they need analgesia to guarantee client autonomy. Implicit in Griep's (1992) model of ethical decision making is the importance of caring for persons as individuals. Similarly, nursing theorists such as Jean Watson have emphasised the need for an interpersonal relationship between each patient and nurse, if the nurse is to provide optimal care.

### **Watson's Theory of Caring**

Jean Watson's Theory of Caring (1985) combines a humanistic philosophy of caring with a scientific knowledge base. Watson stresses that caring can only be demonstrated within an interpersonal relationship. To form such a relationship, the nurse must first get to know the other person, and must view them as a thinking and feeling human being and not an object. Congruence, empathy and 'non-possessive warmth' are seen as essential interpersonal conditions in forming a helping-trust relationship.

Congruence involves the nurse being genuine, without a 'professional front'. There is an openness of feelings and attitudes, with an emphasis on being real, honest and authentic. Empathy refers to the nurse being able to perceive the other person's feelings and then communicating that understanding. Understanding is communicated without analysing or judging the feelings, facilitating a trustful, co-operative approach. Nurses must develop sensitivity and respect for others, as well as being sensitive to their own feelings. 'Non-possessive warmth' promotes growth in others, by providing a safe and trusting environment through acceptance, valuing and an unconditional positive regard. An unconditional positive regard

means that the nurse values the other person in an unconditional way that is non-judgemental, without evaluating the other person's feelings in a paternalistic, or maternalistic way (Watson, 1985).

Effective communication is also seen as an essential component for developing an interpersonal relationship. Watson (1985) recognises that the nurse can reduce a patient's stress and anxiety level by listening, accepting and understanding. The nurse can provide situational support for the patient, enhancing the patient's coping abilities in times of stress.

In a similar vein, Leder (1990, p.161) uses the term compassion to mean "experiencing-with .... We enter into the experience of others through a process of empathic identification." He describes visiting a friend in hospital and having "cognitive awareness that she is suffering" (p.162) and proceeds with kindness to cater to her needs, as much as possible. As they sit talking together, his friend lets out an involuntary moan.

Suddenly my words fall away and something opens up within me. I look into her eyes and, as if for the first time, truly see her suffering. She becomes real ... I begin to feel something of her suffering, her fear and frustration. These awaken an echo of the same within me ... for I have begun to see the world as if through her eyes. Compassion has made one body of us (Leder, 1990, p.162).

Leder goes on to add "the natural expression of compassion is service. Insofar as I embody within myself the suffering and needs of others, it follows naturally that I will seek to alleviate these sufferings and fulfil these needs" (Leder, 1990, p.163).

Current and past descriptions of nursing and caring contain the implicit expectation that nurses will provide relief of suffering (Oberst, 1975). However, suffering may become a consequence of physical treatment, and emotional suffering a consequence of practitioners failing to validate pain (Fagerhaugh & Strauss, 1977). Vilensky (2002) quotes a 1992 statement from the (now) US Agency for Healthcare and Research, saying that they "recognized [that] the ethical obligation to manage pain and relieve the patient's suffering is at the core of a healthcare professional's commitment."

## **The caring relationship as part of nursing practice**

The caring relationship as part of nursing practice has been explored by Irurita (1999). Using grounded theory methodology, Irurita interviewed 23 patients recently discharged from various acute care hospitals in Western Australia. She also observed nursing practice and analysed patient discharge surveys. Irurita found that the transition from person to patient left the patient feeling vulnerable, susceptible to physical and/or emotional hurt and defenceless. When the nurses developed an effective interpersonal relationship with the participants and treated them with respect, dignity and as individuals, vulnerability was reduced and patient integrity maintained.

Irurita (1999) describes four levels of quality of care, ranging from very poor to high quality. Very poor, or “rough-hand care” reflected “caregivers’ abuse of their position of power.” At this level nurses were “threatening, bullying ... impatient, not dependable”, ignored patients or treated patients as “objects or slabs of meat, causing increased patient vulnerability.” Nurses who gave the highest level of care, or “soft-hand care”, in addition to being technically competent, were said to “be there for patients (a sustained presence), be available and dependable ... and demonstrated empathy and compassion.” These nurses did the “little extras to ensure physical and emotional comfort ... [with] the appropriate use of touch.” Patients appreciated nurses acting as patient advocates and the development of an effective nurse-patient relationship.

Irurita (1999) noted that patients themselves had limited ability to influence the quality of care they received. Feeling vulnerable as patients, they “expressed a need to be able to trust that the nurse would be there for them when needed ... and would ‘pop in’ even when there as no procedure to perform.” Patients felt their sense of security was threatened when their call bell was not answered promptly, a common complaint. Patients also expressed a need to get out of the ward environment and be given the opportunity to “see some of the outside world ... just to get some fresh air.”



An effective nurse-patient relationship was said to be central to quality nursing care and one that required time. Once an interpersonal relationship had been well established, patients believed they received more attention and that the nurses showed a genuine interest in them as persons. One of the most important factors in the nurse-patient relationship was said to be “having the necessary interpersonal skills ... [as well as] compassion, empathy and care” (Irurita, 1999). The personality of the nurse also made a difference. The nurse’s attitude, such as being friendly, having a sense of humour and treating patients as individuals was appreciated. Lack of time due to staffing constraints and loss of continuity of their carers (fragmented care) were factors seen to detract from the nurse-patient relationship (Irurita, 1999).

Participants in Irurita’s (1999) study also reported that nurses held stereotypical beliefs related to ageism, impacting negatively on the quality of care received. “If you’re an oldie they think you haven’t got a brain. If you ask a question, then you’re being stupid. If you want a civil answer, you don’t get it ... you don’t count.” Participants also felt the need to be a ‘good’ patient; trying to recover and not bothering the nurses unnecessarily, such as reserving the use of their call bell for ‘emergencies’ only. Patients felt it was important that nurses had the time to sit down and talk to them, especially when they were upset or worried, although they perceived that most of the time the nurses were too busy due to poor staffing levels and so were prevented from doing this.

Another complaint from participants related to nurse accountability with poor care not necessarily being detected by other nurses who were occupied with their own assigned patients. Furthermore, patients did not feel they could turn to anyone else if they were dissatisfied with the care. While participants made excuses for nurses not completing all aspects of their care, such as staffing constraints, they felt they still had a right to expect the appropriate care and be treated correctly. Irurita’s (1999) study highlights the needs of all patients, particularly the vulnerable. Chronic back pain patients are in a similar position to those in Irurita’s study. Unfortunately, most of the time stereotypical beliefs prevent nurses from forming

an effective interpersonal relationship with them, resulting in minimum time being spent.

At the same time nurses working with chronic pain patients often describe a feeling of helplessness and failure and feeling pessimistic when a plethora of treatment modalities have been tried and have been unsuccessful (Griepp, 1992; Walker, 1994). Pain management is a major issue for nurses, as they are often poorly prepared in their course of study.

### **Nursing Knowledge and Management of Pain**

A number of studies have looked at various aspects of nursing knowledge and management of pain including those by Ferrell, Eberts, McCaffrey & Grant (1991) and Zalon (1995). Ferrell et al. surveyed 52 nurses regarding their experiences when nursing chronic pain patients. They examined nurses' clinical decision making with regard to pain management and what factors influenced the decisions made. They found nursing knowledge to be an important foundation of decision making, along with ethical components already identified. Although a large majority (91%) of nurses polled said they asked the patient about their pain in order to determine pain intensity, less than half (45%) said this was the most influential factor in their assessment. Other factors seen as influential were knowledge base, beliefs about chronic pain and observation of the patient. This study raises questions about the preparedness of nurses to competently assess and manage chronic pain sufferers.

Zalon's (1995) study, prompted by her perception of nurses' inadequate assessment and undermedication of pain, reviewed a nursing curriculum and interviewed nursing students and faculty. The nurses identified a lack of preparation in their course of study to manage pain. In assessing the curriculum Zalon found a minimal amount of time was devoted to pain management theory, with a limited amount of information about anything other than physiology within the curriculum provided. Faculty also indicated that the existing curriculum was only moderately effective, suggesting this as a reason for the continued undermedication and inadequate assessment of pain by nurses generally (Zalon,

1995). Anecdotal evidence would suggest that current nursing curricula in Australia and elsewhere are not significantly improved, with an emphasis on physiology of pain still predominant.

It is not only nurses who are under-prepared to treat chronic pain patients, so too are medical students (Gourlay, Heit, & Almahrezi, 2005). Vilensky (2002) identifies a similar deficit in the core curriculum for medical students, as for nursing students, regarding pain management. So too does Gourlay et al. stating that undergraduate medical students are inadequately trained in pain management and addiction medicine.

Deficits in knowledge about the appropriate use of opioids, nurses' fear of creating addiction and undertreatment of pain, led Ferrell et al. (1991) to examine conflicts and barriers that are encountered by nurses in managing patients' pain. The major ethical and professional conflicts among nurses were undermedication and inadequate pain relief. Conflicts with the physician and the patient or family were also cited, together with concern about addiction. Physicians and nurses who feared addiction encountered an ethical conflict, as they were aware they were impeding pain relief for the patient.

Nurses, at times, also doubted that the pain was 'real'. Pain, as already noted, is a subjective experience and Ferrell et al. (1991) stress that the clinician must accept the patient's self report of pain and should not expect patients to behave in any particular way, such as moaning or grimacing, in order to prove their pain to the nurse. The authors noted that the study had some limitations, including convenience sampling at a pain management lecture, representing a skewed population of nurses. The subjects chosen by these nurses for case study also tended to be cancer patients, with a minimal representation of chronic nonmalignant pain sufferers (Ferrell et al., 1991). Nonetheless, other authors support the contention that nurses doubt the existence or severity of the pain experienced by chronic pain sufferers (Burckhardt, 1990; Gardner, 2003; McCaffrey & Ferrell, 1997; Tse & Chan, 2004; Wilson & McSherry, 2006). As already noted nurses have also been found to undermedicate chronic pain sufferers, for fear of addiction.

## **Knowledge of addiction**

The term 'opioid analgesic' is commonly used to include all narcotic analgesics. The reason the term 'narcotic' is not used is because of the negative connotation associated with it. Naturally occurring narcotics, such as morphine, come from the opium poppy and are called opiates. Synthetically manufactured narcotics, such as pethidine or morphine combined with additional drugs, are called opioids. The term 'opioid analgesic' is used consistently in the literature to mean *all* narcotics; that is opiates and opioids (Vilensky, 2002). Opioids are deemed to be an appropriate course of action for chronic pain that has not been satisfactorily relieved by other medications and nonpharmacologic measures (Pasero & McCaffrey, 1997). Nonetheless, it is a common perception that sufferers of chronic, nonmalignant pain treated with opioids, are addicts and nurses are not immune to this belief, with authors such as Gardner (2003, p.27) noting that: "whilst the nurse's role in acute and cancer pain are well defined and respected, their role in chronic nonmalignant pain management often remains ambiguous."

There is an unreasonable fear of creating addiction within the healthcare professions, and a misuse of terms that perpetuate the fears associated with opioid use (Vilensky, 2002). Many people living with chronic, nonmalignant pain remain undertreated because of commonly held beliefs and theories that have developed over time, yet are usually based on fear (Ferrell et al., 1991; Griep, 1992; Zalon, 1995).

Opioid addiction, or psychological dependence, is defined by the American Pain Society as "a pattern of compulsive drug use characterized by continued craving for an opioid and the need to use it for effects other than pain relief" (McCaffrey & Pasero, 2001). Often, physical dependence is a term that is used interchangeably with addiction, however the terms have distinct differences. Physical dependence can be defined as "a neuroadaptive state resulting from chronic drug administration and an expected physiological response in any individual exposed to continuous opioid administration" (Compton & Estepa, 2000). Therefore, while addiction is a disease that warrants concern and avoidance, physical dependence is an

expected, eminently treatable state that should not be feared (Compton & Estepa, 2000; Gardner, 2003).

Fear of addiction is considered to be the major barrier to obtaining even adequate pain relief (Morrison, 2000; Pasero, 1998; Pasero & McCaffrey, 1997). Patients themselves may fear addiction, preventing them from either requesting their analgesia or causing them to prolong the time between doses, or taking less medication than they need to control their pain (Pasero, 1998; Vilensky, 2002). Pasero (1998) found that concerns about addiction in a group of cancer patients led them to be reluctant to report pain and use opioids, having a significant impact on their pain management outcome. With family members often taking on the role of primary caregiver in the home, addiction and side effect concerns at times led them to undermedicate their loved ones, due to extreme fear (Pasero, 1998).

According to Portenoy (1993), the most common source of fear of addiction comes from clinicians, leading to “the systematic undertreatment of pain” and therefore inadequate pain relief for patients. Pain continues to be inadequately assessed because most clinicians lack sufficient knowledge of opioid pharmacology, with fear of producing addiction very prevalent, notwithstanding data demonstrating that the risk of this outcome in medical patients prescribed opioids for painful disease is extraordinarily low (Portenoy, 1993).

Most of the literature agrees that the incidence of addiction amongst this population is less than 1% (Compton & Estepa, 2000; Morrison, 2000; Pasero, 1998; Pasero & McCaffrey, 1997; Portenoy, 1993; Vilensky, 2002). Mathias (2000) concluded that people experiencing pain were less likely to experience euphoria following the administration of an opioid than those without pain, so that “the abuse potential of these opioid medications is generally low in such people.”

The most commonly accepted risk factors for developing addictive disease are considered to be: a past history of substance misuse or abuse, (including polysubstance abuse), a family history of substance abuse and/or concurrent or past history of psychiatric illness (Compton & Estepa, 2000; Pasero & Compton, 1997). Compton & Estepa (2000) also consider a history of childhood sexual

abuse to be a risk factor for addiction. The literature emphasises, however, that patients with a history of substance abuse, or indeed those patients being treated for pain that are currently addicted to opioids should not be ostracised, ignored, or have opioids withheld. With careful management, an addicted patient can still benefit from opioid treatment for severe pain and they are just as deserving as any other patient of having their pain controlled with opioids (Compton & Estepa, 2000; Pasero & Compton, 1997; Pasero & McCaffrey, 1997; Portenoy, 1993).

Vilensky (2002) remarks that fear of respiratory depression is another barrier to the provision of opioid analgesia. He notes that there is *no* upper limit on pure opiates (those not including aspirin or acetaminophen [paracetamol]). During the past 30 years, he has questioned physicians and nurses and notes “not one could recall any patient dying of respiratory failure as the result of opioid therapy in the hospital, since severe pain is its own respiratory stimulant” (Vilensky, 2002).

Vilensky (2002) observes that “physicians have a moral, ethical, legal and medical obligation to treat pain” and that in the United States, there has been a shift in the trend of litigation for over-prescribing opioids, to physicians now being held responsible in malpractice litigation for inappropriate under-prescribing of opioids thus “allowing patients to suffer needlessly in pain.” Whilst the trend towards litigation in Australia is nowhere near that of the US, the potential for litigation exists. Vilensky notes, freedom from pain and living in dignity is the main goal of management and urges health professionals to “not convert the *war on drug abuse* to the *war on patients in pain*”, adding: “Stop the myths – the stakes are too high!”

### **Pain assessment in chronic pain sufferers**

The literature supports the contention that the nurse’s assessment of pain intensity is often not the same as the patient’s self report of pain. Nurses are said to generally feel more comfortable dealing with acute pain patients (Gardner, 2003).

Few studies have investigated nurses’ assessments of chronic pain (Walker, 1994). One study that looked at both acute and chronic pain assessment was one by Teske, Daut & Cleeland (1983). They compared nurses’ assessments of pain with patients’ self reports in acute pain and chronic pain patients. While nurses did

not usually underestimate the intensity of acute pain, they had a significant tendency to underestimate the pain of chronic sufferers. Teske et al. (1983) proposed that one reason for this discrepancy was that patients with chronic pain display less intense non-verbal behaviour relative to their pain, supporting research by Carter et al (2002) and Hillevi (2005) previously referred to.

In similar studies of the self care needs of cancer patients, both Kubricht (1984) and Fernsler (1986) found significant differences in the patient's perception of their needs, compared to the nurse's assessment. They found that patients could express their needs and were more likely to carry out their own self care, once they felt their concerns were understood and were encouraged to participate in the planning of their care. Once again this emphasises the importance of the relationship between the nurse and patient.

MacLeod, LaChapelle, Hadjistavropoulos & Pfeifer (2001) undertook a study of two hundred undergraduate nurses to investigate the way the different coping styles of chronic back pain patients influenced decisions regarding their disability, pain severity and compensation status. Their objective was to examine whether judgements about compensation claimants are affected by the claimants' way of coping with pain. Participants were given five brief vignettes of fictional claimants (or patients) in random order. The vignettes all began the same way, indicating the claimant was middle aged, suffered low back pain, had been off work for several months and rated the severity of their pain as 7, on a 1-10 scale. A brief description of their coping style followed. Each vignette differed in the coping style used. The coping styles were described as either: catastrophizing, praying and hoping, distraction, ignoring and lastly, reinterpreting. The more active styles of coping, such as reinterpreting and distraction "are considered adaptive, whereas catastrophizing and praying and hoping ... are maladaptive ... and are associated with poorer prognoses" (MacLeod et al., 2001).

MacLeod et al. (2001) found that claimants using coping styles considered to be maladaptive were more likely to be viewed as deserving compensation by their participants, whereas those whose coping styles were considered adaptive, with better outcome potentials, were more likely to be viewed as non-deserving of

compensation. Participants judged those that used the catastrophizing and praying and hoping coping styles to be more disabled and have greater psychological distress than those using the other coping styles. Results of the participants' perception of claimants' pain severity also varied depending on which coping style was depicted. This was despite the fact that the claimants had all rated their pain as 7 out of 10, demonstrating that participants' perceptions were affected by coping style depicted, despite the evidence that the claimants did not differ in the severity of their pain (MacLeod et al., 2001). This highlights the problems faced by sufferers in their interaction with health professionals and various authorities, where attempts to 'cope' and minimise symptoms can have negative consequences.

### **Patient Expectations and Experiences of Pain Management**

Hoffman & Tarzian (2001) note that, due to the subjective nature of pain, there is no way to clinically and objectively measure a patient's pain intensity at this time, and that the patient's self report must remain the major indicator.

Patient expectations in relation to pain management in the context of care are variable. A study of elderly patients in the community with persistent pain by Walker (1994), found that patients appeared to have realistic expectations of the nurse in relation to pain relief. However, many patients identified that there was more to pain relief than medical treatment. The patients realised that the nurse was not always able to 'cure', or sometimes even control, their pain. They did, however, appreciate genuine caring, understanding and encouragement.

Walker (1994) documented examples where contact with a nurse could be a negative experience for the patient. The absence of a caring attitude towards the patient was noted to produce a stressful experience. Patients valued nurses listening to them, giving them comfort and confidence. Walker, reinforcing Watson's (1985) theory, highlights the 'potential therapeutic value' of the interpersonal relationship between the patient and the nurse. However, types of pain were not differentiated in the study and the criteria of pain being present for



six weeks may only signify persistent pain, differing from the diagnosis of chronic pain.

Elderly patients' and caregivers' perceptions of care experiences given in a hospital setting were studied by Laitinen (1994). Patients tended to emphasise the psychological and emotional aspects of care, wanting self respect, self determination, privacy and emotional support. Caregivers however, focused on the fulfilment of physical needs to the detriment of more important aspects of the therapeutic relationship (Laitinen, 1994).

Gender differences were also noted in studies of pain assessment and management (Hoffman & Tarzian, 2001; Paulson, 1999). In a study comprising analysis of nurses' and physicians' narratives of men suffering from chronic pain caused by fibromyalgia, Paulson (1999) noted that while men do not talk spontaneously about their feelings, they are considered to be more convincing in their presentation and less likely to stay in the background than women. Men, overall, were found to be more aggressive than women. Paulson concluded that nurses and physicians, in their encounters with the men, must convince them that they really believe each unique individual's narration and the caregivers must behave in ways that convince the men that they really care about them and take their complaints seriously.

Hoffman & Tarzian (2001), in a study comparing the treatment of male and female chronic pain sufferers, concluded that women experience and report greater pain levels, however they are less likely to have their pain taken seriously and are undertreated compared to men. One explanation given for this is that society attributes strength and bravery to men, while conversely women are thought to be naturally equipped to endure pain. McCaffrey & Ferrell (1992) also found that nurses (nearly 50% polled) thought that women could tolerate more pain than men. Hoffman & Tarzian (2001) also postulated that women are socialised to 'look good' and attempted to do so even when visiting their doctors. This can result in their being viewed by their physician as attractive and thus not really in pain. Having better communication skills could also work against women, as their ability to verbalise their emotions caused their responses to be viewed with suspicion (e.g.

considered psychologically based) and thus be treated less aggressively, being more likely to be given sedatives than opioids for the treatment of their pain.

Attitudes such as these emphasise that chronic pain sufferers are frequently judged and stereotyped according to beliefs commonly held by many nurses. Chronic pain sufferers are also judged and labelled within the community and it is therefore useful to consider some relevant theoretical explanations for this, as well as the process that is undertaken by the chronic, often disabled, pain sufferer in coming to terms with chronic pain and disability.

### **THEORETICAL EXPLANATIONS RELEVANT TO CHRONIC PAIN SUFFERERS**

Chronic pain and disability often go hand in hand. Disability, a physical or mental impairment, in a social context is the disparity between a person's capabilities and the requirements of the environment. This disparity is "socially defined as undesirable, and people living with disabilities are often regarded by others or themselves as deviating from what is believed to be normal or appropriate" (Li & Moore, 2001). People with a disability are categorised as belonging to a minority group and as such are subject to group stereotypes. Disabled people then "tend to be evaluated based on their categorical membership rather than individual characteristics" (Li & Moore, 2001).

#### **Labelling and Legitimacy**

In the mid 20<sup>th</sup> Century, Parsons conceptualised illness as a form of deviance in that it represented a failure to fulfil normal social obligations such as work or family commitments (Parsons cited in Turner, 1986). He theorised that when people are unwell, they then have access to the 'sick role'. This gives the person a legitimate reason to temporarily relinquish or hand over their normal family or work tasks, while they access medical treatment as long as they display a willingness, or a 'want' to become well again. As Gray (2006) notes, "the role of the doctor in this process is vital. In particular the doctor acts as the gatekeeper to the sick role as she or he must legitimate the sick person's claim to the status of being ill as opposed to being a malingerer."

The 'sick role' has been criticised for a number of reasons, but primarily because people with a chronic illness are not out of action for just a temporary period and cannot be expected to return to their familiar roles. Glenton (2003) concludes that chronic back pain sufferers often fail to achieve the sick role because they often do not have a definitive diagnosis, do not exhibit the expected sickness behaviours and do not meet the expectations of healthcare professionals. As a result, this often leads to accusations of malingering, hypochondria and/or mental illness.

Labelling leads to stereotypical beliefs about people. "Stereotypes are shared perspectives of the dominant majority ... [and] become part of the established norms" (Canales, 2000). Without developing experiences on an individual basis through interaction, "people often rely on stereotypical representations of those perceived as different, further perpetuating the separation between self and other" (Canales, 2000). As a consequence, myths and stereotypes are depended on, rather than developing an understanding from the individual's perspective (Canales, 2000). The respondents in the study by Miller & Timson (2004) viewed the medical profession as giving value-laden labels "which imply that pain is used as an excuse to shirk social or economic duties." Li & Moore (2001) note that people with a disability who are from a low socioeconomic status tend to rely on the welfare system, making it more difficult for them to achieve respectability and also making them more susceptible to social labelling and discrimination.

## **Stigma**

Stigma is a related concept to labelling, with stigmatising "a process in which a social meaning is attached to behaviours and individuals" (Joachim & Acorn, 2000). Physical deformities, character traits and references to race or religion are the three major types of stigma identified by Goffman (1963). Society and culture 'decide' what attributes and characteristics are considered to be the norm. The norm is not a static concept, as our values are constantly changing and evolving. Currently in Western cultures, someone who is young, beautiful and healthy is seen as desirable. Whatever the norm is considered to be, those who deviate from the defined norm are seen as 'bad' (Li & Moore, 2001). A sudden incident in life

can change a normal into a stigmatised person and they must survive the resulting psychological change. The pain of sudden stigmatisation can come “not from the individual’s confusion about his identity, but from knowing too well, what he has become” (Goffman, 1963, p.158). Once an individual has been labelled, their “deviant status becomes a ‘master status’ that serves to stigmatise them and eliminate their other sources of identity” (Gray, 2006, p.25).

Goffman (1963, p.15) observes that:

by definition, of course, we believe the person with a stigma is not quite human. On this assumption, we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to account for his inferiority and account for the danger he represents .... We use specific stigma terms such as cripple, bastard [and] moron in our daily discourse.

This is true of chronic nonmalignant back pain, particularly if accompanied by disability. Most people with a disability, like any other person belonging to a minority group, wish to be integrated into and accepted by society (Li & Moore, 2001). Goffman (1963, p.65) notes that “visibility, of course, is a crucial factor” and “that which can be told about an individual’s social identity at all times during his daily round and by all persons he encounters therein will be of great importance to him.” Stereotyping or ‘profiling’ of people is a normal process everyone carries out when interacting with others. Disabled people often develop strategies to move past the initial awkwardness or remoteness of a meeting and ‘break through’ to a more personal level where their disability recedes and is no longer the only factor being considered. However, this is not always enough as “familiarity need not reduce contempt. Normals ... often manage quite handily to maintain their contempt” (Goffman, 1963, p.68).

Thus while the stigmatised might define himself as no different to any other human being, those around him can define him as someone set apart (Goffman, 1963). Goffman further emphasises that, depending upon the reason the person is stigmatised, he may have the choice to conceal or disclose his difference. While an obvious deformity cannot be concealed, a past issue, such as that of mental

illness, can be concealed and the person can choose to be seen as one of the 'normals'. However, they run the risk of being 'found out' at a later date, leading to further stigmatisation and the normals feeling betrayed. They also have the choice to conceal or reveal to different people at different times. Thus family and employers may or may not be told (Goffman, 1963). Similarly, a person with a back injury can choose, at certain times, not to use walking aids and by hiding their reactions to their pain, they can temporarily mask their disability.

Being stigmatised can be part of a chronic back pain sufferer's life. As mentioned earlier, the visibility of the physical difference is there for others to see, except in rare instances when the person can choose to 'hide' and become a normal for a limited time. In the community, chronic pain sufferers can also choose to whom, or even if, they disclose their use of prescribed opioids. Family and possibly some fellow sufferers, tend to be the only people informed. Once in hospital, however, they no longer have the choice of disclosure. Healthcare workers are automatically informed and, as indicated previously, stigmatisation regularly occurs (Comptom & Estepa, 2000; Ferrell et al. 1991; Griep, 1992; Morrison, 2000; Pasero, 1998; Pasero & McCaffrey, 1997; Portenoy, 1993; Vilensky, 2002; Zalon, 1995). Language used by health professionals can contribute to stigmatisation. Vilensky (2002) urges physicians, when speaking to a patient, "to eliminate the word 'narcotic', which conjures up images of the craving addict. It is better to use 'opioid analgesic', which has the same meaning but without the stigma."

Compensation claimants are often stigmatised, especially in the media. Being unemployed, although not by choice, often results in the sufferer being labelled as lazy or worthless (Moss, 1988). Once again, chronic pain sufferers may have to decide whether they wish to disclose their compensation status. In some circumstances, such as hospitalisation, they have no choice as healthcare workers are once again automatically informed, creating further stigmatisation (Gardner, 2003; Hillevi, 2005; Vilensky, 2002). As noted earlier, chronic back pain is not always able to be hidden, as it often affects posture or walking aids are required to assist mobility. Stigma is the outward manifestation of others' opinions about the sufferer being different, however the sufferer herself will *feel* different, as her body image and sense of self has changed.

An alternative model to stigma which has had a lot of currency is the social model of disability. This model also challenges the biological or medical model, emphasising disability as a social construct.

### **The social model of disability**

The social model of disability was originally formulated in Britain in the 1970's by activists in the Union of the Physically Impaired Against Segregation (UPIAS). This was a politically and socially motivated group seeking civil rights and the removal of barriers for those with physical impairments. They took great care to separate the terms 'impairment' and 'disability'. Impairment was said to refer to the physical (and was later expanded to include mental) bodily difference(s): that is "lacking all or part of a limb, or having a defective limb, organism or mechanism of the body" (UPIAS, cited in Hughes & Paterson, 1997). Disability was said to refer to "the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (Oliver, 1996, p.22).

Disability is therefore layered on top of the impairment by a society that creates barriers and results in isolation and exclusion from full participation in society. The social model therefore shifts the focus from impairment onto disability, using this term to refer to "disabling social, environmental and attitudinal barriers rather than lack of ability" (Crow, 1996). Thus, while impairment is the functional limitation affecting a person's body, disability is the loss or limitation of opportunities resulting from direct and indirect discrimination (Crow). Thus disability is a form of social oppression (Shakespeare & Watson, 2002). In other words, impairment relates to the biological whereas disability is a social construct (Gray, 2006). "Disability is the social significance of impairment in terms of identity and social participation. Impairment may remain constant, but the meaning of disability changes across cultures and historical periods" (Gray, 2006, p.127).

A major outcome of the British social model of disability was the empowerment of disabled individuals who came to "think of themselves in a totally new way. ...

[They] became empowered to mobilise, organise, and work for equal citizenship” (Shakespeare & Watson, 2002) and could now demand their rights. The British movement therefore promoted social change, in other words the dismantling of barriers and the inclusion of people with impairments, rather than focusing on the medical model of pursuing medical cure or rehabilitation. “If disability could be proven to be the result of discrimination, then campaigners for anti-discrimination legislation saw civil rights as the ultimate solution” (Shakespeare & Watson, 2002).

Shakespeare & Watson (2002) argue that the social model of disability is now an outdated ideology although they acknowledge the importance of the model at the time of its conception and the contribution it has made to social change. There is a continuum of opinion and vigorous debate surrounding this model, ranging from those who strictly subscribe to it in its original form, some who still subscribe to the original approach but take a “less rigid approach” (Shakespeare & Watson), others who feel it requires revision and updating, to those, as is the case with Shakespeare & Watson, who believe a new model is necessary.

A major criticism Shakespeare & Watson (2002) make of those who adhere either strictly or less rigidly to the model is that within the public discourse, impairment is not referred to: only disability and the effects this has on the individual. Shakespeare & Watson quote the slogan that is used: ‘disabled by society and not by our bodies’, but note that “most activists concede that behind closed doors they talk about aches and pains and urinary tract infections, even while they deny any relevance of the body while they are out campaigning.”

Liz Crow (1996) has also criticized the model from the perspective of a disabled person, whilst acknowledging its value at one point in her life and the lives of disabled people “in promoting individual self-worth, collective identity and political organisation” (Crow, 1996). However Crow feels that the model, while still relevant at the collective, political level, needs to be substantially revised. In response to the medical model’s focus on impairment, the social model’s focus is almost exclusively on disability, to the detriment of an individual’s life experience. Part of the individual’s experience is the way in which they experience and perceive their body in terms of image and their sense of embodiment.

## **Body image**

Pain can cause an alteration in one's body image. Altered body image can be described as:

a state of personal distress, defined by the patient, which indicates that the body no longer supports self esteem, and which is dysfunctional to individuals, limiting their social engagement to others. Altered body image exists when coping strategies ... are overwhelmed by injury, disease, disability or social stigma (Price, 1995).

Body image is constructed through interaction with others; it is not constructed in isolation. Awareness of one's body is a profoundly social thing, "arising out of experiences of the corporeality of other people and their gaze directed back upon me. Am I fat or thin, beautiful or ugly, clumsy or agile?" (Leder, 1990, p.92).

Body image can be described as "the picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves" (Newell, 1999), as well as how it is reflected back to us by others (Leder, 1990). Our body image is not static, but is constantly evolving. Significant life stages, such as puberty, pregnancy and ageing, result in our body image being continually altered. Body image develops from early childhood (Atkinson, 2002). Children notice family (or human) similarities. Everyone they see has two eyes, a nose, mouth, ears, and possibly familial traits such as red hair. "The child sees and reacts to the reactions of others and notices how physically their body looks the same as or different from others" (Atkinson, 2002).

Body image is related to, but separate from self esteem, self concept, and self image. Body image is part of our self image relating to our appearance, and is influenced, consciously or subconsciously, by others, fashion and the media (Atkinson, 2002). In nursing, one body image model comes from Price (1990, p.33) where "three related components: body reality, body ideal and body presentation ... exist in a state of tension or balance which together make up a satisfactory body image which humans strive to maintain."



Body presentation refers to body image in public. “People are influenced by body presentation and attractiveness ... to the extent that there appears to be an unconscious stereotype that equates attractiveness with goodness and is rewarded as such” (Atkinson, 2002). People who are disfigured in some way may be treated differently, potentially leading to a loss of self esteem and reduced self image (Atkinson, 2002). At the same time, while pain and disability can impact on body image and related self concept, it can also cause a reassessment of self and a need to reintegrate mind and body.

### **Pain and the Body**

Pain brings the body to the forefront of the mind and:

in most cases pain is an unwanted and aversive phenomenon that forces itself upon us against our will. Moreover, it threatens the very routines and goals by which we define our identity. Aversive, involuntary and disruptive, the painful body emerges as a foreign thing (Leder, 1990, p.71).

Leder, a physician and a philosopher, maintained that the body in health is “essentially characterised by absence” and that it is only when there is bodily disruption that the body becomes present. “While in one sense the body is the most abiding and inescapable presence in our lives, it is also characterized by absence. That is, one’s own body is rarely the thematic object of experience” (Leder, 1990, p.1).

This situation changes abruptly when pain is experienced. Leder (1990) coined the term ‘dys-appearance’ to describe a radical shift in embodiment such as occurs in pain and maintained that at times like these the body can no longer be taken for granted.

Dys-appearance tends to arise when we are away, apart, from our ordinary mastery and health. There is a sense of privation, a reversal of a normal or desired state .... In addition, at times of dys-appearance, the body is experienced as away, apart from, the self. Surfacing in phenomena of illness [and] dysfunction, the body may emerge as an alien thing, a painful

prison or tomb in which one is trapped. The experienced self is rent in two as one's own corporeality exhibits a foreign will (Leder, 1990, p.87).

Pain is a sensation designed to immediately divert our attention to the area in pain, no matter what our thoughts were previously focused on; a survival mechanism (Leder, 1990). When functioning normally, the body is removed from our immediate attention. When the body ceases to function normally, it focuses our attention strongly and immediately. "We then experience the body as the very *absence* of a desired or ordinary state and as a force that stands opposed to the self" (Leder, 1990, p.4). "As it pulls us back to the *here*, so severe pain summons us to the *now*. With chronic suffering there is nowhere to go, nothing to do, no escape" (Leder, 1990, p.75).

During periods of illness or disability, the body may seem 'unuseable'. No longer can activities, previously taken for granted, be undertaken. The person cannot trust that their body will perform as it once did and "the sick body may be experienced as that which 'stands in the way' " (Leder, 1990, p.84).

Buytendijk (1962, p.27) notes that the "senseless abandonment of the human being to pain has its direct result in a cleavage of the self and the body." A consequence of disease, injury or surgery is that body reality is changed. To deal with this and restore balance, the person may alter their body presentation, or change their thoughts as to their new body ideal (Newell, 1999).

### **Renegotiating the self**

Pain is not something that can be loved, but is an alien 'it' within the person, causing emotional distress. Separating pain from the body and rendering it 'other' can be the result of disruption, but can also be an adaptive response, however steps need to be taken to understand the disruption and integrate mind and body. Integrating the mind and body is often a long and ongoing process (Leder, 1990).

Initial phases of integration leave the person with great emotional distress, confusion, anger, loneliness and despair. Many report a need to be connected,

whether to family, church, other sufferers or support groups. Professional psychological counselling is often a necessity to overcome, or attempt to overcome, this distress (Carter et al., 2002; Kralik, 2002; Morse, 1997; Smith & Friedemann, 1999).

Understanding the cause of the disruption, for example finding a diagnosis, is usually the first step. Taking time to recognise and mourn the losses incurred, both present and future, allows the person to then re-evaluate their present circumstances, before they can accept their 'new self' (Atkinson, 2002; Morse 1997). In this way grieving can be seen as a coping strategy (Price, 1990). Throughout the grieving process, the person is likely to need someone to talk to, to encourage them to express their feelings (Atkinson, 2002). Atkinson (2002), talking about altered body image after incurring a wound or scar, emphasises that "it is important for the nurse to spend time listening to the patient and offering support." This is an acute or medium term situation. Nowhere in the available chronic pain literature is this sort of action advocated.

By taking an inventory of their whole life situation, people can reinterpret their disability and fragility into a personal 'ablebodiness' within their own potential (Gardner, 2003). Taking steps to carefully investigate their physical capabilities is one way to take back some of the control previously lost, expanding their interests and focusing on what they can do, rather than what they can't. Some describe this as a 'growth' phase; others describe it as a 'spiritual awakening'. Finally, taking control by setting realistic goals whilst still maintaining hope is seen as the most important 'turning point' to integrating the mind and the 'new' body and thereby renegotiating self (Carter et al., 2002; Leder, 1990; Li & Moore, 2001; Morse, 1997; Smith & Friedemann, 1999).

## **Summary**

The literature supports the notion that chronic nonmalignant pain has devastating physical, psychological, emotional and social repercussions for the patient and their family. Chronic pain sufferers can use a variety of coping mechanisms, not all of them adaptive in the long term. During a hospitalisation, while nurses have the

potential to provide support and comfort to the patient, thus promoting health and allaying anxiety, this is not always the case. Nurses' knowledge and attitudes influence behaviours and decision making, including pain management. Knowledge deficits and fear of addiction can result in nurses withholding medication with subsequent undermedication and suffering for patients. While a caring, interpersonal relationship with patients assists the nurse to provide optimal care, chronic pain sufferers can be stereotyped and stigmatised resulting in the nurse reacting to a label. This may also be true of experiences and interactions in the community at large, with changes in body image and presentation a further cause of stigma and stress for the individual. While theories such as the social model of disability have resulted in a reduction in stigma attached to disability and promotion of self worth, it can result in minimising the individual's sense of embodiment and pain experience. Understanding that the aversive pain response, as well as being stressful, will result in the patient having to renegotiate the self, a process that may take time, can assist in the reintegration of the chronic pain sufferer into society.

This autoethnographic study aims to convey the experiences of chronic pain patients, including their experiences of hospitalisation, from the initial injury or event, as a means of giving nurses, healthcare workers and members of the community an insight into the world of the person living with chronic intractable nonmalignant back pain. In the next chapter I turn to describing the methodology.

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Endnote: Page numbers were used for texts but not for journal articles, many of which were accessed electronically.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **Introduction**

This chapter documents the process of selecting a topic and traces my journey of exploration and discovery, as I explored methodology. The progression through selecting and interviewing participants is then outlined, together with my approach to writing the stories. The chapter concludes with my reflections on the research process including writing the stories.

#### **Selecting a Topic**

Researching this topic was not so much a choice but a need. A need that became more and more pressing during each successive hospitalisation. When I had the opportunity to undertake a research project, I knew immediately the area in which I wanted to study.

As noted previously, I first became interested in patients' hospitalisation experiences when I was training to become a general nurse. Having never experienced a hospital admission during that time, I was interested in the varying impact of admission on patients. I perceived a noticeable change in people's characters once they assumed the patient role. Since that time, I have had numerous hospital admissions following major injuries sustained at work.

After a number of hospital admissions, I developed an indepth insight into the dynamics of hospitalisation and chronic pain from the patient's perspective. My experiences of hospitalisation were challenging, primarily because of nurses' attitudes toward chronic, nonmalignant back pain patients as an homogenous group. Rather than seeing me as an individual, with individual needs, I perceived that nurses were treating me according to various negative stereotypes.

A person experiencing severe chronic back pain brings to hospital a whole range of issues that impinge on their needs, such as being told their pain "is all in their head" by doctors in the past. While they may have eventually found an

understanding doctor, this previous history is recalled when nurses show signs of either not believing the intensity of their pain, or not believing they have any pain at all. I came to believe, and the literature has reinforced the belief, that this was due mainly to their lack of specialised knowledge about chronic nonmalignant back pain, and to beliefs that have become entrenched over time.

During periods of hospitalisation I met with other chronic pain sufferers. In speaking with them, it struck me that all our stories of hospitalisation experiences were disconcertingly alike. Many of these other sufferers had, like me, tried to talk to their caregivers about the 'care' they received and had found, like me, that their words had fallen on deaf ears; we felt we were speaking into a void and were not being listened to, or heard.

After a preliminary search of the literature I found that chronic back pain sufferers were a marginalised group. Chronic back pain has a pejorative connotation, and as noted in the literature review, many negative stereotypes are held by caregivers, in some instances affecting the care the chronic back pain patient receives in hospital (Burckhardt, 1990; Moss, 1988). However, rarely did the published material echo my, or others', experiences of chronic back pain and hospitalisation.

In choosing the topic, I thought about all the different aspects of my life that had been impacted upon by chronic back pain that were worthy of research, but my thoughts kept returning to my experiences in hospital, especially my interaction with nurses. When I chatted with other severe chronic pain sufferers, I was told stories that resonated with my own, and were almost always about traumatic hospitalisation experiences, where they described instances illustrating stigma, labelling, stereotyping, not being believed and feelings of 'loss of control'.

The dramatic change appears to happen when one is admitted to hospital. In hospital, every aspect of our daily living is impinged upon, as you are forced to conform to the hospital's routines and timetables. We all found it difficult becoming a patient. No longer were we a wife, child or sibling in a family unit. No longer were we an independent, confident employee. Rather, we were 'patients', and

were often made to feel subservient and powerless. Our self esteem and self worth are accumulated through our different roles in society, and the sudden loss of familiar roles throws individuals into a period of confusion and self doubt. As a person, we rely on our roles in the world to give us our sense of self and personhood (Goffman, 1971). I therefore originally decided that the focus of my research would be the hospitalisation experiences of people living with chronic nonmalignant back pain.

People with other forms of chronic pain have different needs, although they too experience some of the negative attitudes and stigmatisation by healthcare workers. I believe, however, that chronic back pain has a particularly pejorative connotation. With all my participants suffering the same condition, I felt it would simplify my analysis process because all the participants would present similar characteristics during their hospitalisations.

My study then set out to examine the hospitalisation experiences of chronic nonmalignant back pain sufferers, from the patient's perspective. The overall aims of the study at this point were to identify nursing behaviours that are perceived as caring, or otherwise, by the chronic pain patient and to provide nurses with information that could assist them to provide reflexive, empathetic, optimal, quality care.

I found, however, that my research topic expanded during the interview process, as I discovered my participants wanted to tell me about other areas of their lives that had been affected by their chronic back pain. Their experiences resonated with my own, and I decided my study had the potential to be much more descriptive and informative. Hence the focus of the study became the experiences of severe chronic nonmalignant back pain sufferers treated with long term opioids, including their experiences of hospitalisation, so much a part of the life of a chronic pain sufferer, but also paying attention to their life experiences. A secondary aim was to empower the participants by giving them a voice; that is, allowing their own experiences to be explicated in the final study report.

## **Developing Methodology**

When first deciding on how I would undertake my research, I looked at various methodologies to see which methodology would best suit my study topic. Because I wanted to uncover people's experiences of hospitalisation, I decided that a qualitative approach that would yield richer data was preferable to a survey or questionnaire. I also wanted to be personally involved in the data collection process through interviewing participants myself.

I investigated various qualitative methodologies and decided to use grounded theory with interviews as the method of data collection. Grounded theory appealed to me because initial analysis is performed following each interview. The interviewer is then free to follow up on particular issues or trends, or to probe areas of interest that have yet to be covered. The theoretical perspective underpinning grounded theory, symbolic interactionism, was also appropriate.

Symbolic interactionism contends that the relationship between self and society is an ongoing process of symbolic communication, whereby individuals create their social reality. George Herbert Mead, a social psychologist, is credited with originating the tradition in the early 20<sup>th</sup> century (Blumer, 1969; Charon, 2001). Symbolic Interactionism came to prominence within sociology through the work of sociologists, such as Howard Becker and Erving Goffman, at the University of Chicago.

Symbolic interactionism is interested in understanding the experience and perspective of individual actors as they interact with one another. The notions of self and subjective meaning are central to this perspective. The self, however, is viewed as a social rather than a psychological phenomenon (Mead, cited in Blumer, 1969) and is active and creative. As the name of the perspective implies, meaning is constructed in interaction and attempts are made to understand how individuals construct and negotiate social reality. Symbolic interactionism differs from structural-functionalism in that it does not presume that social institutions are the major contributors to the overall functioning of society, or that different social groups share the same beliefs, values and norms. Rather, far more stress is



placed on the individual's interaction with the environment and how that influences their reality. Many grounded theory studies have focused on the way in which individuals construct and negotiate their reality in small-scale settings such as families, hospitals or nursing homes (Strauss, 1987).

After submitting my research proposal to the university's Human Research Ethics Committee, and being granted ethics approval (see Appendix 1), I conducted two interviews using the grounded theory approach, taking care not to include my own story. I was able to gather some rich data, however I had some issues with the process.

Grounded theory asks the interviewer to 'bracket' their own thoughts, feelings and experiences of the subject being researched. As Berger & Kellner (1981, p.52)

note:

if such bracketing [of values] is not done, the scientific enterprise collapses and what the [researcher] then believes to perceive is nothing but a mirror image of his own hopes and fears, wishes, resentments or other psychic needs; what he will then not perceive is anything that can reasonably be called social reality.

Because I had similar experiences to those interviewed, I found it difficult to remain totally objective, and make no comment on my participant's story. I felt that my participant might feel validated if I was able to reassure her by acknowledging that I too had experienced the same situation. I was finding it difficult to exclude my own voice.

Due to unforeseen medical circumstances resulting in open heart surgery, endocarditis and septicaemia, I was forced to take a leave of absence from my study for 18 months. On my return, I felt I needed to reimmerse myself back into my study. It was also a fortuitous opportunity to re-examine my choice of methodology, in the light of my reservations about the interview technique and the question of bracketing during the interview process. It was at this time that my supervisor introduced me to a methodology that was relatively new to the social sciences and especially to nursing: Autoethnography.

The term autoethnography is said to have been first used by David Hayano in 1979, referring to “cultural-level studies by anthropologists of their ‘own people’ in which the researcher is a full insider ...” (Ellis, 2000, p.739). Another term used is that of the “opportunistic researcher” (Reimer, 1977) or the “indigenous researcher” (Tedlock, 1991), where the researcher is already a full member of the group being studied.

My first introduction to an autoethnographic study was the story of “Abbie”, with insights from the author, who suffered from bulimia and anorexia (Kiesinger, 1998). I was excited! Her story moved me incredibly and I could not put it down. I felt a deep connection and empathy. Abbie’s story was one of the most powerful pieces of writing I had ever read. I was able to see myself in some of the same situations as that of the participant, Abbie, and felt her pain and anguish.

Kiesinger (1998) describes Abbie undergoing “a crucial epiphany” in her life. Abbie’s thoughts and feelings about her changing life situation echoed my own. She is at a stage where she has to reinvent herself. Abbie was in the midst of a separation from her husband and had suddenly found herself having to “build a separate life from his” (Kiesinger). She had to find ways to support herself by finding employment and she talks about the fear associated with this (Kiesinger). I too had endured rejection and a separation from my husband ending in divorce and found myself having to re-enter the workforce in order to support myself.

Abbie describes her sense of loss over the ending of her marriage, and how “she and her husband were strangers to each other” (Kiesinger, 1998). Kiesinger captures these feelings by telling a story that illustrates Abbie’s husband’s lack of sensitivity and compassion for her problems. Reading this brought back memories of my own husband’s lack of support and compassion regarding my back injury and severe chronic pain. Originally my husband was supportive following my first injury. However, as the months then years went by, he began to resent my injury and me because I could not participate in the physical lifestyle that he enjoyed.

Abbie's insights (Kiesinger, 1998) about weight also resonated with my own story. Although I am not bulimic or anorexic, I, like most of the participants I interviewed, have suffered from weight gain as a result of my injury, because of an inability to exercise, and as a result of medication. I have tried numerous diet plans, without great success in the past, and thus have body image issues. I could therefore empathise with Abbie's story, and her insights regarding obesity made me reflect on my own condition. It was a powerful piece of writing.

Christine Kiesinger's (1998) story seemed so much more evocative and meaningful because she was also writing about her own experiences, as well as her participant, Abbie. It was the way her story was written. Autoethnographic studies are usually written in the first person and take a variety of forms, such as poetry, short stories, journals and personal essays, and social science prose (Bochner & Ellis, 1999). In these texts:

concrete action, dialogue, emotion, embodiment, spirituality, and self-consciousness are featured, appearing as relational and institutional stories affected by history, social structure, and culture, which themselves are dialectically revealed through action, feeling, thought, and language (Ellis & Bochner, 2000, p.739).

Bochner (1997) contrasts academic texts with those written in the first person voice. Writers of academic texts are trained to appear detached and objective, concealing their personal selves. The personal voice is ridiculed as being "soft minded, self-indulgent and unprofessional, whereas the academic voice is exalted as the voice of reason, objectivity and rigor" (Tompkins, 1989). Bochner (1997) believes that we pay a steep price for producing texts that sustain the illusion of disinterest and neutrality by keeping the personal voice out. "Our work is underread ... [even academic readers] find our scholarship is boring, dry and inaccessible ... and the public hardly knows we exist."

It was at this point I saw that using an autoethnographic approach was an opportunity to use the participants' stories to heighten my understanding of my own life, while at the same time using my own experiences to better comprehend the participants' stories (Kiesinger, 1998). At the same time, I considered this could add to nursing's and healthcare professionals' body of knowledge and could

conceivably make a difference to the way in which healthcare professionals relate to, care for and treat, their chronic pain patients.

Ellis & Bochner (2000, p. 739) describe autoethnography as:

an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural.... [They] focus outward on social and cultural aspects of their personal experience; then they look inward, exposing a vulnerable self that is moved by, and may move through, refract, and resist, cultural interpretations.

Symbolic interactionism shares a similar philosophy in as far as it contends that the relationship between self and society is an ongoing process of symbolic communication, whereby individuals create their social reality.

After some further reading, I saw a greater potential for the use of an autoethnographic approach in my own research project. That is, it had the potential to enrich my research experience, and analysis of data. I saw that I would be able to use my own experiences of chronic, nonmalignant back pain and hospitalisation, as data. Consequently, I decided to change my methodology from grounded theory to autoethnography.

As I further explored autoethnography, I discovered there were numerous forms of autoethnography. They range from autobiographical, where the researcher is the sole subject, to biographical: one participant is the subject, such as Abbie's story. Some studies are written in a particular way, such as poetics, short stories, journals and personal essays, and social science prose. Other studies concentrate on a particular racial or ethnic group (Bochner & Ellis, 1999).

I decided to use a form of autoethnography called narrative autoethnography. In narrative ethnography, the ethnographer's experiences are incorporated into the ethnographic description and analysis of others' experiences and the emphasis is on the "ethnographic dialogue or encounter between the narrator and members of the group being studied" (Tedlock, 1991). Bochner (1997) describes the narrative approach to research as exploring the way that "stories ask readers to feel their truth and thus to become fully engaged – morally, aesthetically, emotionally and

intellectually.” He considers the texts we create show how people cope with difficult life experiences, “how they invent new ways of speaking when old ways fail them” (Bochner, 1997). These stories:

long to be used rather than analyzed, to be told and retold rather than theorized and settled. And they promise the companionship of intimate detail as a substitute for the loneliness of abstracted facts, touching readers where they live and offering details that linger in the mind (Bochner, 1997).

As already noted, a major reason for the decision to change my research approach was in order to use my own experiences of chronic back pain and hospitalisation as data. As Spigelman (2001) explains, “autoethnographic writing insists that the narrative of an individual’s life is both the product and process of surrounding social and educational narratives.” Personal experiences are individual to each researcher. Each researcher brings to their research study different influences, opinions, thoughts, feelings and experiences, whether or not they are consciously aware of these influences. Similarly, each researcher brings personal contextual factors to their research project. These factors include cultural, historical, social and political contexts in which the researcher is immersed, consciously or subconsciously (Ellis & Bochner, 2000).

Traditionally, writing for the purpose of research has required objectivity on the part of the researcher. Their own interests and even the reason why the researcher has chosen a particular research question often remains obscure. However, important information concerning a researcher’s findings can be deduced by knowledge of their personal, social and political background (Spigelman, 2001). Having declared my personal status, to the participants and within my thesis, the questions of objectivity and bias are examined. As Banks & Banks (2000) remark, “the role, perceptions, and experiences of the author must be assessed along with the claims of the text.”

The effect of reality is created in narrative autoethnography by the texts and stories produced. Characters are shown “embedded in the complexities of lived moments of struggle” (Ellis & Bochner, 2000, p.743). The traditional separation of researcher and subject is transgressed by the author writing in the first person voice, making

herself the object of research. While I believe it may have been possible for me to bracket my personal thoughts and feelings on the subject I was investigating, I believe that it was more beneficial to explore my wealth of knowledge on this particular subject. Apart from suffering from severe chronic back pain, I have also nursed patients with chronic back pain and chronic pain. When they describe their hospitalisation experiences I can often see the nurse's perspective.

Turning to autoethnography did not compromise my own philosophical beliefs or values. I am an Anglo-Celtic female, and my philosophical beliefs and values (including the commitment to: truthfulness, empathy, compassion, justice, equality and environmental responsibility) in research also include treating all participants with respect and dignity, compassion and empathy, giving a 'voice' to marginalised groups, and reporting back to participants for feedback and critique. Feminist researchers are encouraged to take their preliminary findings and stories back to participants for their feedback, to ensure that both the individual and collective voices are being accurately represented. Seeking feedback also empowers the participants. As a feminist researcher, one of my goals is to give this marginalised group of people a voice, and thus possibly facilitate change in organisations (Koch, 1998).

### **Selecting Participants**

My criteria for participation was that the person had experienced severe, chronic back pain for a minimum of six months, and was being treated with long term opioids (an indication of the severity of the pain suffered), was over 18 years of age and could speak and understand English. Each participant was given information regarding my research project including information about the confidentiality of her information (Appendix 2) and she was asked to sign a consent form (Appendix 3).

My first participant was a chronic back pain sufferer whom I had briefly met whilst in hospital. Although I could have continued to select participants using this method, as I had met a lot of chronic back pain sufferers during various hospitalisations, I decided instead to use snowball sampling. I asked my first participant to notify friends and acquaintances she knew suffered from severe

chronic back pain and to provide them with details of the study and my contact number. This was because I didn't want to choose participants that I knew had had difficult hospitalisations, and therefore possibly skew my results.

## **Participant Profiles**

Participant names have been changed to maintain participant confidentiality. The profiles include information obtained at interview.

### **'Allison'**

Allison is single, 44 years old and lives alone. She has suffered from chronic back pain for 14 years following an injury at work. She is unable to work due to her pain and currently receives WorkCover (worker's compensation) payments. She has undergone three major surgeries on her back, as well as multiple diagnostic and treatment interventions, most of which are painful.

Allison is in constant pain. She experiences centralised low back pain that is stabbing and of a deep ache in nature. Allison was asked to indicate the type and location of pain she felt using a pain drawing (Uden, Astrom, & Bergenudd, 1988) (Appendix 4). It radiates the entire length of her spine and she has referred leg pain. At the time of interview, using a 0 -10 analogue pain rating scale, where 0 = no pain and 10 = extremely intense pain, Allison described her pain: 'right now' as 3; 'at its worst' as 7; and 'at its best' as 2.

Allison is currently treated with intrathecal pethidine. Intrathecal opioids are delivered by an implanted, computerised pump that delivers the opioid directly into the cerebrospinal fluid. Her breakthrough pain is managed using opioids, both orally and rectal suppositories. She is also on low dose antidepressants, a common adjunct therapy for pain management (Vilensky, 2002) and antispasmodics. Her medications are prescribed by her general practitioner and an anaesthetist specialising in pain management.

To manage her pain Allison currently uses heat, cold, relaxation, meditation, imagery, aromatherapy and diversion therapy, such as music, reading and crafts.

Allison has had approximately 30 hospitalisations since her injury, and in the twelve months prior to interview, spent 100 days in hospital.

### **‘Sarah’**

Sarah is single, 32 years old and lives with friends. Sarah was involved in a road traffic accident when she was 2 ½ years old, and has suffered from chronic back pain since the age of 7. She is unable to work due to her pain, and is on a disability support pension. Sarah is able to do voluntary work at an animal shelter, two days each week, for 3 hours. She has undergone two major surgeries on her back, as well as multiple diagnostic and treatment interventions, most of which are painful.

Sarah is in constant pain. She experiences centralised deep ache and stabbing pain in her lower back that radiates to her upper thighs, and pins and needles over the same area. At the time of interview, using a 0 -10 pain rating scale, where 0 = no pain and 10 = extremely intense pain, Sarah described her pain: ‘right now’ as 6-7; ‘at its worst’ as 10; and ‘at its best’ as 3-4.

Sarah is currently being treated with slow release oral morphine, with oral opioids for breakthrough pain. She is also on low dose antidepressants, a common adjunct therapy for pain management (Vilensky, 2002) and antispasmodics. Her medication is prescribed by a psychiatrist who is a pain management specialist.

To manage her pain Sarah currently uses heat, massage, relaxation, meditation, imagery and diversion therapy, such as music and reading. Sarah has had two major back surgeries and has been hospitalised approximately ten times since her injury. In the twelve months prior to interview she spent 70 days in hospital.

### **‘Sally Ann’**

Sally Ann is married, with three teenage children. Sally Ann and her husband have separated in the past, due mostly to the stress her pain caused, and are currently “working on” their marriage. Sally Ann injured herself at work 15 years ago and is



unable to work due to her pain. She is currently receiving WorkCover (worker's compensation) payments.

Sally Ann is in constant pain. She experiences centralised low back pain radiating to her right leg, with associated pins and needles over the same area. At the time of interview, using a 0 -10 pain rating scale, where 0 = no pain and 10 = extremely intense pain, Sally Ann described her pain: 'right now' as 8; 'at its worst' as 10+; and 'at its best' as 7.

Sally Ann has had six major spinal surgeries, and seven 'lesser' spinal surgeries, and many diagnostic and therapeutic interventions, most of which are painful. Sally Ann has been hospitalised approximately fifty times since her injury. In the twelve months prior to interview she spent 42 days in hospital. As part of her pain management regime, Sally Ann chooses to be hospitalised regularly, usually three times a year, for approximately two weeks each time. She admits these admissions are "emotionally draining", however she feels they are necessary as it gives her a chance to get some rest and "recharge her batteries."

Sally Ann uses intravenous pethidine via a semi-permanent intravenous access, with a pump delivering a small amount of medication continuously. As she is allergic to morphine and all its derivatives, Sally Ann is severely restricted in which opioids she can take. She is also on low dose antidepressants and antispasmodics. Her medication is prescribed by a rehabilitation physician.

To manage her pain Sally Ann currently uses heat, massage, relaxation, self hypnosis and diversion therapy, such as music, reading, and doing needlecraft. Sally Ann is also currently studying, which she says "keeps my mind active, and makes me feel useful."

### **'Lilly'**

Lilly is divorced, 42 years old and lives alone. She was injured at home 17 years ago, performing a usual task involving reaching, leaning and twisting. Lilly was paralysed for 2 years and in a wheelchair for 3 years. She was not expected to

walk again, but “through sheer hard work and bloody mindedness”, she persevered with rehabilitation and is now able to walk. She is unable to work due to her pain, and is on a disability support pension.

Lilly is in constant pain. She experiences centralised low back and thoracic pain that radiates to her right leg, with associated pins and needles and numbness over the same area. At the time of interview, using a 0 -10 pain rating scale, where 0 = no pain and 10 = extremely intense pain, Lilly described her pain: ‘right now’ as 8; ‘at its worst’ as 10-15; and ‘at its best’ as 8. Lilly noted, however, that she “find[s] this sort of rating very difficult as it doesn’t always seem to explain your pain level at that time.”

Lilly has had fifteen major back surgeries, and fourteen ‘lesser’ surgeries, and has had “more diagnostic tests than [she] can remember” as well as treatment interventions, most of which are painful. Lilly has been hospitalised approximately two hundred times since her injury. In the twelve months prior to interview she spent 20 days in hospital.

Lilly has been taking narcotic analgesics since her injury and is currently taking oral slow release morphine and another oral opioid analgesic for breakthrough pain. She also takes antispasmodics. Her medication is prescribed by her general practitioner. Lilly has a spinal cord stimulator implanted in her spine as an additional, non pharmaceutical, method of pain control. Leg tremors are a side effect of her spinal cord stimulator and, as her father has Parkinson’s disease, Lilly said it was “a family joke and a competition as to whose leg was shaking more! ”

To manage her pain Lilly currently uses heat, massage, relaxation, and self hypnosis.

### **‘Cate’**

Cate is married with four young children. Cate injured her back at work 11 years ago and has been unable to work since. Cate currently receives WorkCover

(worker's compensation) payments. Cate had her first (and subsequent) child against doctors' advice and says she is "extremely happy I did."

Cate is in constant pain. She experiences centralised low back pain that radiates to her left leg, with associated pins and needles over the same area. At the time of interview, using a 0 -10 pain rating scale, where 0 = no pain and 10 = extremely intense pain, Cate described her pain: 'right now' as 7-8; 'at its worst' as 10+; and 'at its best' as 8. Cate noted, however, that she "find[s] rating scales inappropriate most of the time, because they just don't indicate pain intensity, or the effect the pain has on your whole life. Besides, nurses seem to use them to compare one person's pain to someone else's, and you just can't do that."

Cate has had three major back surgeries, and four 'lesser' surgeries, and has had multiple diagnostic tests and treatment interventions, most of which are painful. Cate has been hospitalised approximately thirty times since her injury. In the twelve months prior to interview she spent 56 days in hospital.

Cate has been taking narcotic analgesics since she was first hospitalised for her injury and is currently taking oral slow release morphine and another opioid analgesic by intramuscular injection for breakthrough pain, 3 hourly as necessary. She also takes low dose antidepressants and antispasmodics. Her medication is prescribed by her psychiatrist who specialises in pain management.

To manage her pain Cate currently uses heat, massage, relaxation, imagery, self hypnosis and diversion therapy, such as music, reading, and jewellery making.

### **Approaches to Interviewing**

Being a chronic back pain sufferer gave me an insight into the general issues confronting my participants. Prior to beginning the interviews, I hoped this insight would allow me to delve into my participants' experiences, using my own experiences as a guide. I decided to follow Minichiello, Aroni, Timewell & Alexander's (1995) approach to indepth interviewing.

### **The first three interviews**

Using the grounded theory method, I conducted the first three interviews with Allison and then Sarah and Sally Ann. At this stage of my research, I was still only looking at the hospitalisation experiences of chronic back pain sufferers. After reading and signing a consent form, all participants were asked to fill in some details regarding their personal life situation and their medical history in regard to their chronic back pain (referred to in participant profiles. See Appendix 5). An audiotaped interview then proceeded.

I opened each of these interviews by asking the participant to “describe your experiences of hospitalisation and the care that you received” (see Appendix 6 for interview schedule). I did not interrupt the participant unless I felt she was getting off the topic, and let her decide on the order and content of what she said, so that I would have an indication of the order of importance she placed on the issues raised. I had some probe questions ready, in case the participant was hesitant to continue or looked to me for direction.

The probe questions included such things as the relationships between you and nursing staff and doctors and their response to your pain and medication. Healthcare professionals’ knowledge of chronic back pain and whether there is anything you would like to see changed to improve your hospitalisations. I would then ask the participant whether there was anything else they would like to mention and then, when finished, close the interview by thanking them sincerely for their contribution and participation. Each interview lasted approximately 2 hours, this being the participant’s choice.

As I mentioned earlier, I was at this time using grounded theory methodology and was therefore trying to bracket my own thoughts, feelings and experiences. Each of the participants knew that I was a fellow sufferer, as disclosure of my situation was part of my methodology. Many times during the interviews, the participants looked to me for validation on the point they were making. I would nod my head and make supportive noises, but it wasn’t enough. I was finding it extraordinarily difficult to restrain myself from participating, from relaying my experiences and I felt

I was letting the participant down by not validating them. I felt I was indeed adding to their burden; I became yet another person who was not validating their pain experience!

Despite being in obvious pain after their formal interviews had finished, Allison, Sarah and Sally Ann all invited me to stay for a cup of coffee, which I gladly did. It was during this time that they all spontaneously, without any prompting from me, started chatting with me about the way their chronic back pain affected their lives outside of hospital. They also wanted to hear about my life situation too, so we sat and discussed our lives and chronic back pain.

A couple of minutes into each chat, I realised that the participants were starting to say some things that were quite profound. I said to them, "Do you mind if I write this down? I like the way you've phrased that." The participants allowed me to take notes. I purposefully kept my notes very brief, only writing single key words each time they introduced a new topic, as I knew my recall would be good.

I wanted to give them my full attention and be able to fully engage with them in conversation. Finally I was able to validate their experiences and I could see that they really appreciated it. I spent another hour with Allison and a further hour and a half with Sarah and Sally Ann, and I think I could have stayed for hours longer. They desperately wanted *someone* to understand how difficult their entire life situation really was, without feeling that they had to mask how they really felt, or be thinking that I was sitting there thinking 'all they do is complain, complain, complain...'.

When I left each participant's home, I drove around the corner and parked. This was because the participant would see me safely to my car and watch to see that I drove away, out of concern for me: a fellow sufferer. I wanted to write up my notes as soon as possible, while they were still fresh in my mind. It didn't matter that I was in a lot of pain. I knew that it was important to at least make some detailed notes before I went home, and they were invaluable at the analysis and story writing stages of my research.

## **Turning to autoethnography**

Once I had chosen autoethnography as my methodology, I felt the interview process would be simplified as I no longer had to bracket my thoughts and experiences. Autoethnographers emphasise an interactive interviewing approach. Kiesinger (1998) notes that the researcher must display “a willingness to participate fully in the conversation with her subject/conversational partner, to allow her own life and story to be probed and challenged.” I had to be willing to share details of my own life. For example, I was able to say ‘that has happened to me too’, which did help to validate my participants’ feelings.

I was very mindful that my participation in an interactive interview must not overshadow the participant’s story. It would be very easy to begin by saying ‘that’s happened to me too’ and then to go on and give a long, detailed account of the incident. This would have lost sight of the fact that I was there to hear the participants’ stories.

I was also very aware that I must still be open to new experiences or issues raised by the participants. Other people experience the same situation differently, and will have come into contact with issues and incidents that I had not experienced. For example, one obvious difference was that I do not have any children, and do not have to face any of the pressures and emotions that chronic back pain brings into their lives, so my aim was to give participants a voice but not to speak instead of them.

## **The final two interviews**

The first interactive interview I did was with Lilly. It was a very different experience compared to the previous three interviews. Lilly is a naturally talkative person and I knew we had spent quite some time talking, but when the interview was finally finished, I was very surprised to see that 5 hours had passed!

We covered an enormous number of issues and topics. I began by asking Lilly to “tell me what it’s like living with chronic back pain.” Then I just let her talk, and talk she did! I had prepared one or two probe questions, or areas of interest, but did

not need to use them as Lilly covered everything I had thought of, and more. Lilly really opened up to me. She told me later that she felt comfortable talking to me because she knew I would understand and would not judge her because I had been there myself. Lilly told me of a suicide attempt, something she had never admitted to anyone before.

The second interactive interview was with Cate. I took care to watch the time during this interview and managed to complete it in 3 hours. I asked the same opening question as I had with Lilly, and again had no need to refer to the prepared probe questions. Cate confided in me too. She spoke about family dynamics and role changes that had occurred due to her back injury. She said later that, as she was talking to me, some of her issues were clarified for the first time in her mind.

Both Lilly and Cate thanked me for giving them the opportunity to talk about not only their chronic back pain, but also their lives as they lived with chronic back pain. I felt privileged that they allowed me to come into their homes and that they chose to speak to me with such candour.

## **The Process of Analysis**

### **Grounded theory**

After the initial three interviews I analysed the transcripts using a grounded theory approach (Strauss & Corbin, 1990). I initially coded section by section arriving at a number of codes which were eventually reduced to six major codes or themes. These were: *loss of control*, *speaking into the void*, *body image disruption*, *stigma*, *fear of addiction* and *everyone else knows best*.

Each code was defined, for example 'loss of control' involved the person changing from an independent, self-reliant, self-assured adult to that of a patient, dependent on the hospital and its staff for all requirements. 'Speaking into the void' represented the frustrating feeling of not being listened to, or heard. It's like "talking to a brick wall". 'Body image disruption' results from changes to the body following pain and disability. 'Fear of addiction' and 'stigma' are self explanatory.

'Everyone else knows best' describes the frequent treatment advice given to chronic pain sufferers by friends, relatives, acquaintances and even someone they've just met as to how they can best heal themselves.

### **Autoethnography**

When I changed my methodology to narrative autoethnography, I revisited the transcripts and field notes that I had written after each interview. With a new perspective, and being able to use my own experiences as data, and with the goal of telling representative stories, I re-examined the data. Initially, three stories were identified. The initial themes are still represented within the stories, but are not always explicitly stated.

### **The first story identified**

The first, most obvious story was that of a pain management hospitalisation, as it was that experience that prompted me to undertake this research. The title of this story became 'Here we go again'. This story illustrates 'typical' experiences and issues that chronic back pain patients face each time they are admitted to hospital, usually in a pain crisis, for pain management.

Within this story, the main character feels a loss of control from the moment of admission until she is discharged. The 'speaking into the void' theme is represented in the courtyard scene, when a group of chronic pain patients discuss interactions with their nurses. It is also evident during the many discussions the two main characters have with the nurses regarding the provision of medication.

Stigma regarding chronic back pain patients and receivers of compensation is a recurrent theme within this story, at times unspoken and at others quite obvious in the nurses' attitudes. Fear of addiction is explicitly demonstrated when a nurse confronts the main character, saying "you know you're addicted" to opioid analgesics. Body image disruption is a theme not dealt with within this story. Although it is an issue that is always with us as sufferers, it is covered in two other stories: "Mourning the loss' and 'Walk a mile in my shoes'. 'Everyone else knows best' is also not dealt with in this story. It is ironic that in hospital, nurses are



*supposed* to know best, but in our case, it is we, the pain sufferers, who know more about our pain and its treatment.

### **The second story**

The next story identified is titled: 'The merry go round: searching for a cure', in which the central character searches for the elusive 'cure', often being told her pain is "all in her head". Hearing that so often means you even begin to doubt yourself, only to find out sometimes years later, with better diagnostic tests available, that there is a biological cause for the pain.

Loss of control over the course her life is taking is implicit in this story. 'Speaking into the void' is also implicit in this story, as the character fights to have her pain validated by the numerous doctors she sees.

### **The third story identified**

The idea for the next story was to describe 'a day in the life' of a chronic back pain sufferer, to give the reader an insight into the daily struggle chronic back pain brings. For quite some time I had trouble working out how to write this story. My supervisor suggested I write it as a diary or journal entry, but I soon realised it would be a very boring story. On days spent at home, it would have been resting, possibly some basic household tasks, and then some more resting! If I described a day out, I felt it would be hard to write anything but a long list of complaints.

I puzzled over how to write this story because I recognised that there was merit in giving the reader a glimpse, or a snapshot, of the day to day reality of living with severe intractable chronic back pain. I then got the idea of writing 'Walk a mile in my shoes'. Initially, this was written as an angry response to people who say to all of us "I wish I could have an extended holiday like you". I asked the reader whether they would be prepared to 'swap' lives with one of us, as we would be glad to be able to 'trade in' our lives and have the opportunity to start again.

Finally, after discussion with my supervisor, I decided that this story would be more powerful if it was written in the form of a letter. The letter is addressed to the next

nurse who is to look after us in hospital; to doctors both past, present and future, who question the validity of our pain; to student nurses and medical students: our future carers, learning about the pain experience.

In 'Walk a mile in my shoes', I ask the reader to imagine themselves to *be* a chronic intractable back pain sufferer, to literally walk in our shoes. The tone of this story is not conciliatory and I make no apologies for that. The style of writing in this story is meant to be confronting, hard hitting and thought provoking.

The theme stigma is heavily represented in this story under the heading 'From compassion to suspicion' when the character speaks about people learning that her injury is a compensatable one, and notices a change in people's attitudes. The character feels that people are silently asking: "Are you faking it for the mythical big payoff? Are you participating in the renowned fraudulent insurance scam? Are you in it for the drugs, either for yourself or to sell illicitly?"

'Everyone's an expert' is a subheading within this story. People she meets may notice walking aids, for example, and respond with suggestions that either they have tried for their 'sore back', or they know someone who has found a miraculous new 'cure'. Body image disruption is identified in this story when the character describes a decreased libido due, among other things, to her changed body image. Loss of control over her life is implicit in this story, as she has lost her employment, her husband and now has little control over her future.

### **A new story emerges**

A fourth story, 'Mourning the loss' was at first encompassed in 'The merry go round: searching for a cure'. After some deliberation it was decided that it could be expanded and deserved to stand alone as a story in its own right. 'Mourning the loss' explores the process of coming to terms with the fact that a cure will not be possible and severe chronic back pain is now a lifelong condition. Another issue that has to be faced is that the pain can only be managed; it is extremely unlikely that any specialist will be able to treat you so that you are pain free.

The themes covered in this story are: loss of control, body image disruption and stigma. Loss of control is an undercurrent theme throughout this story. All themes are encapsulated in a quote from the story: "I was mourning the loss of the body I once had."

Body image disruption is a theme heavily represented in this story with quotes such as "I can't bear to look at myself in the mirror. The reflection does not match my mental image of myself. I don't like what I see. There is this semi-hunched, lopsided person where I used to be." Issues of weight gain also reflect body image disruption in this story. "I had never had a weight problem before, but now that it is impossible to do any sort of exercise except a slow, awkward walk, it didn't take long for the weight to stack on. I feel like an elephant."

A sense of being stigmatised is implicit when the central character is talking about the potential for a future relationship. "I could not envision why any man would want to be with me. I feel that all any man will see will be my walking crutches, and would run a mile."

### **A final story is written**

'We're not in Kansas anymore' is a story about an acute emergency admission. The central character in this story is not a composite and I have chosen to use my own name to identify this fact.

Loss of control is evident from the first moment in this story and continues throughout. 'Speaking into the void' is also a recurrent theme. No-one listens to my point of view in this story! Stigma is also apparent very early and continues throughout the story. It is not only stigma about chronic back pain, but also about psychiatric illness. Stigma about narcotic analgesic use is also an undercurrent theme as I fight to get any, let alone adequate, analgesia.

## **The final ‘line up’ of the stories and chapter headings**

Chapter 4. ‘This is your life: Coming to terms with loss and disability’ is comprised of:

1. ‘The merry go round: Searching for a cure’
2. ‘Mourning the loss’
3. ‘Walk a mile in my shoes’

Chapter 5. ‘Hospitalisation: An inevitable part of life’ is comprised of:

4. ‘Here we go again’
5. ‘We’re not in Kansas anymore’.

Although chronological, some of the stories present the protagonist as childless and others with children, representing the different situations of the five women.

## **Reflections on the Process of Writing**

Naively, I thought that once I had done the data analysis and decided on the story lines, the actual writing of the stories would be easy. Having been an avid reader all my life, I assumed that would translate into being able to write stories. After all, I was writing about a subject I knew very well and to which I could relate.

I couldn’t have been more wrong! My first challenge was to make the story interesting. My first draft was factual and informative, drawing on the themes, but was also dull and uninspiring. I knew that if I wanted to hold my readers’ interest, so that they would want to read through to the end, the story still had to represent my participants’ and my own experiences and be informative, but more importantly they had to be ‘a good read’. I thought back to the first autoethnographic story I had read by Christine Kiesinger (1998). It was exciting to read and I hadn’t wanted to put it down. I decided, in order to make the story more gripping, I would write it so that readers would feel like they were in the room with the characters; as if they were a ‘fly on the wall’. That meant that it had to be written in the first person and in the present tense. By using the first person voice, the central character becomes the narrator as well. Using the first-person voice lends weight to personal narrative and “adds energy and vitality, giving ... [the] story an evocative

power quite different from that normally accomplished when speaking in the third person” (Kiesinger, 1998).

The next hurdle I faced was getting the grammar right. I consider my English skills to be above average, but I was having trouble getting the tenses right. Every time I would read back a paragraph, I would notice that my tenses were changing three times in one sentence! The problem was that my own experiences echoed my participants extremely closely, so I was describing things that had happened to me in the past, but I was writing as if they were happening now.

It took me a long time and many, many re-writes to learn the art of writing evocative stories. As Kiesinger (1998) notes “as interpretive ethnographers, the sentences we construct, the images we paint with our words, the characters we depict, and the scenes we bring to life are the products of our own experiences as well as the products of the relationships we foster and share with our participants.” Learning the art of creative writing has been a challenging but wonderful journey.

### **Physical and psychological challenges**

The most unexpected and difficult challenge I faced whilst writing the stories took me by complete surprise. I wrote the last story: ‘We’re not in Kansas anymore’ first, virtually as it happened. I was just about to commence writing the stories identified from preliminary analysis at the time that hospitalisation occurred. I told my supervisor about my bizarre experience and we both decided it would illustrate the stigma surrounding chronic pain. As every detail of this episode was indelibly etched in my mind I felt the story would flow easily. Besides, I could not stop thinking about it and knew I would not be able to concentrate on the other story lines, barely conceived. I decided to write the story presented last, first.

It was starting to come alive when I began feeling sick. This wasn’t unusual, so I didn’t think anything of it. During the next two days, I got steadily worse. I was lying in bed, curled in the foetal position when a sudden realisation hit me.

When I thought about my symptoms over the last two days I realised that they were different from my usual ones. It had started with a sick feeling in my stomach, which isn't unusual as I often feel nauseous. However, when I thought about it for a while, it dawned on me that what I was experiencing was fear. Starting to write my story had brought back the incredible vulnerability I had felt in hospital. I had been progressively spiralling down as all I had been thinking about was my recent hospitalisation.

The absolute loss of control I felt was very confronting and, although it had been a few weeks since my discharge, the fear I felt was very real. I didn't want to write, as I knew that I would continue to re-experience the emotions I felt in hospital. I considered leaving this story for a while and moving on to writing another. It didn't take me long to realise that I had to face my demons. I knew that if I was going to write it at all, I had to do it now.

Whilst writing the story I experienced a range of feelings including anger, vulnerability, helplessness and fear. I even came to have a sense of humour about it and could even laugh at the ludicrousness of it all. It really shouldn't have happened at all and certainly not in the manner it did. I found writing the story had a cathartic effect and was therapeutic in helping to heal the wounds that the hospitalisation had created.

When I came to writing the story about a pain management hospitalisation, it took me some time to understand that I was again exhibiting avoidance behaviours to escape having to write the story. I was surprised that once again I was confronted by the deep seated fear I have of hospitals; and the vulnerability and loss of control I feel. I really didn't expect to be affected this way.

Writing all of the stories was confronting in various ways. 'The merry go round: searching for a cure' stirred up feelings of anger as I remembered being continually and unnecessarily told my pain was "all in my head." Whilst writing 'Mourning the loss' I seemed to go through the grieving process once more. Being reminded of all that I'd lost just didn't seem fair. What had I done to deserve this? I thought I'd successfully dealt with these issues. Writing about them, however, brought them

to the forefront once more. Writing 'Walk a mile in my shoes', on the other hand, gave me an opportunity to use my anger and resentment in a positive way, with a therapeutic outcome.

### **Personal reflections**

Being 'researcher as subject' has not necessarily been an easy journey. I have had to confront memories that I have intentionally repressed. I've had to re-live emotionally painful incidents. Writing about my own experiences also leaves me in a vulnerable position. Once my situation, experiences, thoughts and feelings are in the public domain, I am open to comment and even criticism. What if people think I have not handled specific situations particularly well? Ellis & Bochner (2000, p. 738) note "the vulnerability of revealing yourself, not being able to take back what you've written or having any control over how readers interpret what you've written. It's hard not to feel your life is being critiqued." A protection of sorts is offered however, through writing about 'group experiences'.

### **The reader interacting with the stories**

The stories are presented in a way that I hope will move and engage the reader. I anticipate that the reader will make their own connections with the following stories on two different levels. Firstly, on a conceptual level, that will reflect what has been read and thought at the time of reading. Secondly, I expect that the reader will connect with the stories on a more emotional level, in terms of how it personally affects them. As Koch (1998) remarks, well written, participants' stories allow the reader to imagine themselves in the participants' world, forming an empathetic understanding.

The following chapter, Chapter 4: 'This is your life: Coming to terms with loss and disability', consists of my interpretation of my own and others' lived experiences. The three stories or narratives within this chapter describe what it is like to be confronted with a serious back injury from the moment of injury; then traces the journey the injured person undertakes as she moves from having an acute injury into a chronic condition.

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Endnote: An earlier version describing the methodology was published as a journal article. See: White, S. (2003). Autoethnography: An appropriate methodology? *Qualitative Research Journal* 3(2), 22-32.



## **CHAPTER FOUR**

### **‘THIS IS YOUR LIFE: COMING TO TERMS WITH LOSS AND DISABILITY’**

#### **Introduction**

All people with chronic back pain go through the same steps illustrated in this story. In order to have chronic pain, you must first have had an acute episode as ‘chronic’ literally means lasting longer than the expected acute phase. All sufferers have an exceptionally similar story because chronic back pain is notoriously hard to diagnose and treat.

This adds to the enormous pressure that doctors are already under to help their patients. I believe this pressure stems from society as a whole, from patient expectations and, indeed, from their own expectations. Doctors are trained for years to diagnose, to treat people and to problem solve. Although it is now less common for patients to see their doctors as ‘gods’, most of us nevertheless have a deep seated expectation that we only need to attend a consultation to be cured, or be given a referral to a specialist. It seems it is ingrained in our society to expect our doctors to know all, see all, and fix all. If only it were so easy!

#### **Story One**

##### **‘The Merry Go Round: Searching for a Cure’**

Note: When the main character is speaking, the text is in regular font and quotation marks. When another person is talking to her this is indicated by using italics and quotation marks.

#### **Seeking ‘the cure’: the first step**

Diagnosis is obviously the first step. A diagnosis seems such a simple thing. Unfortunately, in the case of back injuries diagnoses can be complicated. There are so many areas of the spine that can be diseased or injured, either alone or in combination. Often similar symptoms result, making diagnosis difficult.

After undergoing initial diagnostic testing, my local doctor could not find anything wrong with me. At first I was treated conservatively, but as I did not improve I was referred to a neurologist. He ordered numerous tests, most of which were very painful and required hospitalisation for a few days. I was relieved when he promised on admission that he would find my problem. After enduring every test he had arranged, and a few more, my doctor recommended spinal surgery and a neurosurgeon.

The neurosurgeon was confident that spinal surgery would successfully strengthen my back and eradicate my pain. Following rehabilitation and recovery time at home, I was left with unforeseen severe back and leg pain, which did not resolve. I spent the next couple of years being referred to a variety of specialists: orthopaedic surgeons, orthopaedic consultants, neurosurgeons, neurologists and rheumatologists.

Some specialists were content to review the results of previous tests, while others asked me to undergo the same tests, because *“my technician is the best, and I don't trust other people's results”*. Although these tests were exceedingly painful, I agreed to have them performed again, because I still believed the surgeons when they told me that they *would* find a diagnosis and then would find a cure. When doctors have been *promising* to cure an injury for all those years, believe me you cling to those empty, ill-advised promises.

### **From the weird to the wonderful**

One of the strangest encounters I had was with a doctor who, once again had promised, then failed, to deliver a diagnosis. I'd been discharged from hospital a week earlier after undergoing 'minor' back surgery, which was supposed to 'cure' my back pain. It had gone horribly wrong. My back pain had increased dramatically in hospital which, incidentally, they failed to treat, claiming I was a 'drama queen'. I had tried speaking to my nurse and the unit's charge nurse to no avail. It was only after I had spoken to the nurse in charge of the hospital that they

realised that I was indeed in serious pain and commenced me on intravenous morphine.

Walking into my doctor's rooms for a follow-up appointment, I'm anxious to hear what news he has for me. He smiles as I enter the room, saying "*Anna, how nice to see you. Sit down. I have some good news for you!*" My heart is pounding! At last, I have found a doctor who has found my longed for cure. I'm so excited. I can hardly wait to hear what he has to say! "*I have a patient, very much like you. She's completed a new treatment, with extremely good results.*" I can hardly believe my ears! Is he saying that he's discovered a new treatment that will be a way out of this never-ending pain? I've been dreaming of this moment for so long, I can hardly believe it's here. I'm sitting on the edge of my seat, staring directly into his eyes, so I won't miss a word.

Eagerly I ask "so, what is this new treatment?" He answers me, but due to his very strong European accent, I can't understand him. "Could you repeat that please? I didn't catch what you said." Once again, I can't understand what he's saying to me. It seems to be just a single word, but I can't make it out. I'm feeling so frustrated. Just at the moment I'm supposed to be hearing my dreamed of cure, our communication fails! Finally, exasperatedly I say, "could you write it down for me?"

He hands me a small piece of paper. With my heart in my mouth, I look down. There is a single word on the paper: 're-birthing'. Feeling stunned, I just sit there. I can't believe that someone I had been told is an eminent neurosurgeon was recommending such a bizarre and unconventional course of action. "Are you serious?" I ask incredulously. "*Yes, certainly. My other patient, she's amazing now.*" "So, you're saying that there's nothing physically wrong with me. Is that right?" He doesn't seem to want to answer that question. Attempting to convince me to try re-birthing, he hands me the therapist's business card.

Feeling stunned and insulted, I sit there for a moment. I just can't believe this is happening. Coming to my senses, I stand and tear up the business card. "This consultation is over! If that's all you have to offer, I'll find someone else to help me." As I'm walking out of his office he casually says, "*make an appointment to see me again Anna, and let me know how it works.*" Turning back in disbelief, I shake my head. "Don't you understand? As far as I'm concerned, for you to seriously offer re-birthing as a quality medical intervention, is beyond belief. And believe me you will *not* be seeing me again!"

Walking out of there blindly, I make my way outside into the fresh air to find a seat, as my legs are feeling like jelly. I am so angry, I'm seething. I had wanted to call him a quack, and I don't know why I censored myself. How dare he treat me with such condescension? I had walked into that room hoping for a diagnosis. When he said he had good news, I thought my search for a cure had at last come to an end. To have those hopes so cruelly dashed was hard, but to be given what I felt was such a fanciful remedy left me feeling angry, frustrated and disillusioned, to say the least.

### **The blame game**

It would seem that many doctors cannot even subconsciously accept that they may fail. If *they* can't find the solution, there isn't one to be found. Instead of accepting that they have failed to find a cause, it seems to me that it gets turned around, and somehow becomes the patient's 'fault', who is then 'accused', or 'blamed' for being in this situation. Either the doctor doesn't believe I have pain, or the severity of my pain is questioned. Or, it is assumed that I have poor coping skills, or a 'low pain tolerance'. Hearing "*it's all in your head*" again and again really is extremely disheartening.

I had always believed that I had a physical cause for my ongoing pain. When doctors first began telling me 'it was all in my head', I would get upset, then angry and frustrated. After hearing it so many times, however, I became vulnerable, and began to doubt myself. *Could* my mind be playing tricks on me?

I struggled with self doubt. Self doubt is frightening. I felt powerless. Who was I, a lowly patient, to question or disbelieve what all these authoritative specialists were continually telling me? I looked deeply into myself, and examined whether I could have any subconscious motives for having pain. I soon concluded that I did not. Pain was keeping me from returning to my life.

I soon saw that self doubt was dangerous, as I could see myself quickly sliding into a deep depression. I consciously chose to take back the power that had been taken away from me and believe in myself; to have faith that I would eventually be justified in my claims. When I was told *"it's all in your head"*, I simply became more determined to prove the doctors wrong.

My new determination proved to be useful when I was told *"it's all in your head"* by yet another specialist. I was so sick of being fobbed off with what I now considered to be 'a line', that I stood my ground. "I don't expect you to be able to tell me what's wrong with me if you can't. I *do* expect you to show me some respect and just say 'I don't know', instead of 'it's all in your head'." He looked silently at me for a moment, as if he was seeing me as a real person for the first time. *"I'm sorry Anna. I don't know what's wrong with you."* "Thank you", I replied quietly and left. I felt a tremendous sense of self satisfaction. Not only had I not accepted the same old rhetoric once again, but I had actually demanded respect.

It took a long time, but eventually my doctors *did* find a physical cause for my pain. I felt so relieved. It sounds crazy to feel relief when you're being told that something is wrong with you, but at least it meant that I wasn't crazy!

### **Finding validation**

Although finding a diagnosis did not generate a cure, it did mean that I was finally referred for pain management. It seemed now I had a 'legitimate' diagnosis, my pain was believable, and warranted treatment. It took some time to find the right pain management specialist for me, but when I did, it was worth it!

My new pain management specialist was a godsend. During our first consultation, he could not believe my history. He was particularly appalled, hearing that I had been made to endure repeated invasive tests that he felt were unnecessary. I was most impressed though, when he sat closely facing me and said simply, *“I believe you have severe pain Anna.”* He was the first doctor to validate my pain without question.

### **Accepting the unacceptable**

There comes a time when you just cannot keep trudging from doctor to doctor, in the vain hope that someone, somewhere, has the answer to your prayer: to turn back the clock to those glorious pain-free days of the past. It seemed futile to stay on the merry-go-round of endless doctors appointments. It took an enormous amount of energy, both physical and emotional, to attend these appointments so often. I would start to hope once more, each time I was referred to someone new. I soon learnt though, that I had to rein in my hope in order to protect myself. Even so, every failure hurt me deeply, but I seemed compelled to continue nevertheless.

I felt real conflict when I considered letting go of what had become my mission. I felt that I had failed. I had the feeling that it would somehow be my fault if I ceased searching for that elusive answer and I continued to suffer pain. What if the next doctor I was to see had some new, miraculous remedy? It was much easier to continue, rather than face what to me was unthinkable: lifelong pain.

My psychologist was the first to openly raise this subject. She questioned me about how I felt, learning to cope with chronic pain. When I told her I was still expecting to be restored to health, she looked at me and said gravely, *“You are going to suffer from severe chronic pain for the rest of your life. You must understand this, and come to terms with it.”*

## **Story Two**

### **Mourning the Loss**

#### **Losing the life I once had**

During the period that I was still seeking a cure, I was able to believe that my limitations would be temporary. I could still imagine myself as I used to be. I would fantasise about the things I would do when I was 'normal' again. It was not until I was forced to come to the conclusion that I would be this way for the rest of my life that I had to confront what turned out to be major demons.

In the beginning, I was overwhelmed with feelings of grief. I was mourning the loss of the body I once had. My mind began reeling as I thought about all the things that I would never be able to experience. From parachuting to hang gliding, to bungy jumping and skiing. Whether I would ever have tried these things was immaterial. Now, I no longer had a choice. Coming down to earth, I realised that although these activities might be entertaining, their loss was hardly earth shattering. Having never experienced them before, I was hardly going to miss them. Still, it was as if I was ageing before my time. I was just angry for a while; angry at stolen opportunities.

All I could think of was in terms of what I had lost. First and foremost, I had lost the physical health and abilities that I had taken for granted. I had never, in my previous life, sat and given thanks for being able to do whatever I liked, when I liked. This realisation caused me immense sadness. Going through life taking health and happiness for granted, without giving thanks, seemed immensely shallow and superficial with the benefit of hindsight. How could I have been so blind?

#### **Loss of future employment opportunities**

I am also angry at the loss of potential employment opportunities. My future career path was wide and varied, and I had planned so much. To have this abruptly taken away, through no fault of my own, seems so unfair. Watching my friends climb

further and further up their chosen career paths is frustrating. Although I am happy for them, I am terribly envious too.

Losing the ability to work has other significant ramifications. It amazes me how many people say to me *“I wish I didn’t have to work. It would be like being on holiday all the time!”* I wouldn’t wish my life on my worst enemy! Consider this: What is the first question someone you’ve just met at a party usually asks? *“What do you do for a living?”* I know it’s just a conversation starter, but it’s a hard question to answer honestly, without sounding like an invalid or a ‘sympathy seeker’. People also make a lot of assumptions based on your answer, the first one being whether it’s worth their time to continue to talk to you!

Not only do others define us this way, but we also define a big part of ourselves this way too. Once I had stopped working, I felt worthless. I have a strong work ethic and I felt I wasn’t contributing to society. It didn’t matter that I didn’t choose this way of life and didn’t want to continue like this. My self esteem and self worth plummeted very rapidly and I became very depressed.

### **Losing friends and potential children**

Before, I did not have to plan my activities around my need for rest, medication and pain relief. I could be spontaneous, impulsive and whimsical, doing anything I chose on the spur of the moment. To lose that ability is devastating. Having to plan activities days in advance is not only restricting, but becomes very boring, and even isolating. When friends ring up and ask, *“would you like to go out and grab some lunch today?”*, I would like nothing better than to be able to say, “that would be great.” However, I usually have to decline because I have not factored this activity into my day’s plan. It doesn’t take long for those friends to stop ringing.

Closer to my heart, I cried as I mourned the loss of ‘normal’ interaction with my future children. I had always envisaged being a mother. How could I possibly pick up a toddler? As it was, at present I couldn’t even manage to stand and hold my



friends' babies for more than a few minutes. And could I even carry a pregnancy to term? As drugs would cross the placenta, I knew I would not take them. I promised myself that if I was lucky enough to fall pregnant, I would remain drug free, even if it meant complete bed rest. I knew I could achieve this because it would be for a finite time and, more importantly, for a spectacular reason.

### **Losing intimate relationships**

Physical limitations even became an isolating influence within my marriage. My husband had always been basically supportive in the initial stages when we were still searching for 'the cure'. We could both accept temporary constraints, as long as we kept an eye on our immediate future, which in our minds was a return to normality. Once it became clear that our future was looking decidedly different from what we expected, it didn't take long for our relationship to change.

I would always try to minimise the effect my pain had on me so my husband would not see me as an invalid or a burden. I was more successful some times than others. I never asked my husband to help me around the house because of the guilt I felt. I kept telling myself, 'he's been at work all day, he should be able to rest once he gets home. I'm not working, so even if it hurts, it's my job to take care of the housework'. As a result I often felt frustrated, irritated and at times angry, because he never offered to help. At the time of our marriage, we both had the expectation that we would have an equal partnership. Following my injury, I felt more like an unpaid, albeit struggling, housekeeper rather than a lover and a wife.

### **The beginning of the end**

I had noticed that my husband, David, had been a bit withdrawn lately. Once it was clear that my physical limitations were to be permanent, he had become more distant. He had been working late, three to four nights a week. I had put it down to the stress of starting a new job. I had tried to be supportive, saying "I'm sure it'll get better once you've been there awhile and you've made some new friends."

He didn't seem to want to discuss it, so I decided to give him some space rather than be a 'nagging wife'.

David has just come back from a weekend away skiing and I have a strange feeling that something is wrong. "How was your weekend, did you have a good time?" I had hoped that a weekend spent doing something he loved would have been a physical release for his stress. He is hiding his head and, from the look on his face, I can see that this hadn't happened.

Looking at him, a 'light bulb' has suddenly gone off in my head. A thought that would have been unthinkable even a month ago, has just occurred to me. "Are you having an affair?" My husband turned to look at me as if to say 'where did that come from?' I breathed a sigh of relief thinking 'thank goodness, it's just my mind playing tricks on me.' Instead of protesting, he turned to me saying, "*well yes, I am.*"

I'm suddenly feeling totally overwhelmed. My world has suddenly come crashing down around my feet. Shaking my head in disbelief, I ask "who is she? How long has this been going on?" "*I work with her. I've been seeing her for a couple of months now.*" "So, those late nights you were supposedly working?" "*I wasn't working, we were together.*" My mind is racing and I have to get out of here!

I went for a walk, not paying any attention to where I was going, or even where I was. I can't believe this. I've been at home, worried about the stress my husband was so obviously under, doing my best to provide a stress free home life for him. All the while, it isn't stress I'm seeing, but guilt! I could understand it if he's had enough of living with someone in constant pain; I've had enough too! But to do it this way, that's what makes me so angry. Why couldn't he have done the decent thing and made the decision to leave me first, before finding my replacement? And why don't men have the guts to come out and tell you themselves? How long would he have continued this way, if I hadn't confronted him? It just makes the betrayal even worse.

Returning home, it feels like I am entering an alternate universe. This doesn't feel like my 'safe place' anymore. *"Don't worry Rachael, I'm not going to leave you."* I look at David incredulously. "Are you saying that you've been sleeping with a co-worker for two months, but it's not serious? I thought I knew you better than that."

That night, for the first time since we were married, we slept in separate bedrooms. It felt very strange! Over the next week or so I began to take an inventory of our life together. I knew that my back injury had been taking a huge toll on our marriage. I would have had to have been blind not to have realised that! I still thought, however, that considering everything, we had a good marriage. I, at least, had been happy.

The thought that keeps recurring to me is 'is it my back pain that is causing this rift, or something else?' I have to know. "David, why did you turn to someone else? Is our marriage so bad?" *"I want to share my life with someone who can enjoy life with me, including physical activities, such as skiing. She has an active lifestyle and can do everything I can, and more."*

We ended up separating, and ultimately divorcing. I was devastated. When David told me he was leaving me, I felt stunned at this earth shattering news. I couldn't see how the world could go on as normal, as if nothing had happened. I literally expected to see 'Rachael and David have separated', headlining on the evening news!

I took my marriage vows very seriously, and expected to be married 'until death do us part'. However, the section of the vow that covers 'in sickness and in health', is usually said in the glow of good health. Most of us, especially when we are young, have the 'it won't happen to me' attitude, and take this part of the vow as just something that is traditionally said. I think, for my husband, it took on a much more

sinister connotation when I became chronically ill, and a challenge he was ultimately not up to.

### **I was no longer ‘me’**

The loss of being able to do certain physical activities was nothing compared to how my changed physical abilities affected my body image. I no longer saw myself as I used to. I used to see myself as reasonably attractive, but I didn't have tickets on myself! I now can't bear to look at myself in the mirror. The reflection does not match my mental image of myself. I don't like what I see. There is this semi-hunched, lopsided person where I used to be. Not only that, but I have put on an enormous amount of weight. I have never had a weight problem before, but now that it is impossible to do any sort of exercise except a slow, awkward walk, it didn't take long for the weight to stack on. I feel like an elephant!

Following my divorce, I could not envision why any man would want to be with me. I feel that all any man will see would be my walking crutches, and would run a mile. I know how hard it is to live with chronic pain, and I cannot believe a man would choose to live that life with me, when there are plenty of able-bodied women around to choose from. I don't like, let alone love, my own body. How could a man love what I don't? I feel that I'm unlovable, that I am 'damaged goods'. I sometimes become quite sad and sit at home imagining myself alone, for the rest of my life.

I question why this has happened to me. What have I done to deserve this? It feels like I'm being punished. For a while I felt angry. Angry at my body for letting me down. Angry at the doctors who not only couldn't find out what was wrong with me, but blamed me for being in this situation; in chronic pain. Angry at the unfairness, the injustice of it all. Angry at the world.

### **Putting on ‘the mask’**

In the beginning, friends were amazed at how well I coped. Little did they know! They only see my ‘public face’. They don’t see me when I am at home alone, when I don’t have to hide my reactions to the pain, or my feelings. They only see me on social occasions, when I put on my ‘all is well’ mask.

### **A rare social ‘escape’**

I’m getting ready to go out to dinner tonight with friends. I don’t get to see them very often, as they are all working and have busy lives. Unfortunately, evenings are usually one of my worse times, as the effect of activity and gravity on my spine as I am upright throughout the day aggravates my pain. I have therefore spent most of today resting so that I can be in the best position I can be to enjoy a rare night out. I take care to apply my makeup well and to dress nicely. This is as much to give myself confidence as well as being the outer façade of my mask.

I like to drive myself for a number of reasons. Firstly, it means I can choose to leave any time I need to, if my pain becomes unbearable. I also find it more comfortable being the driver, as there are no unanticipated turns or braking which, if I haven’t braced myself correctly, jars my back. When I’m out, the car also offers me an excuse to go outside.

I make sure that I’m one of the last to arrive because there’s no use wasting good sitting time by myself. Walking into the restaurant I see my friends. “Hi, how is everyone? I haven’t seen you all for such a long time!” I choose a seat that will allow me easy access to get up from the table without disturbing my friends. *“Rachael, you’re looking well!”* “Thank you”, I say smiling. It always amuses me that I usually get this comment when I’m at my worst. I don’t know if I have an extra ‘glow’ in my cheeks, but it happens so often I don’t question it anymore. I never correct their impression of my ‘wellness’ and have learnt to accept any compliments I get gracefully.

*"What have you been up to?"* "Oh, catching up with family, stuff like that. What about you? Tell me what's been going on in your lives." I purposefully turn the conversation away from myself, as I find it difficult making small talk about what I do during the day because, unless something amazing has happened, I really don't have anything to say. In preparation for a social event like this, I always make sure that I at least read the newspaper headlines or watch the news, so if the conversation does lapse, I have something to talk about. People certainly don't want to hear about my pain. I've learned that the hard way!

I have become very good at suppressing my pain. I literally put up a mental barrier so that my brain doesn't receive the pain signals. I can maintain this barrier for quite some time. I help myself to do this by using a few 'tricks' I've developed. I can manage to sit at a dinner table for around half an hour if I can move around in the chair a little, to change my position. I don't make it obvious, but, for example, 'accidentally' drop my serviette so I can have a good stretch.

"I'm just off to the toilet" I say quietly to my friend beside me. "Don't worry if I'm away a little while." *"Sure Rachael. Everything's O.K. isn't it?"* "Of course, no big deal!" I slip quietly out of the restaurant and go for a walk in the cool air. Due to my medication, I get extremely hot even in cool weather. Tears are rolling down my face from the agony of the suppressed pain that is forcing its way to the surface.

Sneaking back inside, I'm now going to the toilet to give myself an injection to hopefully take the edge off my pain. Returning to the table smiling, I act as if I'm having the time of my life. It's astounding how little my good friends really know about me. They don't know that tomorrow I'm going to have to spend the whole day resting in bed as a result of tonight's outing; and possibly the same the day after. It is my choice to live like this. I don't, of course, have a choice as to whether I live with pain: that's a decision that's been taken out of my hands. I could sit at home, never going out and as a result have less pain. I choose not to live this way as much as I can because I am isolated enough as it is. Socialising

with friends is an important part of anyone's life and I'm damned if I'm going to miss out all the time!

When I get back, the conversation has turned to work. *"I've just got a promotion!"* says Noelle. We all congratulate her. "So, what does your new job entail?" *"I'm setting up a new birthing unit where I work."* "That's fantastic! Were there many applicants?" *"They interviewed about 35 people I think, but they got hundreds of resumes."* "You must feel great. That's a wonderful accomplishment Noelle." "And what about you Sandra, what's happening with your work?" *"Well, I've settled into my new position at the bank now and I'm pretty happy. With the kids being a bit older now, it means I have a bit more flexibility, which is great."* "Are you still up to your eyeballs at work Kirsten? Are you still enjoying implementing your new patient 'at risk' indicators on the wards?" *"It's very demanding, but very rewarding too."*

Listening to my friends discuss their career opportunities is difficult. I am very pleased for them; that they are progressing well in their chosen career paths. At the same time, it once again reminds me that I am continually slipping further and further behind my peers. Through no fault of my own, my career is stalled, perhaps indefinitely. What's worse is that I have to sit there, smiling. In my head I'm screaming 'this isn't fair! It should be me getting a new promotion or telling my friends how well *I'm* doing!'

Noelle turns to me saying, *"How do you cope, Rachael?"* Jokingly I answer "well, it's either cope or suicide, what other choice do I have?" I said this because I knew she really didn't want to hear a long, drawn out explanation of how I was suffering. I do appreciate her acknowledgment of my strength.

### **Coping with the never-ending pain and the inner pain**

What my friends don't know however, is that although I said my options were to either cope or suicide in a joking manner, it is actually not a joke, but the truth. I

have seriously considered suicide on a number of occasions and have attempted it once, but called someone at the last minute. This sounds dramatic, that I must have been either frantic or desperate, but I wasn't. It is surprising how calm and matter of fact I was. I was in such indescribable pain and looking at a future with more of the same. It was in fact an easy decision to make. I felt that I wasn't living; just existing. I have even planned how I will successfully take my life, if and when I choose to.

What stopped me from committing suicide? Guilt. That is the only thing that has stopped me on several occasions. I feel guilty about the pain I would cause to my loved ones. Even if I left a note explaining my actions and the reasons behind it, and made it clear that no-one was 'to blame', or could have done anything more than they are doing, I felt that people wouldn't understand and would suffer. I could not do that to them. And, I couldn't leave my pets. I think they, above all, are my saving grace, with their ever-present, all encompassing acceptance and unconditional love.

It surprised me that I reacted in this way. Prior to being injured, if you had asked me how I defined myself, I don't believe my answer would have even referred to either my work or family role. I didn't feel I needed anything or anyone else to complete me. I suppose, if asked, I would have described my personal characteristics, such as being a good listener, a caring person and intelligent. My injury has changed none of these attributes, yet I don't feel that I am the same person anymore.

I began to feel I was really losing my independence. I found it extremely difficult to ask for help, yet I really needed it as I was failing miserably with everyday activities. It's weird. I used to talk to elderly people and tell them that there was no shame in asking for help when they couldn't manage anymore. I used to say, "you've paid your dues, now it's your turn." I guess that's the difference though. As a relatively young adult, I expected to retain my independence. I had the expectation that, sometime in the future, in their twilight years, my parents may



need my help, which I would happily give. I did not expect to be in the position of once again requiring their help, or having them feel the need to help me. I felt like a child again and resented feeling this way.

### **Discovering and understanding the process**

Coming to terms with my chronic pain is an ongoing process. It is not dissimilar to the grieving process associated with death and dying. It has been a rollercoaster of emotions, some of which I have worked through, and others continue to this day.

Denial was my initial reaction, closely followed by disbelief and anger. Denial as an emotion wasn't available to me for long, as I was forced to recognise my circumstances. I do use what I call 'conscious denial' when I need to. This is when I'm in a situation where I can't, or don't want to, acknowledge my pain. I like to feel and act like a 'normal' person too sometimes!

I believe I have successfully dealt with my feelings of anger and the unfairness of it all. After all, none of us has a guarantee of good health, even though we all expect to live to a ripe old age and die peacefully in our beds. I think everyone is surprised when they become ill. It's just in our nature. I do still feel that I didn't make full use of my health while I had it and I regret that. The old saying that 'you don't appreciate what you have until you lose it' is all too true.

One of the classic stages of grief that I haven't experienced is bargaining. I have read that many people try to make a bargain with God. In exchange for a cure, they will promise to do, or give up, something. Even during the times I believed I would find a cure, it never crossed my mind. I have never particularly liked being this way, but now that I am, I feel I have to make the best of it.

As I have mentioned, I have also had periods of confusion, guilt, depression and despair, but thankfully not for some time. The emotions I continue to regularly

experience are most commonly frustration and isolation, and at times fear and uncertainty. At times it all gets too much for me and I feel totally overwhelmed. I want to hide under my bedclothes and say, “stop the world, I want to get off! ”

The hardest part of coming to the point of acceptance was that I felt I was giving up; that I was accepting failure. It took me quite some time for me to realise that acceptance does not mean giving up, giving in, defeat, resignation or submission. For me, acceptance now means coming to terms with reality and actively participating in life. I still have dreams and aspirations. The fact that they are now different from those I had prior to my injury just means that I have grown, just as ‘normal’ people do!

I now realise that if I concentrate only on the things I cannot do, on my disability alone, I will make myself miserable. I would sink deeper and deeper into depression. I have to concentrate on what I *can* do and on my remaining abilities. It was not easy at first, as my mind would keep reverting to negative thoughts, or I would be confronted with something beyond my capability. I was sick and tired of feeling sick and tired, and I recalled the saying ‘fake it until you make it’. In other words, to feel happy, first I have to act happy. I keep this in the forefront of my mind and try my best to maintain a positive attitude and a happy outlook.

## Story Three

### Walk a mile in my shoes

This story is written in the form of a letter. The letter is addressed to the next nurse who is to look after me in hospital; to doctors both past, present and future, who question the validity of my pain; to student nurses: my future carers, learning about the pain experience; to medical students: my future doctors. This letter is a heartfelt cry for understanding. It is written to everyone whose lives may intersect with mine, particularly healthcare workers. I want the nurses who look after me during my next hospitalisation to understand what I face on a daily basis. I don't understand why you appear to dislike me and don't believe my pain is real.

#### **Dear reader (*your name goes here*)**

I am writing to you so that, after reading this letter, you will be able to have *some* insight into what my life is like outside the hospital. When I come into the hospital, you can have no idea of the issues I face daily because of my injury and the severe pain it causes. I am asking you, as you read my letter, to actually imagine yourself to *be* a chronic intractable back pain sufferer. I want you to literally walk in my shoes and try them on for size. So, imagine that I have just given *you* a diagnosis of severe chronic nonmalignant back pain that you will have to manage for the rest of your life.

#### **Prior to my injury, I was just like you ...**

I took my health and my body for granted prior to my injury. I would think nothing about making plans weeks, months, even years into the future, confident that I could choose whether or not I wanted to fulfil these plans. We all think we're invincible; that nothing will happen to us. How often do you think about, or give thanks for, your health? My guess is that you don't. I certainly didn't.

#### **You will look forward to...**

Are you ready for severe back pain? I don't mean having a sore back, or a back ache. This pain is excruciating, agonising, unbearable and, at times the intensity is so high it is impossible to put into words. If the pain occurred only once in a while, I imagine that most people could deal with it for a short time, if they had to. However, your pain is not just for a short time and it is not intermittent. It is

constant. By that I mean you will suffer pain every minute of every day (and night), for the rest of your foreseeable life.

I can hear you saying to me: *“Ah, but you get to have really strong narcotic drugs that take away the pain.”* While it is true I am prescribed such analgesia, it never ‘takes the pain away’. I am prescribed my injections 3 hourly, and it usually takes between 30-45 minutes for it to work. That doesn’t sound a long time to wait does it? Well, when you’re in severe pain, time stretches. The hardest part to deal with during this time, is knowing that I could choose to have another injection straight away, as they are sitting beside me. I don’t, because intellectually I know doing that won’t make it work any faster, but the temptation is still there.

Once the injection has been absorbed, my pain is eased, but it is certainly not relieved. The edge is taken off my pain, bringing it down to a level that is just tolerable, as long as I use other methods of pain management I have learnt, such as meditation and hot packs. Of course, I don’t always have the luxury of being in a place where I can use meditation and hot packs. When I’m out, I have to use other methods.

You would think that if I’m ordered 3 hourly injections, they’d last 3 hours wouldn’t you? No such luck! I’m lucky if I get 1½ -2 hours of effect. Sometimes I feel no noticeable effect at all. I’ve spoken to a number of doctors, including anaesthetists, who’ve told me that it’s well known that injections only last 2 hours. The temptation to have more, that I spoke of earlier, really rears its ugly head now. Of course, once again I know intellectually more won’t work faster, but would it work better? Two things stop me from finding out. Firstly, and most importantly, I know my doctor has prescribed me the highest safe dose and most frequent usage available, and I am always compliant to his schedule. The second reason is that if I have extra earlier in the month, I will run out toward the end of the month. I would therefore be stealing from myself, because it’s not as if I can go down to the local shop and get some more. I would have to survive without and that’s unthinkable. How strong do you think your resolve would be? Can you resist such intense temptation?

Oh, by the way, if you're afraid of needles, hah! I'll bet you \$5.00 that you'll soon be begging your doctor to allow you to stick them into yourself as often as he lets you. You'll even look forward to them, not because you get a 'high' euphoric effect, but because they offer some relief from your agonising pain. Injections, of course, are not the only method of delivering analgesia. Believe me, if I haven't tried it, I've investigated it. I've met many chronic pain sufferers and most of them are treated with different methods. Not one of them has found a satisfactory answer. There are no easy answers.

And don't forget the tablets. A couple of them will be directly related to treating your pain. Many more, however, are to treat the side effects from your pain medication. Then you'll find you'll need more tablets, to treat the side effects resulting from the tablets you're using to treat the original side effects. Are you confused yet?

It may sound as if my life revolves around medication, and in a small way it does. My life actually revolves around my pain most of the time. I can assure you this is not the way I want it, but it is something I've had to come to terms with, and live with. It's something *you* are going to have to live with now.

### **Get ready for change**

Although I've described my pain intensity to you, you still can't have any idea of how bad it really is. It's impossible to put into words. Until you've experienced it, you can't know. I bet you think, '*she's exaggerating. She might not be able to cope with it, but I'll be able to*'. Do you *really* think so?

I suppose you think you'll be spending your time off having fun? Think again. Your friends don't have the 'time off' that you do, so you'll find you have a lot of time by yourself during the week. You might think now that that would suit you, but you'll soon find it becomes very tiresome. You can't just do anything you want. You've now got this little thing called severe back pain constantly holding you back.

At first your friends may be genuinely interested in how you are, but as time goes on you'll soon find they won't want to know. You'll soon learn that nobody likes to hear anyone who complains, even if you have good reason. You'll have to fake a smile and act like you used to, as far as that's possible. Of course, when people see you doing this, more often than not they'll think you're a fraud and a malingerer, leaving you feel judged and stigmatised.

Don't think things will remain unchanged at home either. Your relationship with your partner is very likely to change. During initial phases, most partners are supportive. But when it becomes clear that this is a lifelong change for you, the strain on your relationship is likely to take the greatest possible toll. You are no longer the person your partner committed to. This was definitely not a part of your future plans.

You will no longer be able to participate in any of the physical activities you used to enjoy together. Any extreme sports are automatically disqualified. Rockclimbing, bungee jumping, wet water rafting, the list goes on. Take skiing for example. You'll find it excruciating even walking in the snow, let alone skiing or snowboarding. You might think, as I did, that you could still go for the 'après ski' scene, and so still share the experience with your partner. I tried it once and never repeated my mistake again. The group of friends we went with were all eagerly off early in the morning and I didn't see them until dusk, leaving me alone to fill in my time as best I could. Trudging in the snow escalated my pain so much that I ended up having to rest in bed most of the time. My husband found it hard, seeing me in so much pain, but there was no point in him staying inside with me, when we had spent a lot of money to be there. Our 'friends' were not so sympathetic, as they thought I was putting on a martyr act to gain attention.

You may think skiing is an extreme example, but all physical sports and activities will be difficult for you now. With severe back pain, the most you can look forward to is slow gentle walking. You may be able to swim if you don't push it too hard, but it is possible that hydrotherapy is all you can manage. So how are you going to cope with having to give up all of your favourite physical pursuits?

Speaking of physical activities with your partner, I'm sure you won't be pleased to hear that your sex life will definitely suffer. Sex aggravates back pain intensely. You might try to hide it from your partner for the sake of your relationship, but it's something that can't be hidden. Unless a sadist, your partner won't want to inflict more pain upon you, even though it's unintentional. Unless you're a masochist, I'm afraid you're not going to enjoy it as much as you used to, if you enjoy it at all.

Coping with severe pain all day will also sap your inclination to make love to your partner. Dealing with your pain will not only make you physically tired. You will be mentally and emotionally exhausted. Lovemaking will be the last thing on your mind and so your sex drive will do a nose dive. You will probably accept your partner's advances occasionally, as you desire intimacy, but also because you feel guilty withholding sex. Things will deteriorate so much that you'll find that the frequency of your sexual activity decreases until it's nonexistent.

Sex is an integral part of a relationship. I know that intimacy can be shown in ways other than intercourse, but for a lot of couples this isn't enough. It also doesn't help that you'll suffer from insomnia. I found myself going to bed much later than my husband, as I hated having to lie there quietly, trying not to disturb him, just staring at the ceiling. Because of this, we even missed snuggling up together last thing at night.

The outcome of all areas of your life together drifting apart is, unfortunately, usually the end of your relationship. Most couples in this situation end up separating. It happened to me. I am now divorced. My husband told me he wanted to spend his life with someone who can share all of his interests, most of which were physical pursuits. This may seem harsh, or shallow, but I don't blame him. He met and then married someone who no longer exists. How do you feel now, knowing that your relationship is at risk?

It's not only your relationship with your partner that will change. Your relationship with your children will undergo a transformation as well. You are going to find it extremely difficult, if not impossible, to pick up your toddlers and carry them. You may even find it difficult to hold your baby unless you're sitting down. How are you

going to feel when your child is crying for you and you can't comfort her by picking her up as you would like? Believe me, it will break your heart every time.

Young children are wonderfully adaptable, but as they get older you will find that your pain causes *them* great distress. Seeing you in constant pain and not being in a position to do anything about it results in feelings of helplessness. They are also affected by your frequent hospitalisations. You will have to decide if and when it's appropriate for them to visit and see you as a patient, reinforcing their distress. Even so, whether or not they visit, you will still be separated from them; missing from the home.

As your children get older you are also going to find your role within your family has changed. You used to be the parent who looked after your children. Now, in many ways, your children have to look after you. Physically, you can no longer do the things you used to. Pain will also sap your energy to such an extent that doing even small tasks exhausts you. Household chores do not, unfortunately, take your changed health into consideration. Everything that you used to do around the house still has to be done. Regrettably, you will find that your children will have to bear some and, at times even most, of this burden.

Pain doesn't sap only your physical energy. Emotionally, you'll be drained as well. Your children will sense this even if you try not to show it. You'll find they start to mother you. At first it starts with them doing small things for you, such as making you a cup of coffee. Soon they'll be watching out for you, telling you to rest when they pick up your small unintentional cues that tell them your pain intensity is rising. Your roles will be reversed.

As your children grow up with you in pain, you are likely to feel guilty because they have to face issues and shoulder burdens that other kids don't. I feel that I am robbing my children of their childhood and adolescence. Just as my pain has made me age before my time, so too have my kids. I think at times my children resent the impact my pain has on their lives. They too ask 'why'? When children take on an extra burden, they often prefer to distance themselves emotionally. Inevitably the relationship suffers.



Financially, things are going to change too. You are no longer able to work, so you can't rely on your income. People who are able to claim some form of compensation, due to a work or road traffic accident for example, usually get a percentage of their basic wage. Those who have a non-compensatable injury find it extremely difficult to survive financially, especially with the cost of medications being added to the family budget. When you signed your mortgage, did you factor this injury into the commitment? I certainly didn't. Stressing about money worries is the last thing you and your family will want to do, but unfortunately it is now a part of life.

### **Putting your face on**

Unless you like playing the invalid role, you are going to have to modify the visible signs of your body's natural response to pain. It's not possible to totally eradicate every sign. Still, with a lot of hard work, concentration, willpower, as well as a great deal of energy, it is possible to mask most of them.

The easiest way to begin to establish this mask is by creating your external disguise. When seeing friends you'll find it important to dress well and wear makeup. Although this is only a superficial façade, you'll find it necessary on two levels. Firstly, it will affect how your friends think of you. If you don't do this, they'll think you're depressed and have 'given in' to your pain. Secondly, but more importantly, you'll find it makes a difference to how you feel about yourself. You'll feel more 'normal'; more able to 'fit in'.

As I said, the outward, superficial mask is the easiest way to display 'normality'. It is much harder to hide the pain itself. Take going out to dinner with friends, for example. Having a meal at a restaurant usually lasts around 3 hours. There is no way you will be able to sit that long, so you'll need to develop some strategies so that you don't draw attention to yourself, and be seen as disabled. This may sound as if I'm prejudiced against disabled people. I'm not. But see how you like being thought of as 'different', or even have people pity you. It's not pleasant.

Going to the bathroom is something that is ordinary to do, but can be used to your advantage. In the bathroom you have privacy, which is very important, as it is the only way you can have medication, including an injection, without people knowing. It also gives you the opportunity to do some stretches, which helps to release some of the muscle stiffness sitting in a chair for any length of time creates. It gets you out of your chair and walking too, which is a major bonus.

Unfortunately, you can't be going to the bathroom every five minutes, unless you want to look like you have a very weak bladder! The rest of the time, you're going to have to manage seated. Changing position can help to prevent and relieve stiffness. You will learn to occasionally shift subtly in your seat so nobody notices. Another ruse is to look for a 'dropped' serviette. These physical devices will help give the impression that you're not in pain. However, alone they will not be enough to complete the picture. The injection will help, but will not counteract the act of sitting for so long.

You are going to have to draw on mental strength that you have previously never thought possible. You will have to mentally suppress the pain, sometimes for hours. I sit there and imagine there is a physical barrier across my spine through which my pain signals cannot pass. Believe me, this is a skill that is going to take a lot of time to learn, if you can learn it at all. Pain signals are very persistent. I can manage to do this for as long as I need to. It's a skill I taught myself, and even psychologists are amazed I can do it. It is especially difficult when, at the same time, I have to be smiling and conversing. It takes a lot of energy to compartmentalise my thoughts and feelings, and is very tiring. Do you think you could teach yourself such skills?

### **Now for the rest of your social life**

Remember I said blocked pain signals are very persistent? Believe me, once I'm home the pain I've suppressed comes back with a vengeance. I can hardly get the key in the door before it starts. My pain levels will at least double that night, but that's not the worst part. For the next two days the intensity of my pain is indescribable, leaving me on bed rest, only getting up to go to the toilet and

possibly make myself a cup of tea. I could of course avoid this aggravation, by not going out and seeing my friends. I choose to go on such outings because I believe it's important to socialise with my friends.

I work on what I call my 'pay back system'. In other words, is the nature of the event pleasurable or worthwhile? If the answer is yes, then I'm prepared to take the consequences. I must plan ahead. One outing can obviously not follow another. Even though I feel I have the inclination and even the same willpower, the excessive pain intensity makes it impossible to sit even uncomfortably for more than ten minutes, let alone put up a façade. I simply cannot attend events frequently. Are you excited by the severe restrictions now placed on your social activities?

I can hear you saying, *'there are other social activities that are not physical. How about going to see a film?'* Sorry to disappoint you, but you'll find this problematic too. Once again, you're in a position where you'll be sitting for around 3 hours. You can use the bathroom excuse if you're happy missing part of the movie. Wriggling in your seat though, is not a popular act with the other patrons. I tried it once and the person behind me ended up kicking the back of my seat every time I moved. Not being able to stretch my legs because of the minimal leg room also caused me great discomfort. I hobbled out of the cinema and have never returned.

I have tried many activities that I thought would fit my needs, and have not been very successful. I thought seeing a local live band or poetry reading could work well. This time it wasn't sitting too long that was the problem. There was no available seating for most of the night, and when I did find a seat it was on a stool, hard to balance on and a very uncomfortable option for me. I may try this again, but next time I'll do my homework and ask about the venue to be sure that their facilities will cater for my needs.

At first, I never even considered that visiting friends in their home could be an issue. It never crossed my mind that their couches would be too low or too soft. I usually had to perch on the edge of the chair and had great difficulty standing up

again. I was embarrassed when friends offered to bring a dining room chair into their lounge room for me as it emphasised my pain and disability once again.

### **Everyone's an expert**

On the days you are unable to successfully mask all signs of your injury, people will ask you what has happened. They may have noticed something about your behaviour that is different. Although always severe, your pain intensity will be higher on some days. On these days there will be some signs, such as a limp or a difference in your posture, which you are unable to hide. If you tell them that you have injured your back, I can tell you what their most frequent responses are likely to be.

The most common response is, *"I have a sore back too. My back often aches after work, so I can really sympathise. Sometimes, my back is so sore I have to take panadol. I don't like to take tablets, so I only take them when my pain is really bad."* I hope you're good at holding your tongue, because you're going to hear this repeatedly. And if they're not talking about themselves, they'll tell you about a friend.

After hearing them describe their situation, you may feel that they have no right to compare their pain intensity with yours. Using the word 'sore' instead of 'pain' is usually followed by a description of less damage to their back. The fact that they are still able to work and only occasionally require over the counter pain relievers, also gives the impression that their pain is not having a significant effect on their daily life. Although this happens regularly, I always show them understanding, as I never devalue anyone's pain experience. In fact, I *always* tell them to look after themselves, with a warning that they really don't want to end up like me.

I hope you're ready to be given a lot of advice and recommendations for a whole variety of treatments and 'cures' too. Although offered with the best of intentions, I find it difficult to stop myself getting annoyed and even angry. Someone has a friend with back pain who has just undergone surgery and now is miraculously

cured, therefore I'm told I should try it. Someone has used a cream and their back pain is gone, so why don't I try it?

The list is unending and wide ranging. I don't deny that these people may have improved or even been cured. The trouble is, every back injury is different, so there is no 'one size fits all' treatment or cure. There is also the problem that I feel such suggestions are usually given in a condescending tone. I may be over sensitive. It may be because I've heard it all before, or heard another suggestion from the same person, but it's got to the stage that it seems *everyone's* an 'expert'.

The thing that annoys me most about such tips is that I feel they insult my intelligence. I have tried everything I think could help, including traditional and alternative therapies. I also know my pain management specialist is constantly updating his knowledge, within Australia and overseas, so I trust that he will know of *any* new treatments available, even unusual ones. How will you feel when people speak to you in this manner?

### **The 'f train'!**

The most annoying comment I hear all the time always comes from people who are genuinely caring and trying to inject a positive note. But, because I've heard it so many times, it's become a platitude; a cliché. I always smile and agree with them. Then, under my breath I say what I'd love to say out loud, but don't, because I know it would be cruel and would give the wrong impression. What is this comment I always hear, and my unspoken answer? *"Well, at least there's a light at the end of the tunnel."* "Yeah, and it's a fucking train!"

I told this story to a friend of mine who has severe chronic back pain too, to give her a laugh. She surprised me by saying she's had the same experience of hearing that comment all the time. For some reason I thought no one else heard it. Imagine my surprise when she said she felt the same; it had become a platitude, but the answer she would like to give was too rude. So, what's *her* unspoken answer? *"Yes, I'm in a long tunnel. My life is flashing before my eyes. I'm being*

*drawn towards the light...*” In other words, she is describing a near death experience! We had a good long laugh at the craziness of it all.

### **From compassion to suspicion**

People will frequently ask you how you hurt yourself. If you mention that it's a traffic accident or work injury, there's often a noticeable change in people's attitudes. Their manner rapidly changes from compassion to suspicion. Are you faking it for the mythical big payoff? Are you participating in the renowned fraudulent insurance scam? Are you in it for the drugs, either for yourself or to sell illicitly? How will you feel now, when people are literally thinking you're a criminal? Oh, be prepared that, at any time, you may be under surveillance and videotaped too.

Where do people get these ideas? Primarily from the media. How many times have you seen an exposé piece on television depicting someone claiming to have lower back pain being 'secretly taped' lifting heavy material? It's a regular feature on all the 'current affairs' programs. I'm not saying there's never been a fraudulent claim, but the frequency and repetition of this subject leaves people thinking that *everyone* is doing it.

News articles about worker's compensation and traffic accident claims always blame the 'blowout of expenses' on fraudulent claims, especially back injuries. Back injuries are considered easy to fake and so are easy to blame. Of course the insurance companies never look closer to home, at their own inefficiencies in dealing with their claimants. I know in my case, every time my case officer changes, the same repetitive questions are asked. I often have to go back to the start of a negotiation, or see even more doctors, when all the work for approval has already been done.

Stories about people selling their drugs on the illicit market are also starting to appear. I was amazed when I attended a conference for healthcare workers on pain management that they had a police spokesperson who voiced their concerns that this was happening. They had no direct evidence, only suspicions. What

surprised me was that many of the doctors seemed to agree that it was possible and every patient they spoke of had a back injury.

The distrust of people claiming to have sustained a back injury seems to run very deeply within our society, embedded in our culture, indeed into our psyches. One former WorkCover (worker's compensation) employee told me that the figure for fraudulent injury claims was actually only around 0.1 percent of all claims. It seems the distrust and stigma is hardly warranted, but it obviously makes a good news story!

I am even getting sick of the increasingly frequent television advertisements for over the counter pain relievers. *"If you have strong pain take ... [insert product name here]."* The tablets they are advertising are just slightly stronger than paracetamol. I suppose it is the examples they use that annoy me most. A man saying something like *"when I wake up, I have back pain. I take xx, so I'm able to work."* Then he is shown happily lifting big boxes at work. Give me a break! If he has genuine back pain, it's ludicrous to think he'd be able to do such work without causing serious pain and further injury. He isn't even using correct lifting techniques!

All of the ads vary, and thankfully for once they are not all about back pain, but they consistently use the terminology 'strong pain', and always include the outcome [after using their product] of being able to work. This bombardment is not only selling their product, but is, I believe, perpetuating the myth that you *should* be able to work, even with pain. Every time I see one of these ads, I feel as if they are, once again, pointing the finger at me. How will you feel after this continual barrage of how 'normal' people *should* be able to cope?

### **How about a holiday?**

Yes, you are actually allowed to go on a holiday. That's the good news. The bad news is, unlike a worker who takes a holiday from his work, *you* cannot take a holiday from your pain. It comes with you. In fact, you don't get evenings or weekends off either. This is a permanent gig.

You can, of course, go on a holiday. You will have to do a little more research than usual. You have to consider the environment at your destination. For example, if you're staying at a resort where the terrain is hilly, you may have trouble if you have to constantly negotiate stairs to get around the resort. Still, it's easy to find somewhere to suit your needs. You will find it difficult if the flying time is more than a few hours. You will also have to plan rest days too. You won't be able to go the distance like you used to. With proper planning, you can have a great holiday and I recommend it highly. If anyone needs to recharge their batteries and have a change of scenery, it's you.

### **Explaining the myths**

In hospital you'll be considered to be a 'difficult' and 'demanding' patient. I would like you to take a moment and consider it from my point of view. Chronic back pain patients admitted for pain management are generally self caring. We have learnt at home to do for ourselves, no matter how much pain we are in. The only thing we can't do in hospital is give ourselves our medication and that's only because we're not allowed to!

It takes a lot of courage to give up that control, especially when we know what happens to our pain when medication isn't provided in a timely manner. Believe me, we *know* that our nurses are busy. I am careful to make sure that the only time I use the buzzer is to ask for medication. I don't want to bother the nurses unnecessarily. I think this works against us in hospital though, because the nurses get the impression that we are 'drug seeking'. In a sense we are, but that is why we were admitted in the first place!

The main thing I want my nurses to know is that I don't expect them to be able to relieve my pain. I do, however, expect to be treated with respect and dignity. I would much rather work in partnership with my nurses, rather than be in an adversarial relationship. I would like to be able to negotiate my medication needs, either at the start of my admission or at the beginning of each shift. The only reason I ever become 'demanding' in hospital is because I am treated as a less



worthy patient than others. I *never* want to be in hospital, but when I am, I expect to be able to have my injections as frequently as my doctor has ordered them.

You never hear of a diabetic missing their injections, why should I be treated any differently? When I am ordered 3 hourly injections and on average only receive them 4-5 hourly because my nurses have been busy with '*really sick*' patients, then yes, I do start to become 'demanding', 'difficult' and start to 'clockwatch'. Can you blame me? I would love my nurse to pop in every 3 hours or so and ask whether I need an injection. If I could negotiate such a strategy and trust that it would happen, then I believe we would have a very different relationship. I know nurses don't have a lot of time, but I would really appreciate them occasionally spending some time just talking to me, with kindness.

### **Do we have a better understanding?**

So, I've painted a picture of my life for you. Does it sound as attractive as you thought it would be? I wouldn't wish my pain on my worst enemy. I certainly wouldn't choose it for myself! If you think you (or someone you know) would like to swap lives with me, I'll do it gladly. If you are working in a good job (or any job) and are in general good health, bring it on! Married, children, I'm not fussy. I now know when to count my blessings. If you're a fan of daytime television, you're in for a treat! I'll even throw in personal coaching on meditation, visualisation and self hypnosis. I'm an expert and believe me, as you embark on your new life, you're going to need it.

I hope now that you've read this, you'll think about me differently when you next see me. I want you to see me as a real person, with real feelings and needs just like anyone else. I hope you understand that I don't choose to be like this and that I'm doing the best that I can. Don't judge me by what you think you know about me. *Please* get to know me as an individual.

Yours sincerely

Penny

## **Chapter Summary**

No-one chooses to have chronic pain, to have their life turned upside down. Searching for a cure is a natural and normal action as we all want to get well and must investigate every reasonable avenue to health. However, once chronic pain becomes a reality, there is no choice but to deal with it. Part of this process is mourning the loss of the life and body that no longer exists in its previous state. This grief-like process is dynamic and ongoing and generally leads to some sort of acceptance which is necessary to be able to concentrate on managing and living with the pain.

## **CHAPTER FIVE**

### **HOSPITALISATION: AN INEVITABLE PART OF LIFE**

#### **Introduction**

Relatively regular hospitalisations are an inevitable part of a chronic back pain sufferer's life. Often for no apparent reason, pain intensity will spiral upwards until usual home treatments are no longer sufficient and hospitalisation is a necessity. At other times, it may be necessary to change medications. Commencing a new opioid and ceasing the current one must again be done as an inpatient. Some chronic pain patients also plan to be admitted to hospital as a part of their pain management regime.

#### **Story Four**

##### **Here We Go Again...**

My pain has been getting worse for weeks now and I'm really struggling to cope. I've tried using all my usual coping strategies, but when my pain is so high, they're just not as effective as they generally are. I've been putting off telling my doctor because I know he'll tell me that I need to be in hospital. I hate being in hospital so much that I would prefer to be on bed rest at home and suffer extraordinary levels of pain, rather than be in hospital.

I can't stand it any longer. I've finally had to relent and call Godfrey, my pain specialist. After explaining how desperate I am, Godfrey said he would find the first available bed for an emergency admission. After so many years treating me, Godfrey knows that if I say I need to be in hospital, I must be desperate! Unfortunately, it seems I'm going to have to wait 2-3 weeks for a bed due to shortages, even in the private hospital system.

#### **Trying for an 'open mind'**

Sitting in a hospital bed is bringing back a lot of uncomfortable memories. I just want to go home. I have to stop thinking this way. If I continue to remember past experiences there is no way this admission is going to be unlike the others. I have

to keep an open mind and hope that this visit will be different. I am going to have a positive attitude and assume that all will be well.

I've been waiting patiently for ages for my pain specialist, Godfrey, to come and admit me so that I can have some analgesia. At times like this, when I suddenly become a 'patient', I become very aware of the control I have lost over my environment. At home, I manage my injections myself and am able to have one when it suits me, once it's due.

Godfrey's rounds are likely to be hours away. He would not want me lying here in pain, especially as improved pain relief is the very reason I have been admitted. I have buzzed my nurse as I have decided to ask her to ring him. *"What can I do for you?"* said my nurse as she walked into my room. *"Could you call Godfrey, and get an analgesia order for me please?"* *"We don't like to disturb the doctors if it can wait until their rounds, unless it's an emergency."*

On previous admissions, the nurses have allowed me continue to have my usual medications until I've been admitted by my doctor. I asked my nurse whether that would be possible. Her response to me was a curt *"there's no way that's possible. You'll have to wait until he does his rounds."*

*"I will not be able to last without an injection until then. I usually have injections 3 hourly at home, and it's already been 5 hours since my last injection."* *"I'm sure you'll manage. Just lie down and try to relax. You don't look like you're in severe pain."* *"I suffer from severe chronic back pain. I am here because my pain is out of control at the moment. I don't 'look' like I'm in pain because I am very adept at hiding it, but I'm telling you now that my pain is extreme right now."* The nurse just shook her head 'no' and walked from my room without a word.

What a great start to my stay. I've calculated that I will have to wait another 3-4 hours until Godfrey is likely to come, which would make it 8-9 hours between injections. There is no way I can survive that long. I know that I will not be able to persuade my nurse to reconsider her decision. She has left me no choice.

I have just rung Ann, my doctor's secretary. Having attended his rooms for so long, she knows me well and I have a good relationship with her. She knows how desperate I've been at home, as she's the person I've been liaising with for the last three weeks. I informed her of my predicament and she's put me straight through to Godfrey. *"Catarina. I didn't even know you'd been admitted yet. I gather from what Ann said that you asked your nurse to ring me for an order?"* "Godfrey, I begged her to ring you! As I told her, it's already been 5 hours since my last injection. I knew I wouldn't be able to last until your normal visiting time." *"Don't you worry. I'll fix it up for you now, and I'll see you later, OK?"* "Thank you so much." I feel much better after speaking to Godfrey. I have no qualms whatsoever about ringing him directly because I did try to use 'official' channels without success.

Shortly after my phone call, my nurse walked in carrying my injection. *"Your doctor has just phoned through an analgesic order."* Her confident manner seems a little forced and I'm wondering whether she wants me to think that she's relented and phoned my doctor or that my doctor had coincidentally rung her, straight after our 'discussion'. Usually, I would let an incident like this slide for an easy life. This time, however, I think I'll call her bluff.

"Oh great! So, did you decide to call Godfrey after all?", I asked her in a conversational tone. *"When I thought about it, I decided that I should call him. After all, as you said, you have been admitted for pain control."* I can't believe she's looking me straight in the eye while she's blatantly lying to me! "I know that you did not ring Godfrey because I rang him directly and he was displeased that you hadn't rung him. Why do you feel the need to lie to me?"

My nurse just straightened her shoulders and without answering my question, proceeded to carry on. *"This is a rather large dose of Morphine. Are you sure you'll be able to handle it?"* I asked her what my doctor had prescribed. "That's my usual dose that I have every three hours at home." *"Since this is your first dose in here, I think we should start you on a normal dose and see how it goes. If it doesn't work, we can gently increase it each time, up to the prescribed amount of 30mg."*

“What do you consider a ‘quote’ ‘normal’ dose of Morphine to be?” “10mg.” “10mgs of Morphine is the usual dose that you give to your acute pain, or post surgical patients isn’t it?” “*That’s right.*” “Chronic pain patients are different to acute pain patients. I’m in too much pain to debate this with you now. If Godfrey has prescribed me 30mg, then that is what he knows I need. Please bring it for me now. I’m in serious pain and I can’t afford to wait any longer.” My nurse looked doubtful and began to argue with me again. I can’t believe I have to go through this every time I go into hospital. “I’m asking you to administer Morphine 30mg, as prescribed, straight away. I don’t want to have to ring Godfrey again, but I will if you force the issue.”

My nurse has gone to prepare my new injection. I already feel so frustrated that I want to walk out. I don’t mind discussing my medication with the nurses, but the problem is that it’s usually at the time when I’m in severe pain and at my most vulnerable. The only time the nurses talk to me about my medication is at administration times, a time when I’m not at my most relaxed! It also takes an inordinate amount of time and I am conscious that every comment further delays my pain relief. It has taken me a long time to be assertive. In the past, I would explain my thoughts to the nurses, but if I couldn’t convince them, I would begrudgingly accept defeat, suffer the consequences and wait for my doctor to fight my battles for me.

My nurse has just returned and given me my new injection. “*All right. Just to be safe, you’d better rest in bed for the next hour, and I’ll keep a close eye on you.*” It always amuses me when nurses say this to me. If I rested for an hour every time I had an injection at home, I’d be resting one out of every three hours; one third of my time. Besides, I find that it often takes up to an hour for me to feel the effect of an injection. In hospital, I am getting up just when it’s been fully absorbed and is therefore at its most potent. I’m in too much pain and too tired to argue the point at the moment and I don’t want to introduce any further conflict just now.

My hour of confined bed rest is finally over, so I’m off for a walk. The analgesia has taken the edge off my pain, but I need to stretch and walk for a while. I can never stay in any one position for extended periods of time. Although lying down is

my preferred position for comfort, hospital beds always leave something to be desired.

As well as my physical pain, I am fighting to retain my emotional stability. Having to fight the nurse before I've even had a chance to settle has really frustrated me. I am already feeling as if the walls are closing in. It's incredible how quickly this feeling overcomes me. Getting out of the room and sitting in the fresh air is like a pressure relief valve for me. I can sit and watch the passing parade for a while, or read a book and mentally turn myself back into a 'normal' person again, giving me the inner strength to return to the ward.

When my doctor came to see me I said, "I hope you didn't mind me ringing your rooms. It's just that I was in so much agony and the nurse refused to ring you, and I knew I wouldn't be able to wait until now." *"Of course not Catarina. In fact, when I rang the ward, I asked to speak to your nurse personally. I told her I was absolutely furious with her for not ringing me, and that she had better bring you your injection as soon as she got off the phone. I couldn't believe she had left you in pain for so long, and I told her so!"*

"Could you speak to the nurses about my Morphine dose? The nurse earlier wanted to commence me on 10mg, even though you had just given her an order for 30mg. I explained that 30mg was my usual dose at home, but it was only when I threatened to ring you again that she relented!" Godfrey shook his head in frustration, told me he'd sort it out and then we spoke about the plan for my stay.

### **Sharing the space**

I am in a two bed ward. The other patient, Emily, is an elderly lady who is very pleasant to chat to. We've been chatting during the afternoon. She's due to go home tomorrow or the next day and she's anxious to go home. She's had a bout of pneumonia, which is thankfully over. Her doctor has kept her in for a couple of extra days because she lives alone, which she is finding very frustrating.

The nurses are settling their patients for the night, so I'm going across to talk to Emily, as it's our first night together. "Emily, do you think the light from my television will bother you during the night? I use earphones, so you won't hear anything and I keep the curtains drawn. The only thing that may bother you is the flickering light from the TV. If you think this will bother you, I'll turn it off as soon as you're ready to go to sleep." *"The nurses give me sleeping tablets and I usually sleep right through the night. You go ahead and watch your TV. I'm sure it won't bother me."* "Thank you Emily. Promise me that you *will* tell me during the night if it does bother you." *"I will Catarina. I hope you get some sleep."* "Hopefully we both will."

In hospitals, the nurses always settle their patients for the night around 9 pm. This is extraordinarily early for me because at home I don't usually even attempt to sleep before midnight. It's different for me here too, because I am not 'sick' in the traditional sense of the word, as other patients are. I always have difficulty sleeping. My pain makes it hard to get comfortable enough to get to sleep and usually wakes me 3 to 4 times overnight. I usually average only about 4 hours of sleep a night.

During the night, the nurses came in a couple of times and complained that my TV was bothering Emily, who was, each time, asleep! I explained that I had negotiated my night TV use with Emily. They seemed unimpressed, but left me to it. I went for a couple of walks early in the night and then settled down to try to sleep. I find the best way that suits me is to drift off in front of the TV. I know the experts say this is not ideal, but it drives me batty tossing and turning and staring at the ceiling for hours. I finally drifted off to sleep and suddenly woke with a start. The nurse has just turned my TV off. "Why did you do that?" I asked sleepily, and a bit tersely. *"You were asleep, you didn't need it on. Besides, it bothers the other patients."* I looked at my clock and realised I had only been asleep for about 15 minutes. "Turning off my television immediately wakes me up, as I sense the change in my environment. I have *a lot* of trouble falling asleep, so in future could you *please* leave it alone!"



It is finally morning. I managed to get a few hours sleep eventually, but of course was waken at an ungodly hour (for me), by the day staff marching around, chatting together loudly and opening the curtains. “Good morning Emily, how did you sleep?” “*Very well thank you, Catarina.*” “Did my television bother you overnight?” “*Not at all, I didn’t notice it.*” “That’s good. The nurses hassled me all night about it, saying I was bothering you.”

### **Differences in care**

During the day I’ve noticed a difference between when Emily rings her buzzer and when I do. If Emily rings, a nurse generally appears within about 5 to 10 minutes. When I ring, I usually have to wait 20 minutes for a nurse to respond. This has been a consistent difference since I’ve been here. I’ve noticed too, the nurses’ general demeanour and tone of voice change depending on whom they are talking to. With Emily, who needs a higher level of care than I do, they smile, are very cheery and bright, chatty and banter with her, and take the time to sit and talk with her. In contrast, when they are dealing with me they are brusque and often abrupt, and spend only the minimum amount of time with me that they can.

It feels as though the nursing staff consider me to be a ‘second-rate’ patient, not deserving any more of their time than is absolutely necessary. I tend not to have a lot of medical technology surrounding me, all the ‘bells and whistles’ that attract their attention. As I said earlier, I am not a typical surgical or medical patient requiring a lot of hands on nursing care. What I do miss, however, is the ‘care’ in nursing care. When a nurse takes even a few minutes out of her busy day to sit and talk with me and really listen to me, I feel valued and validated, and it means a lot to me. One nurse taking the time to learn and understand my needs and expectations can make a huge difference to my interactions with the other nurses, as she plays the role of patient advocate.

Emily was discharged later in the day and I have the room to myself for the moment. While I enjoy the freedom of not having to worry about disturbing others, I do find it incredibly quiet and boring, and the days seem interminably long. As

beds don't stay empty for long, there is also the constant wonder of whether your next roommate will be a horror or a delight.

### **A friendly face: rekindling a friendship**

*"You'll be getting a new roommate today, Catarina"* a nurse said as she made up the other bed. Hopefully, it will be someone friendly and easy to get along with, or at least someone who is not too sick, so that I don't have to be really quiet. I generally like the company of other patients. I have found single rooms to be very isolating in the past, as the nurses only come in when they have to.

*"Hello stranger."* I had been dozing and hadn't noticed the arrival of the new patient. Turning over, I saw someone I had made friends with a few years ago, when we shared the same hospital room. She too had severe chronic back pain and was also under Godfrey for her pain management. "Lilly! How are you? Not great I suppose, since you're in here! It's so good to see you. When they told me a new patient was coming, I was hoping it'd be someone I could talk to, but I didn't dream it would be you!"

"Did you have to wait for a bed?" I asked Lilly. *"Yes, I've waited a week to get in. What about you? How long have you been here?"* "I had to wait 2 ½ weeks. I've only been in for a couple of days. Did you do what I did and wait until you were absolutely desperate before you made the first call?" *"Oh yes! I hate hospitals so much I always do that. We'll never learn will we?"* We both laughed.

We spent the day catching up with what had been happening in each other's lives, and gossiping about news of other pain patients we have both come to know. They are not all back pain patients. I know patients suffering from a range of different painful conditions. I usually find there are at least one or two other pain patients that I know in hospital at the same time as I am, and there's a healthy 'grapevine' about the group that fills me in about the general condition of the others. I find it actually works well as an informal support group while I'm in hospital.

As pain patients, it seems a lot of us have the same habits, such as needing to walk and sit outdoors in the fresh air. We therefore meet up with each other in the courtyard downstairs. We don't schedule meeting times, but it's rare to go out and find no one else there. Each patient has the choice to release only the information about themselves that they want to be common knowledge, as it's understood that people are concerned about others in the group and ask about them.

Personally, I refuse to discuss my medication. I generally don't discuss this anyway, but as it happened when I first joined this informal group the others were all discussing their medication. They began asking their doctors about what other patients were on and it almost became a competition as to who was on the most. I decided that I wanted to keep my treatment private to avoid this, although sometimes it is quite difficult as some patients really want to know. I know it's only because they're desperate to find the best treatment available. I have learnt just to say that it is something I don't discuss and leave it at that.

### **Struggling against inevitable labelling**

As Lilly and I are woken at the same time in the morning and we both always wake in pain, our injection times have synchronised. This also assists us during the day, as when one of us buzzes the nurse, the other can ask for their injection at the same time. As it generally takes our nurse around 15-20 minutes to respond, it certainly saves us waiting time. It is actually helpful for our nurses too. Because our injections come under the 'drugs of addiction' category, the protocol is that there must be two Grade 1 Registered Nurses double checking each stage of the drawing up and delivery process. The nurses always say that, because they are all busy, it is hard to find another nurse to do the checks with them. As they can prepare and deliver both of our injections together, it saves them time.

Lilly buzzed about 15 minutes ago and a nurse has just responded. *"Could I have my injection please?"*, asked Lilly. I waited until the nurse had finished with Lilly, and then as she started to walk past my bed I asked, "Could I have my injection too please? I think you'll find it's due." Without a word, the nurse grabbed my chart, checked it and walked out of the room before I could even say thank you. *"Did you*

*see the way she rolled her eyes at you?"* Lilly asked me. "Yeah, I caught that. I think she sees my request as some type of conspiracy."

Two nurses came in and individually checked and administered our injections. "You girls look well today", said one nurse brightly. "Thank you", I said smiling. She then looked directly at Lilly, as if waiting for a response. "You look bright and happy too", said Lilly in reply. I noticed what I can only describe as a 'sly look' pass between the two nurses, as if it had been a test and we had just failed. "Did that seem strange to you?", I asked Lilly once the nurses had left our room. "What do you mean?" "Well, I might be paranoid, but I found it very unusual the way that, once they were finished, one nurse brightly said how well we were looking. Usually, they don't bother to chat with us; they hardly ever speak to us at all."

"After I had said 'thankyou', and smiled at her, I watched her turn and look at you, until you responded", I told Lilly. "They did look very strangely at each other when they went out, I did notice that." "I think they expected us to say something like 'my pain is really bad at the moment', because they had just given us both injections. "That really frustrates me," said Lilly. "I get so sick of being judged on how I look and act. I don't ask for an injection unless I need it. What do they think I do? Wait until I'm feeling bored, then say to myself, 'I might as well have an injection now, I've got nothing better to do'."

### **Sharing stories**

Lilly and I decided to wander (or more correctly slowly hobble) downstairs to clear away the cobwebs and buy a decent cup of coffee. The hospital has a nice café with both indoor and outdoor sitting areas. We sat at a nice table outside in the courtyard. It's lovely to feel the sun on your face and the breeze gently blowing. I love sitting and watching the almost tame sparrows that cheekily hop around gathering crumbs. It only takes a few moments in the fresh air for me to return to my 'normal' self again, shaking off the patient role for a short time.

We had been sitting there for about 5 minutes when three other pain patients joined us. I had met Sarah, Rose and Anne over the last few years in this very

courtyard. We caught up with what had been going on in our lives and what had brought us in here. These people act as an unofficial support group. It is only among such company that I feel truly understood and comfortable talking about my pain. Everyone here has had startlingly similar experiences, so long explanations are unnecessary. We usually end up laughingly finishing each other's sentences.

Meg came over and joined the group. *"Can I borrow a cigarette from someone? God, I'm frustrated. Those fucking nurses have been pushing me from pillar to post all week!"* Everyone chimed in at once, offering support and giving her a hug. After a minute, Rose said smilingly *"shut up everyone, let Meg tell us what's happened."*

*"I can't do anything right"* Meg answered. *"One nurse tells me to do something, so I do it, and then I'm told off by another nurse for doing it. For a couple of days, I've been putting up with it, not wanting to make trouble."*

*Just now was the last straw. I'd finally been given an injection after waiting for half an hour, as usual. I was told to rest in bed for an hour, so that's what I was doing. About 3 minutes went by and another nurse came in – one who's been on my case – and told me to 'stop being lazy and get out of bed'.*

*'Don't do this to me again please', I begged the nurse, as I began to get out of bed. 'I was only doing what I was just told. Don't you nurses communicate with each other?' Out of frustration, without realising, I raised my voice a little and the tone of my voice became sharp. The nurse turned round to me and said extremely loudly, 'I don't know who's told you what, but I am telling you to get out of bed right now.' The nurse stood there with crossed arms, and watched me slowly get out of bed, as if she was checking that I would do as she said. 'I am getting out of bed,' I told her. 'I can't spring out of bed at the drop of a hat.' Just then the first nurse came into the room. She couldn't see the other nurse because her view was obstructed and she obviously didn't know she was in my room because, as she stormed in she yelled, 'Megan, what is all this noise, and why are you already out of bed when I told you not 5 minutes ago to rest in bed? I'm very annoyed at your*

*disobedience and your attitude, Megan.’ Pointing towards the other nurse I told her, ‘That’s why I’m out of bed. I’ve had enough of your games. I’m not too happy with your attitudes either. I’m going for a walk. While I’m away, maybe you can both agree what my treatment is to be!’ One nurse tried to stop me and I just shook my head ‘no’, and pushed past her.”*

“Regardless, we’re always treated as difficult patients, aren’t we? At least you finally stood up for yourself though. I don’t know whether I could stand that sort of treatment for so long.”

“*And demanding*”, piped Sarah. “*I mean, what do we demand? The only thing we ask the nurses to do for us is to give us our medication and that’s only because we have to.*”

“*Yeah*”, Anne responded. “*It doesn’t matter how much pain I’m in, or how disabled I am, I always shower myself, dress myself, and generally look after myself. I even bring my pick-up stick in because I learnt early on that the nurses became very cross with me if I asked them to pick up something I’d dropped.*”

“And why do they think we’re lazy? I suppose it’s because we can’t work. I would give a lot to be able to work again. And, like Meg, I’ve been accused of both staying out and in bed by different nurses.”

Rose laughed, saying, “*have you ever noticed how differently they treat you after a painful procedure? It’s ‘can I make your pillows more comfortable?’, ‘would you like a hot pack?’, ‘do you need help turning over?’, or ‘is there anything else you need?’. It’s laughable. I feel like saying ‘why don’t you treat me with the same respect when I’m in here for pain management?’*”

“That’s interesting” I said. “Why don’t we say such things to our nurses, point out their inconsistencies and discrepancies? I don’t know why I go the extra mile, trying to be the ‘perfect’ patient. I am always so frustrated, but I just sit there and take it.”

Everyone agreed.

After further chat, laughter and general merriment, Lilly and I pottered back to our room. We felt refreshed following the stimulation of pleasant company, the warmth of sunshine on our backs and a lovely view.

### **Striving for normality: putting on a face**

*“How about a nail painting session?”*, asked Lilly. “Great idea.” Lilly and I had had great fun in the past doing our nails. Besides passing the time, which is difficult to do in hospital, it’s a chance to have fun and for us to be ‘real’ people again. We painted each other’s fingernails and toenails outrageous colours, adding decorative stickers to add to the effect, which made us have a good laugh.

Lilly is an inspiring person to watch in hospital. She is naturally very tall and beautiful and has a lovely spirit. Lilly meticulously applies and maintains her makeup each day, no matter how she’s feeling. She always wears gorgeous silken pyjamas and a long flowing silken gown. She honestly looks like a movie star. I understand why she takes such care. I use similar tools, although the resulting package is not quite as attractive! At night I wear the usual cotton nighties, but during the day I always wear comfortable and colourful day wear. The reason is not as obvious as looks would have it. What other people think of us is not important. What matters is how we feel within ourselves.

Wearing makeup and dressing in clothes not usually worn in hospital helps us to feel less like patients and more like everyday people. So many nurses don’t understand. It makes me laugh because when a nurse sees me in day clothes in the morning, she says in surprise, *“I didn’t know you were going home today Catarina.”* It’s an outer layer both literally and metaphorically.

For me it forms part of the mask that I put on when I’m not alone. Putting on a face for the public is a way of distancing myself from my pain and its associated problems, so I can socialise and function as normally as possible. Of course, when I get home and can drop the façade, I pay the price with an associated increase in the intensity of my pain. My mind seems to store a memory of all the pain I would have felt and then releases it once the façade is dropped.

Needless to say the nurses don’t have any understanding of this coping mechanism that is part of our lives. Whilst we were having fun doing our nails, a

few nurses stuck their head in when we were laughing, then frowned and moved on. It felt like we were the unofficial sideshow for the shift.

*“Obviously we’re not allowed to have fun”* said Lilly. “No. The nurses expect patients in pain to be writhing around the bed in pain, moaning. They don’t realise that I’d have to be on my deathbed to react in that way.” *“Chronic pain patients have had time, usually years, to learn to deal with their pain. Acute pain, on the other hand, takes someone by surprise.”* “Yes. They’re surprised, scared and often shocked at the intensity of their pain. It’s natural for them to be in bed, to move and moan with the pain. The nurses are so used to caring for acute pain patients that they believe this is the only true representation of severe pain.”

### **Nurses know best**

My pain is going through the roof, so I’m checking my notebook to see when I last had an injection. I write it down because I can never remember when I last had one. The nurses get cross if I ask them when my injection is due. They see it as ‘drug seeking behaviour’. All hospital days seem the same, because the hospital routine never changes. When I try to remember times, all the days and times merge. I can’t remember if I had it at 11 o’clock today, or was that yesterday?

The nurse has come after I rang her for an injection. After looking at my drug chart she’s turned to me saying, *“you’re not due for another 15 minutes.”* “I realise that. I’m asking you now because by the time you prepare it and bring it back, it’ll be due.” *“We don’t do it that way. Ring again in 15 minutes, when it’s due.”* I’m in so much pain, and I am in no mood to put up with such disrespect and disregard for my pain.

“I am prescribed 3 hourly injections am I not?” *“That’s correct.”* “Do you know that I am lucky to get them even 4 hourly in here? Sometimes it’s closer to 5 hourly, because you nurses make me wait so long. There’s no point me being in here if I can’t get my injections on time. I may as well be at home. At least there I’m the one in control. What is the purpose in telling me to ring again in 15 minutes when I’ve just told you what I need?”



*“You have to wait and follow the rules like everyone else.” This was incredible! “How do you know so precisely when your injection is due?” Before I could answer, my nurse started to examine the clock on my bedside locker. “Do you set your alarm for when it’s next due?” “No. I don’t need to set an alarm to remind me. My pain is a remarkably accurate ‘internal alarm’ as to when my injection is about due and it’s one I could certainly do without. You see, it takes up to 1 hour for it to be absorbed, and then I get approximately 1 hour when my pain is at its lowest intensity. At the end of the second hour, my pain intensity shoots up again and I spend the third hour with pain that’s back up to pre-injection levels. If I had my way, I’d have 2 hourly injections, but unfortunately that’s not possible. That is why I’m desperate for my medication as soon as it’s due. As it’s now due in a couple of minutes, perhaps you could get it for me? Thank you.”*

*Once the nurse had left the room, I turned to Lilly with a raised eyebrow. She grinned saying, “that was a bit full on wasn’t it? I thought she was going to do a locker search or something.” Now that I think about it, that conversation explains her behaviour earlier. You were resting with your back to the door and I was watching the TV. I saw that particular nurse hovering outside our door regularly and I thought it was a bit odd because she didn’t seem to be doing anything when all the other nurses seemed to be scurrying about. Thinking back, it was around the times our injections were due. I think she was ‘spying’ on us, trying to determine how we knew when our analgesia was due.” “I wish they would just ask! Why do they have to be so suspicious of us?” “I know. Anyone would think we were criminals.”*

### **Here we go again: playing the waiting game!**

Lilly has just rung for an injection and is once again playing the waiting game. As time passes, I can see she is getting more and more desperate. At first, she was resting in bed, chatting to me. She’s now out of bed, pacing, pacing, pacing. The more time passes, the faster she’s pacing. I can tell she’s starting to get into trouble. She has already waited 25 minutes for her buzzer to be answered. I’ve decided to poke my head into the corridor, to see if I can find one of the nurses

dealing with us today. I don't recognise any of the nurses sitting at their desk. Why isn't anyone answering Lilly's calls?

Unfortunately, today our injection times have not synchronised, so Lilly couldn't utilise the nurses' appearance with my analgesia to ask for her own. Watching her, and knowing her, I recognise some of my own coping mechanisms and so can gauge Lilly's current pain intensity. Her pain is obviously very high and I can see she's becoming stressed.

Looking at the clock, I've just realised that Lilly has now been waiting for 55 minutes, despite both she and I buzzing again. "I've had enough of this Lilly. I'm going to go and see if I can get things moving for you." It's weird. I always find it much easier to advocate for someone else when, if it were happening to me, I'd probably put up with it and just be a bit grumpy with the nurse when she finally arrived.

"Excuse me", I said politely to one of the nurses at the nurses' desk. She looked at me and then looked enquiringly at one of her colleagues, who whispered something to her. *"I suppose you've come to ask for more drugs again?"* "I've come for my roommate actually. Could someone come and organise her analgesia please? She's in extreme pain and needs her injection." *"Why hasn't she buzzed? Oh, I see she has. Who's looking after you today?"* "If you mean 'what is my nurse's name?', I couldn't tell you. For some reason our nurses never introduce themselves." After some discussion with the other nurses, she said, *"your nurse is Amber and she's at lunch. You'll have to wait until she returns."*

This is outrageous! Standing my ground, I said, "Lilly has already waited 55, no, it's now 60 minutes for her buzzer to be answered. Surely one of you can tear yourself away from your chat and go to her? I'm not leaving here until you do, or until I speak to the unit manager. I find this disgraceful." The nurse looked at me seriously, crossed her arms and said, *"Catarina, please return to your room. A nurse will be there in about 5 minutes."* I purposefully looked at the clock above her head to indicate my determination and returned to my room.

"A nurse will be here in 5 minutes", I told Lilly as I entered our room. *"Thank you Cat. Did they say what the problem was?"* "It seems our nurse is at lunch and they hadn't even noticed you'd buzzed. You'd think they would have organised someone to look after her patients while she was away. That's what they usually do." *"It wouldn't surprise me if she forgot about us altogether"*, Lilly said with a weak smile.

The nurse that I had spoken to at the desk has just walked into our room and over to Lilly's bed. I'm lying on my bed with the curtain partially drawn, to separate myself so the nurse won't feel I'm interfering any further. Lilly was cycling between pacing and sitting on the side of her bed. *"So, I'm told you have some pain. Where is it?"*, the nurse asked Lilly. *"In my lower back, where it usually is"* said Lilly sarcastically. The nurse picked up Lilly's drug chart. *"OK, let's have a look. You're ordered a few things for pain. I'll get you some panadol and see how that goes."*

*"Panadol?"*, exploded Lilly. *"You might as well give me a fucking lolly!"* The nurse looked unimpressed and said, *"I've found that panadol works well for a lot of my patients. Why don't you try it and if it doesn't work we'll see about something stronger. Besides, you don't look like you're in severe pain, the way you're walking around."* Lilly looked furious. *"I do not believe this. I was admitted because my chronic back pain was out of control. If you care to examine my drug chart, you'll see that I'm ordered Morphine injections 3 hourly, which I've been having as regularly as I can get it in here. The only reason panadol is on my chart at all, is because I asked my doctor to prescribe it, as I get frequent headaches. My injection is now well over an hour overdue, so will you please get it now!"*

Lilly finally had her injection and we spent the next couple of hours resting on our beds chatting quietly. It was then time for my injection and, after waiting the obligatory 30 minutes, my buzzer was answered. You can imagine my delight when it was the same nurse I had spoken to at the nurses' desk. She was smiling as she entered, but when she saw me her smile froze. *"What do you want now?"* "Could I have my injection for pain now please?", I asked quietly. Without a word she grabbed my drug chart and strode out of the room. When she hadn't returned

in another 40 minutes I buzzed again because I thought she might have forgotten me.

When no one came, I decided I'd better wait as patiently as I could. After my earlier confrontation with that particular nurse, I didn't want a repeat performance. Lilly asked if she could help, by doing for me what I had earlier done for her. "Thank you, but I get the feeling that it wouldn't be a good idea. She was not amused when I advocated for you. In fact, I was sent to my room like a naughty child! If you reciprocated, I think she'd see it as some sort of conspiracy. I've decided to wait and see how long it takes her to respond. If I lie here without moving at all, I can just about 'hold on by my fingertips', as a friend of mine likes to say."

A further 35 minutes has passed. The nurse has finally walked in carrying my injection. "Oh, thank God you're here." Although I said this with relief, she seemed to take this as a personal criticism. *"You're lucky I'm here at all. We've been attending to really sick patients."* I have heard that particular response on so many occasions and it really hurts, because it makes me feel like the nurses consider me to be a second rate patient.

I started to turn on my side so the injection could be administered. I was obviously not moving quickly enough for her because she put her hands on my hip and started to firmly push me. I froze saying sharply, "don't touch me. I am in so much pain, it has caused my back to be in complete spasm. I have to do this slowly by myself." *"If you ask for an injection, you should be ready when we come. We don't have time to wait around all day while you move yourself."* This was too much. "I did turn on my side after you took my drug chart to be ready for you. That was an hour and 15 minutes ago. I cannot stay in the same position for that long and, since there was no sign of your return, I made myself comfortable."

After giving me my injection, the nurse looked at me and said, *"you know you're addicted to this stuff, don't you? That's why you're so cranky now. You're in withdrawal."* "You've got your terminology wrong", I said tiredly. "I am *not* 'addicted' to my medication. I may be physically dependant, but that's entirely

different. And, I am *not* in withdrawal because of your slow delivery of my analgesia. That takes a day or two to start to manifest.”

I was tired and in pain, and quite happy to leave the discussion there. My nurse, however, seemed to have other ideas. Apparently she didn't like to be corrected. *“Everyone knows morphine is addictive.”* “Yes, morphine *can* be addictive. According to the literature, chronic pain patients are the least likely to become addicted. In fact, they almost never become addicted. Do you know the difference between addiction and dependence?” *“It’s just terminology. The words are basically interchangeable.”*

I took a deep breath and said, “No, they are not interchangeable. Addiction refers to the psychological need for a drug. The reason people usually become addicted to a drug is because they experience a euphoric state or a ‘high’ from it. They continue to use the drug because they are forever searching for that same ‘high’. I have *never* experienced such a state. The only reason I continue to take it is because it treats my pain. If, by some miracle, I had no pain, I would cease to use it. I’d be jumping for joy in the streets!”

“Dependence is different. Continually taking such medication means that the body physiologically adapts to the drug in its system. There is no psychological component to it at all. There are some withdrawal symptoms if it is withdrawn suddenly. When it is decided that a chronic pain patient is to cease taking their medication, it is usually withdrawn slowly, minimising or even alleviating withdrawal symptoms.”

“People think we *want* to be on medication. And, if our analgesia happens to be injectable, we are treated as if we are junkies or criminals. We have the right to have our pain treated using the best available methods. Tell me, if I was suffering from spinal cancer and was ordered the same analgesia, would you hesitate to administer it?” *“Certainly not. Spinal cancer is extremely painful so I would try to make them as comfortable as possible. We often ring their doctors to see if there is anything else we can do.”* I noticed she said she would make ‘them’ comfortable

when I had asked her to imagine I had cancer. I didn't correct her, but it makes me feel even less validated; as if she couldn't even imagine *me* having 'real' pain.

"You might be interested to know that I was referred to an oncologist here for a second opinion of my pain management regime. He told me that my pain intensity was equivalent to that experienced by someone with spinal cancer." *"Oh, I don't believe that! Cancer patients act entirely differently."* "I don't suppose you would believe me. Cancer patients obviously act differently because they are ill at the same time. The oncologist was referring to pain intensity alone, as I said. It's in my medical notes. I have no reason to make it up."

"I can see by your attitude that you don't believe in the intensity of my pain. If some of you sat down with your chronic pain patients and just talked to us, you might find it a lot easier to deal with us if you understood us a little better. I don't know about you, but I am exhausted by this eternal struggle between us that happens day after day. It's psychologically traumatic." *"I don't have time to sit and chat. I told you, we have really sick patients here."* "You know, part of nursing is assessing your patients and, if you're going to assess me, then you at least have to make some time to have a basic understanding of my needs and my expectations." *"As far as I can see, the only expectation you have is to have your drugs as soon as you snap your fingers."* "Just when the doctor has ordered them actually", I said sarcastically, "but if you talked to me you would understand that I actually only seek caring and understanding from you." *"You've wasted quite enough of my time"*, she said over her shoulder as she strode from the room. It seems our 'conversation' is over.

### **'Hardened criminals'**

Lilly turned to me. *"You might have been joking about people treating us like criminals, but it's actually a real suspicion for people in the pain management industry. I've met a nurse who has severe back pain like us. She went to a conference with pain management professionals. The theme for that particular conference was chronic pain. One of their keynote speakers spoke about the 'very real problem of patients selling their drugs on the street'. When she told me about*

*it, I laughed saying 'sell it? You've got to be joking! I can only get enough to just get me through the month. Why would I give it away?' It would literally be asking me to give up my freedom, and I've fought long and hard to come this far."*

"If they don't think we're hoarding it and selling it, they think we're junkies", I replied. "You wouldn't believe the number of nurses who've told me they could never inject themselves. I always tell them that if they had my pain, they would be surprised at what they could and would do, to try and relieve it." *"I've had that said to me countless times too. I find it's not just the words they're saying, but their tone of voice and body language. For me, it comes across as a superior, 'I wouldn't sink to that level', arrogance. You can tell they've never experienced shocking pain for any length of time. Besides, I'd have to be in hospital all the time, or have 3 hourly home visits from nurses. I really don't have much choice."*

### **Time out**

After tossing and turning, trying to rest for a while, I couldn't stand it any longer. "I don't know about you Lilly, but these walls are closing in on me. Are you feeling well enough to go for a walk outside?" I was fuming about my recent tussle with the nurse and I could see that Lilly was still thinking about how the nurse had treated her. I thought a change of scenery was the best medicine for both of us.

As soon as we got outside, I felt the rush of cool, fragrant air. The sun was shining. It was a beautiful spring day. We sat at a table in a shady corner. "Listen", I said to Lilly. *"I can't hear anything."* "Exactly. Inside the hospital it's so noisy. Isn't the silence beautiful?"

We both sat there, not talking, soaking up the atmosphere, allowing our minds to wander and daydream. I found myself naturally beginning to meditate and realised that it would be rude to continue as I would be ignoring Lilly. *"You were far away Cat,"* Lilly remarked as I roused myself. "I was enjoying the warmth of the sun on my back and the gentle breeze. When I closed my eyes I was transported to my favourite place. I had to bring myself back because I wanted to be here with you. Besides, I can go there anytime."

Looking at Lilly, she appears to have calmed down somewhat, but I can still detect a hint of anger smouldering under the surface. “That nurse was something else wasn’t she?” *“I hope I don’t have to see her again. I am so angry at how dismissive she was. It’s obvious she didn’t believe I was in pain. In fact, she said that didn’t she? What right does she have to judge me when my doctor has assessed my needs? Can you believe she offered me panadol? What a fucking joke!”*

“I always feel like I’m an exhibit at the zoo”, I said light-heartedly to Lilly. “However I will not perform tricks for them. I feel their words prod me as a lion tamer uses a whip to control his animals. They expect me to be lying on my bed, groaning and writhing when I ask for analgesia. If I did play that role, their first thought, I’m sure, would be that I was exaggerating and a malingerer. In other words, I can’t win.”

### **Hanging in there - caring for each other**

A group of other patients joined us and we enjoyed ourselves chatting about the outside world. The conversation turned to stories about treatment, or I should say mistreatment by nurses that we have endured during different hospital stays. In other words, horror stories. We laughed a lot, as each story topped the last. The tragedy is that if these stories were written as fiction, it would appear nonsensical and overly dramatic.

It’s great to be able to talk openly and honestly amongst this unofficial support group. None of us have to maintain the pretence that we bear our pain easily. This is a unique forum in which we can drop the façade, no longer pretending by putting on a brave face to show to the world. I can relax and let my guard down. It is also unique in that I am understood, as only someone undergoing a similar experience can truly know what I am feeling.

Hearing that other people suffer from the same stigmatisation, both in hospital and in the outside world, is extremely comforting. In the past I used to wonder what was wrong with me. What had I done wrong? Was I being punished?



Back pain is so often portrayed negatively. It is considered an easy injury to 'fake'. We are all constantly bombarded with media stories and images when someone who supposedly has back pain is 'caught out' lifting heavy objects. It has become so entrenched that it's not just the 'current affairs' shows that routinely recycle these stories, but it is now appearing as a comical parody in advertisements. It is even more suspicious if you are a worker's compensation recipient or a road accident victim, as there is a mythical notion that somehow there is a big 'pay off' if you claim to have a back injury.

### **Emotional trauma**

Having been here for a few weeks now, the daily scuffle with the nurses is starting to take its toll. I am tired of having to fight the same battles day after day. For example, each new nurse wants me to try a lower dose first and I'm finding it hard to keep my composure. If I finally make a breakthrough with one nurse it makes no difference, as I find myself having the same 'discussions' with the next one. There is no continuity of care and, from what I can tell, no detailed communication or documentation between the nurses dealing with me.

This adversarial stance is not helping me deal with my pain. Every time a nurse walks in I find myself tensing up in anticipation. I'm having difficulty meditating successfully, due both to noise and stress. The only peaceful place is outside and the nurses have started to question and complain about where I am going and how long I spend outside. They seem to think we're sitting out there plotting something. Lilly went home yesterday and I really miss her company, good humour, and her elegance. She really lights up a hospital room!

### **Home sweet home**

I'm finally going home today. Was it all worth it? Well, my pain has de-escalated to my former 'holding pattern'. Mentally though, I'm a mess. There's a reason I don't like being in hospital. It takes me months to get back some level of control over my life again. I've been in here for four and a half weeks. It always feels much longer than it actually is.

The drive home feels eerie and unreal. I think it's the pace of the outside world. My senses seem to have shut down. Cars everywhere. Noise. It's not until I've been delivered by my parents back to my own home and am sitting quietly cuddling my cats that all seems right with my world, or as right as it can ever be.

## Story Five

### **“We’re not in Kansas any more!”**

*“WAKE UP SUSAN, WAKE UP!”* I opened my eyes to find myself sitting on my bed with four men standing over me. “I am awake, I am awake.” Looking at them, I realised they were ambulance men and asked them what was wrong. As I heard my own voice, I was surprised to find it sounded a bit slurred. I had just woken up and my mouth was extremely dry, however that didn’t account for the slurring, which concerned me. The next thing I knew I felt a hand on my chest pushing me roughly back down on my bed.

*“Susan it’s time to wake up now. Wake up Susan.”* I tried to sit up, but felt hands holding me down. *“Wake up Susan! What are you trying to do?”* “I just want to sit up.” *“Just lie down and relax.”* My instincts, when being told to wake up, were automatically telling me to sit up and orientate myself. I tried to sit up again and this time five people surrounded me and roughly held me down. I tried to tell them that I was really uncomfortable, that my back was absolutely killing me and that I needed to sit up. I was told, with my arms, legs and chest being held extremely firmly, that I had to lie down.

I woke up again suddenly with the urgent thought that I was late for work. I tried to get out of bed and found I couldn’t lift my legs. I could feel the muscles contracting, but I just couldn’t raise them. Just then I noticed someone walking into my room and realised it was my sister. I tried to attract her attention, but she seemed not to notice me. She eventually walked right by my side, so I asked her if she could help me by lifting my legs. As soon as she was close to me, it dawned on me that she was not my sister, although she did bear a strong resemblance to her. She told me my legs were tied down. “No they’re not, could you please lift them?” I begged. She just ignored me and kept walking. I tried lifting my legs again and couldn’t feel any restraints at all. I lay there feeling very concerned and confused.

As I woke up more, I began to look around me. I noticed that there was someone on a bed to my left. Looking to my right, I saw that another person was in a bed there too. Two people talking to each other walked past my bed and I realised that they were nurses. I was incredibly thirsty and I asked one of them for a drink of water. *“You’ll have to wait, we’re really busy.”*

A nurse came over to me and said she needed to ask me some questions. *“Can you tell me where you are?”* “In hospital.” *“Do you know which one?”* “No.” *“You’re in the Emergency Department XX Hospital”,* which I recognised as a major public tertiary hospital in Melbourne. *“Do you remember how you got here?”* I thought about it and said no, and was told I had been brought in by ambulance.

*“Can you tell me what day it is?”* I wasn’t sure, but I said I thought it was Wednesday. *“What month is it?”* It was a really curious feeling to not know which month of the year it is. I was thinking to myself, ‘is it August? No, that doesn’t seem right.’ The nurse asked me again and I said I was thinking about it, trying to work it out. She said, *“It’s February.”* “Oh yes, it’s just been Valentine’s Day.” *“That’s right. Now, what year is it?”* I knew it was 2005, but it kept coming out as “five-t-five”. I had a clear thought of what I wanted to say, but when I went to say it, it wouldn’t come out right. I tried over and over again, but all I could say was “five-t-five.” After a while, she asked *“do you mean 2005?”* “Yes”, I agreed thankfully.

I was still awfully thirsty, so I looked around for someone to ask for some water. The next nurse to come near me was the nurse that I had thought was my sister, who did actually look remarkably like her and had the same name (I had heard someone calling to her). “Could I please have a drink of water,” I said. *“You’ll just have to wait Susan, you’ve been very naughty all night.”*

I lay back feeling absolutely astounded and shocked. How dare she call me naughty and scold me like a small child? I was a patient in hospital and, even if I had been confused, that did not mean that she could treat me in such an uncaring, unprofessional way.

Laura, a friend who had been staying at my house from interstate then appeared at my bedside. How nice it was to see a friendly face! *“How are you feeling now, I was so worried about you. Do you remember what happened?”* “I remember expecting you back from your trip and you phoning me. The next thing I remember is the ambulance guys in my bedroom and then waking up here.” *“I came home to find you on the floor beside your bed, unconscious and fitting, so I called the ambulance.”*

“Was I really fitting? What was I doing?” *“You’re upper body was really thrashing about.”* “I’ve never had a fit before, I’ll have to ask the doctors about it.” *“What have the doctors told you so far?”* “I haven’t spoken to a doctor yet.” *“You’re joking! You’ve been here for hours and hours. Listen, I’ll go home now, but I’ll be back tomorrow. Ring me if you need me. Take care Susan.”* “Thanks for coming in. I really needed to see a friend.”

A male nurse walks by my bed. “Could I *please* have a drink of water, I’m so thirsty.” *“Of course you can, just a minute and I’ll get you some.”* He came back and I couldn’t believe how cool and refreshing it was. “Thank you so much, that’s like nectar!” *“There’s nothing like really cold water when you’re thirsty is there? I got it from the water cooler for you.”* “What’s your name?” *“Tom.”* “Thank you Tom, you’re the first person who’s been kind to me.” *“You’re more than welcome”* he said in a lovely soft Irish accent.

My ‘sister look-alike’ nurse, Cindy, announces to me that they are going to have to catheterise me because I *“haven’t had a wee”* since I’ve been there, which has been about 20 hours. She walks away before I can consent, protest, or even offer an opinion. When she returns with two colleagues, I try to tell her that it is unlikely that I have a full bladder because I’ve only just had one glass of water since I arrived. Cindy doesn’t even bother to reply. She does something down at my feet and suddenly I can move my legs. I was tied down! I don’t have time to process this information however, as the other two nurses were roughly trying to position my legs while Cindy prepared to insert the catheter.

“Please just tell me what you want me to do”, I begged them. “You are really hurting my back by doing that.” *“Bend your knees as wide as you can.”* I did as I was asked. *“You’ll have to do better than that”* they said. “Listen, please. I have a very serious back injury, and I just don’t have the same flexibility as everyone else.” Cindy came over and said, *“that’s not good enough.”* The other two nurses each leant over me and pushed down hard on my legs. Tears were streaming down my face as I pleaded with them to stop hurting me. *“It won’t take long”* Cindy snapped.

She was right! Cindy cleaned the area with one haphazard swipe, then forcefully spread my labia apart with one hand, then thrust the catheter in with the other. *“There we are, all done. I told you it wouldn’t take long, I’m good at this. I suppose we can leave your legs untied. I don’t think we are going to try and escape now are we? You just lie there like a good girl”* she said and walked away.

I turned on my side and curled up and just cried. I was traumatised. I feel so violated and angry. I feel as if I’ve been raped. ‘Yes Cindy, you are good. I just know I’m going to get a urinary tract infection now’. That’s all I need! Why am I being treated so harshly? I can’t understand it. And what did she mean about escaping? All I had wanted to do was to sit up!

I spent the next two hours trying to attract the attention of any passing nurse. I had no buzzer and no one was coming anywhere near me. I was too scared to sit up for any length of time, in case they tied me down again, so I would watch the nurses in the large mirror that ran the length of the room a few metres in front of my trolley. Any time I would see a nurse, I would raise myself up on one elbow, and call out or wave. I was still so *thirsty*. Either everyone was deaf and blind, or they were ignoring me. No one acknowledged me; they just kept on with what they were doing.

At one time, the nurse attending to the patient in the next cubicle walked around my side, so I asked her if she could help me. *“I’m not looking after you. I’m sure your nurse will be along shortly.”* “Could you tell her that I need her when you next see her please?” *“Just be patient. I’m sure you won’t have to wait long.”* I started

to explain that I hadn't seen her for ages, but she pulled the curtain around her patient which necessarily ended our 'communication'.

I was also very apprehensive about falling asleep again. I felt somehow that it wouldn't be a good idea, although I wasn't sure why. Nobody had come and talked to me about what was happening to me, and I had been here a lot longer than I had realised. I felt really scared and alone.

A doctor came over and asked me whether it was all right if a psychiatrist came and talked to me before I was transferred to ICU. I had no problem with it, although I was surprised that I was being asked! He asked me whether I had taken an overdose of my pain medication. "Absolutely not" I said firmly. "Are you sure?" "No, I did not!" "Could you have taken an overdose by accident?" "No. If I was ever unsure, I would take *nothing*. I remember the last dose I took, and that was a normal dose, in the afternoon. I am a nurse and I'm not stupid."

"Have you ever been involved with the police?" "No!" I said indignantly. Who did they think I was? I have never been asked that question before and it would be fair to say that my appearance is conservative. The psychiatrist didn't ask me any more questions, but he walked away looking unconvinced. He spent a total of about 8 minutes with me.

### **A safe haven?**

When I moved myself from the trolley into the ICU bed, I realised just how much pain I was in. My back was in complete spasm. Any movement whatsoever caused severe pain. More pain than I had ever experienced before. My back felt extremely unstable. I had had about eight falls in the preceding couple of weeks, really brutal falls where I tumbled "ass over tit" as they say, leaving me extensively bruised.

Once I was settled in bed I began to assess the reasons for my unusually high pain level. My first thought was that I had been lying on a very uncomfortable trolley for an extremely long time, without being allowed to change my position. When I'm

resting in bed at home, I change my body position very frequently, as I get dreadfully uncomfortable and my pain escalates if I don't move. One of the worst positions for me is lying flat on my back without a pillow under my knees. This was the position in which I had been forcibly shackled in the Emergency Department, for hours without respite.

On contemplation of my extreme pain and spasm, I became aware that I had not been able to take my regular anti-spasmodic or analgesic medications for approximately 48 hours. This combined with the lack of regular repositioning, uncomfortable trolley, and the impact of the falls, had caused a total pain 'meltdown', the like of which I had never experienced. I'm really concerned. Every time I move, my spine feels extensively unstable. I gently rolled over a minute ago and heard a fizzing sound and felt a spurt of bubbling sensation at the base of my spine. I honestly feel that if I move the wrong way, I'll literally become a paraplegic.

I used some of my relaxation, visualisation, and self hypnosis techniques to try to start to manage my pain. The pressure mattress on the bed vibrated as air was pumped into it. Because my spasm at this level feels like electrical shocks passing through my back, I tried visualising that I was only feeling the vibration of the bed. I was only partially successful, as I would just convince myself that my back had settled a little, when I would be startled each time the bed started its cycle again.

I visualised myself sitting on my favourite beach. The sun was shining, there was a gentle breeze rustling through the palm trees and the surf was gently rolling in. I was sitting in a luxurious, reclining massage chair, a new addition to the scene, and was being served luscious, chilled, refreshing cocktails by a beautiful island waiter.

Once settled into ICU, Judy, my night nurse, took my history. Judy told me I was in ICU because I had ECG changes. I asked her why and she said they hadn't worked that out yet. She said they would be getting a cardiologist to look at it, but that it was slowly improving and that I should only be in ICU overnight.



*“Would you like some water, and some soup and sandwiches too?”* I hadn’t realised it, but I was actually quite hungry as I hadn’t eaten, I calculated, for about 48 hours or so. *“Water would be divine. I’ve been begging for some for hours. I would also love some food, but as I’m a diabetic, you’d better do my blood glucose levels first as they haven’t been done at all.”* Thinking about it, I couldn’t believe that they hadn’t been done in the Emergency Department. I asked Judy to check the notes and she confirmed this. She was quite amazed too, as they knew I was a diabetic. After I had eaten, Judy encouraged me to sleep, but I found I couldn’t in that environment.

The ICU doctor came to see me to discuss my medications. She said one of the ward doctors would take a full history in the morning. I listed all of the medications I was currently on, which was quite a few. She was unfamiliar with some of them, which made it a little difficult.

The doctor came back after a while and asked me *“is all of the medication you have with you yours?”* *“Well, I assume so, but as I arrived by ambulance and was unconscious when I was brought here, the ambulance men must have brought it for me. If you show it to me, I can verify it with you.”* The doctor brought over my medication bag which I checked and said *“yes, this is mine, but there’s some missing.”* *“Those are the ones I want to ask you about. We’ve locked away the ‘drugs of addiction’.”*

*“Did you have anyone else’s drugs at home?”* *“Of course not!”* *“Look, you can tell me the truth, Susan. We’re concerned that someone else may be ‘hanging out’ for their drugs. You’ve got enough to stock a small hospital!”* *“I would never ever take any medication that was not prescribed for me. I have to be very careful about drug interactions. I can’t even take ‘over the counter’ tablets, like cold or flu remedies, without talking to my pain management specialist first. Besides, I would never deprive someone else of their medication. I know what it’s like to rely on medication, just to manage my pain in my daily life. I wouldn’t put someone in that position!”*

I couldn't imagine what the ambulance men had found. I didn't have anywhere near what I would consider could 'stock a small hospital' at home. "Please phone my doctor, he'll tell you what he's prescribed for me and how much. I would *never* take anyone else's medication and he knows it. He's treated me for 10 years!"

*"It's just that not all of your drugs have got your name on them."* "Well, I'm sure you'll find they haven't got anyone else's name on them, or torn labels. My pharmacist puts a label on only *one* box out of 24 boxes", I said exasperatedly. *"Oh, I didn't know that,"* she said. *"I will speak to your doctor though."* "Good, I want him to know I'm here, and what's happening to me. And can I *please* have something for the pain? I haven't had anything at all since I've been here and I'm in *severe* pain. I think I've been very patient." *"Yes, I'll speak to your doctor and then sort something out and then come back and talk to you."*

The doctor went away and I could see her talking on the phone for quite some time. Eventually she came back to talk to me. *"Because of your ECG changes, we want to start your pain medication slowly, is that all right?"* "What pain medications will I be on?" *"We are not happy giving you the drug that you add to your narcotic at present because it's very strong, so we'll be giving you the narcotic injection alone, OK?"* "Yes, I understand your concerns and the injection still works well on its own, so I'll agree to that."

"What about the oral slow release morphine? It gives me a consistent, sustained release of medication to manage my baseline pain and I use the injections for breakthrough pain." *"We only want to start you on one drug at a time, at a low dose, but we'll increase it as you tolerate it, and we'll make sure that your pain is controlled, and that you don't suffer from uncontrolled pain."* "Yes, that sounds fine as long as that *is* what happens. It's just that I've had problems in the past, when one doctor orders me something and then another doctor takes over." *"I'll make sure it gets passed on to the day staff, OK?"*

I asked my nurse for an injection as soon as the doctor left. As my normal dose was 2ml and this injection looked much less, I asked her what dose I was having

because the doctor had neglected to tell me the starting dose. *“Don’t worry, it’s your normal dose, it’s just in a different concentration.”*

This surprised me, mainly because the doctor had said she would commence me at a dose lower than I had at home and, secondly, because I thought I knew all the available concentrations. After an hour I hadn’t noticed any effect from the injection, but I decided that my pain level was so high that wasn’t unusual and I would have to wait until the next dose to notice any marked difference.

My thoughts wandered back to the Emergency Department. I had a clearer picture now of the events that had occurred. For a long period of time I had obviously drifted in and out of consciousness, or perhaps was only able to be aroused with a lot of stimulation. Judy, my ICU nurse, had told me that the Emergency nurses’ notes said I was “obstructive”. I can remember being yelled at to wake up. When I’m asleep and someone shouts at me to wake up, my natural instinct, and I would think most people’s, is to sit up to see what’s wrong. I didn’t know where I was! At that time I had no memory of being in any difficulty whatsoever.

To be called obstructive when all I had done was to try and sit up, seems exaggerated. Shackling me after I had lapsed once more into unconsciousness seems excessive. I would have thought that their professional experience would have informed them that it would be natural to be confused if one minute you’re in your own bedroom and the next thing you know strangers are shouting at you to wake up. It is not a normal situation.

I do remember one nurse asking me what I was trying to do and that I answered “sit up”. Instead of either letting me sit up, or questioning me further as to why I wanted to sit up, she just dismissed me and told me that I had to lie down. There was no medical reason that made it imperative that I lie flat. The nurses could have prevented all that drama if they had only *listened* to me.

Lying in the ICU bed, I started to think about some of the things that had happened in the Emergency Department. Why was I treated so harshly? I’ve never attended this hospital before, so it’s not as if I’ve got a reputation. In fact, I’ve only ever attended an Emergency Department once before and that was six years ago; and I

ended up having complicated open heart surgery that time! It's not as if I turn up at an Emergency Department every week trying to obtain drugs. A sudden revelation hit me. Putting together the psychiatrist's questions about overdosing, and the ICU doctor's comment about my having "*enough drugs to stock a small hospital*", means they must see me as a 'junkie'. It suddenly occurred to me why I was treated with such disrespect. They didn't see me as a legitimate patient. The way they refused to allow me to make myself comfortable, even when I was no longer confused and was compliant with their every demand, tells me that they did not consider me to be a severe pain patient. I can't wait to get out of here and go home!

The nurse, Cindy, is predominantly on my mind. To be a confused patient puts you in a vulnerable position. I am still reeling from her degrading remark that I "*had been naughty all night*" which had an enormous impact on me. Her catheterisation technique felt like a violent rape, however to be called "*naughty*" by her feels like being raped all over again; this time emotionally. I am still feeling exceptionally vulnerable, violated and extremely angry because of her degrading and demeaning remark and attitude.

I believe now that the nurses were punishing me for my earlier 'naughtiness'. The form that punishment took was the refusal of one of a person's most fundamental needs: water. Withholding water for any length of time without medical reason is a form of torture and I can attest that it is very effective!

The night in ICU passed very slowly. I have not managed to get any sleep. Judy asked me whether I thought I would be able to walk to the shower with her and shower myself. "Sure, I'm dying to get out of bed to have a stretch, and a shower would be heavenly after all this time in bed." I managed really well and felt so much better for it.

After I had settled back into bed I asked Judy "do you think I am well enough now to be discharged home? I know the doctor has to see me first and that it is his decision, but I'd really like your opinion. I feel well enough to go home." "*It is of course the doctor's decision, but in my opinion I don't see any reason why you*

*shouldn't go home today.*” “That makes me feel a lot better. I've already had enough of this place! ”

A doctor walked up to me. *“I'm one of the medical team and I'm here to admit you. I need to ask you some questions and take your history.”* He started to ask me about my medical history. I attempted to answer all his questions, however I found that he was not giving me enough time to answer his questions fully before he would move on to the next. I was continually interrupting him as parts of my history are not straightforward, but are quite complex and confusing.

He's starting to throw in some odd questions amongst the medical questions, such as *“what is your first memory as a child, do you have any siblings and how many, and what was your relationship with your parents like during your adolescence?”* I can't really understand what this has got to do with my back injury. I'm answering him because I want to be seen as compliant, so I can be discharged home. Again he's not giving me enough time to explain my answers to my satisfaction. I am starting to feel quite intimidated by him.

He will not let me explain myself and, even to me, some of my answers sound a little dramatic. For example, I told him that my parents had encouraged me to discuss and question world events or opinion. “We can have really good arguments about politics and religion and we can agree to disagree if we have different viewpoints.”

I am using the term 'argument' meaning a line of reasoning, but as the doctor seems to be taking this as a negative practice, I believe he is thinking that we were having fights, not discussions or debates. The doctor is not giving me the chance to explain that I view this practice positively. It developed my maturity and taught me to be able to see both sides of an issue, and to understand that everyone has the right to their own point of view, even if I don't agree with it.

*“I'll go and write up my notes and I'll be back soon”* the doctor told me. He left me feeling puzzled by his questions and I have a nagging feeling that he has a questionable understanding of me, my history and my family dynamics. Why was

he asking me such unexpected questions? Never before have I experienced such a strange approach to taking my medical history.

*“Susan, I’m going to admit you. You don’t need to remain in ICU, so I’m going to transfer you to the ward.”* “I think I am well enough to go home.” *“No, I really think you should be on the ward.”* “If I don’t need an intensive care bed, surely I can go home and remain under my own doctor’s care?” *“No Susan, you are going to be admitted.”* This doctor just won’t take no for an answer! “Why do I have to stay? What’s wrong with me?” *“I just think it’s best.”* “How long do you think I would have to be there?” *“Until Monday, or maybe Tuesday.”*

“Look, my back is already acutely severe. The hospital beds on the ward are only going to exacerbate my pain to unbearable and intractable levels. My bed at home is set up for my exact needs. Plus I’m going to experience the stigma of chronic pain on the ward which will intensify the experience to such an extent as to be intolerable. I want to go home now please.” *“I promise you I will make sure that those things don’t happen, Susan.”* With that he walked away and it seems as if the decision has been made for me. I feel really intimidated by him as he would not listen to anything I had to say. I just know I am going to have problems on the ward. I always do.

### **Welcome to my nightmare!**

Eyes. Watching me. Everywhere I go, someone is watching me. Not that I can go far. I have been restricted to the ward, only allowed through their hallowed doors when escorted. While I am a lady, this is not the 19<sup>th</sup> Century and I do not usually require an escort. Besides, my escort is not to be an exciting young beau, but a nurse or a security guard!

I was given no warning by my admitting doctor in ICU that I was to be confined to the ward. In fact, I only found out when I went to inform a nurse, out of courtesy, that I was going out for a walk. I never actually agreed to go to the ward from ICU, but submitted to the doctor’s pressure and allowed the transfer to happen. Had I been informed of this restriction, I certainly would not have bowed to his pressure so easily.

Later, I asked whether a friend or family member could escort me. *“No, it has to be either a nurse or a security guard.”* “Could I arrange a time for a nurse to take me downstairs then?” *“It’s not a nurse’s job to escort patients.”* “Could you please ask a security guard then?” *“It’s not their job either.”* What is the point of telling me I have these two alternatives to go for a walk if neither of them is going to be possible? What is this, a conspiracy to drive me crazy?

Even when I am alone in my single room, I can feel eyes watching me. You may think this sounds paranoid, but sadly it is true. My room is adjacent to the unit’s nurses’ desk and the separating wall contains two large windows that overlook my room. There are blinds for these windows, however they are on the nurses’ side only, and I therefore have no control as to whether they are open or closed. For some reason, one blind is kept open, day and night. I have absolutely no privacy, and nowhere in the room is immune from view. This is apparently used as a ‘delirium unit’; a ‘low stimulation’ area. It is actually the reverse: ultra stimulation! I do not have the usual sanctuary of privacy in my own room. It’s like living in a fish bowl.

Privacy is not the only issue affecting me. I am having major difficulty resting. I am unable to rest because my hospital bed is so hard; it’s about as useful as a block of concrete. I pleaded with the nurses to change the bed, but was told that my bed was *“an orthopaedic bed, designed for maximum support for back care. It is exactly what you need and we won’t be changing it.”* As I can’t even rest on it comfortably, I know that I’ll get absolutely no sleep while I’m here.

As time passes, I am finding that I am reacting in ways most unlike my usual self. I am generally a kind and courteous person, not in the habit of responding with sarcasm and even rudeness. When I was first transferred to the ward, I decided I would try and make the best of the situation, even though I really didn’t want to be there. I chose to have an open mind, as I had never been a patient at this hospital before, and perhaps the ward staff would surprise me and not believe the common stereotypes.

It didn't take me long to feel the atmosphere of the ward, at least where I was concerned. I noticed immediately that all of the nurses were using a very cool tone of voice towards me. During the first couple of days, I made sure that I was always pleasant, calm and respectful toward the nurses in the hope that they would respond in kind. Unfortunately, this has not had the desired effect. In fact, it seems to be having the reverse outcome.

It appears that the nicer I am, the colder the nurses become. Is it possible they feel I am taunting them? I have now given up trying to be nice and am only managing to maintain the barest civility. A complete lack of sleep is definitely influencing my mood. 'Thirst torture' was bad enough, but prolonged prevention of sleep is truly torture. After all, they use it in prison camps, don't they? When a nurse is rude to me, I answer rudely. As I said, this is most unlike my normal self, but I must admit it feels very liberating in these circumstances!

### **Interrupting the status quo**

My usual daily routine for managing my pain is in complete disarray. At home, I generally rely on a range of strategies to minimise my pain. Together with pharmaceutical therapies, I combine meditation and self hypnosis with physical rest and diversion techniques. To be able to successfully practice meditation, I must be able to concentrate on the mental imagery I generate. As it is impossible for me to find a comfortable position for any length of time, I am thus being prevented from using the mainstay of my pain management techniques. Every time I have attempted to meditate in here, I just get started when suddenly I am brought back to earth with a jolt, as my extreme pain interrupts my stillness.

I do, of course, also rely heavily on medication at home to relieve my pain. Usually, I take slow release oral morphine to maintain a baseline level of analgesic cover, and then use intramuscular opioid injections 3 hourly to cover the breakthrough pain. When I arrived on the ward, I found out that I was only ordered the injection 12 hourly. My expectation had been that they would slowly increase the frequency of my injections, until I was back to my usual regime. In response to



my query, the covering doctor replied “*I’ve looked at your notes, and there’s no mention of increasing the number of your injections per day, or of your oral slow release morphine. You’ll have to wait until Monday.*” The doctor that treated me in ICU had promised me that I would not be left in pain. Looking back on it now, I wonder how could I have been so trusting and naive?

I sat in my room and took a close look at my situation. For the next 2 ½ to 3 days, I was to have basically no analgesia. That alone was going to be enough to send my pain skyrocketing. Added to that, I was not going to be able to rest comfortably because of my rock hard bed. My meditation and self hypnosis were also out the window for the same reason. Even diversion therapy is out as I can’t have a TV in here because it’s their ‘delirium unit’. I’m attempting to read, but am not having much luck. More importantly though, the fact that I am unlikely to get any sleep will mean that my coping abilities are going to be stretched to the limit.

### **All semblance of normality dashed**

Staying here under these circumstances is going to aggravate my pain to extreme levels, so I’ve decided that the best place for me to be is at home. I’ve asked the doctor to come and see me. “I would like to sign myself out. The undertaking I was given concerning my pain management has not been forthcoming. I was *promised* that under no circumstances would I be left suffering uncontrolled severe pain. Having nothing more than 12 hourly injections for the next 2 ½ or 3 days will be intolerable.

I was also *promised* that under no circumstances would I be left in a bed that would exacerbate my back pain. I predicted to the admitting doctor that a ward bed would not be suitable for me. I cannot get *any* rest on this bed and it is now apparently impossible to have it changed. I cannot use my meditation and self hypnosis techniques if I can’t find a comfortable position to rest. *All* of my pain management strategies are being taken away from me here. At home everything is set up to cater to my exact needs.

I have spoken to my own specialist by phone and he told me he sees no reason that I can't go home. If I can't get reasonable treatment here, you leave me no choice but to sign myself out. If you will go and get the forms, I'll be happy to sign them." The doctor has left my room. Hopefully I'll be out of this place very soon!

John, the doctor, came back looking very serious. "*Susan. Do you understand that you have ECG changes?*" "Yes, I have been told that." "*Do you understand that some people in the community have these changes and have died?*" "What treatment are you giving me here to cure these changes?" "*We'll just be monitoring you.*" "I'm obviously not sick enough to be continuously monitored or I'd still be in ICU." "*No, we'll be doing daily ECG traces.*" "I can get daily ECG traces at home." "*We'd prefer you to stay here. I want to make sure you understand. Do you realise you could die?*" "I understand completely. I am prepared to take that risk. If I die, I die. I honestly still want to go home."

*"Do you know what you are saying? I am not comfortable sending you home in this condition."* "John, I want you to understand me. I feel I can take all the same precautions at home that can be taken here. I would like to sign myself out now please." "*I'll need to go and talk to my consultant.*"

I am feeling very apprehensive. John did not seem to understand my position. He certainly doesn't appear to take my pain very seriously. When I said I didn't care if I died at home, I really mean it. I am not feeling suicidal, but I just don't have the feeling that it will happen, and if it did – well, then it's my time. My intuition is telling me that the reason they want to keep me here is that they think I overdosed and am a 'junkie', and the ECG changes are just a red herring.

John is back yet again. "*Susan. My consultant has made the decision that you are not to be allowed to sign yourself out. If you try to leave the ward without permission and you are caught, you will be in big trouble. You will not even have corridor privileges.*" "So what, you'll throw away the key", I said jokingly. He stood up. "*I am very serious Susan. This is not a joke. If you try and leave, you will be caught. Do you understand me?*" I am suddenly feeling very small and very intimidated. Without actually saying it, John is giving me the strong impression that

if I did try to leave, he would involuntarily commit me and lock me up for 2 years and I would never see the light of day.

Why won't anyone listen to me and believe that I know what's best for me? Drawing the curtain across the doorway, I lie down on the bed and curl into the foetal position. I am shaking all over. Tears are pouring down my face and I'm sobbing uncontrollably. How can this be happening to me? I feel so alone.

### **Plotting my escape**

My mind is racing. I have 'cabin fever'. I am thinking the same things over and over again. The one thing I usually do to relieve the tension that builds from my stress at being cooped up in a hospital room is to walk and sit outside in the fresh air. Now that I have lost my liberty, I really can't see how I am going to prevent myself from going 'stir crazy'. I am really quite fearful now of the potential impact this enforced incarceration may have.

I have been pacing up and down thinking about where I could run to, that the hospital, or even my family, has no knowledge of. I would like to be near home, so I could secretly see my cat. Perhaps a neighbour friend of mine has a spare room? "Ellen, it's Susan. Do you have a spare room?" "Yes we do, *why?*" "It's a long story, but I was wondering whether I could borrow it for a while?" "I'm sorry Susan, I have guests at the moment. Any other time it would be fine. Are you all right? Is there anything else that I can do for you?" "I've been better. There's nothing you can do. Thanks anyway." Hmm ... Where else can I go?

Perhaps I'm thinking too small. My sister has brought in my things. I have my purse with me. I have street clothes with me. I could take a taxi from outside the hospital and go straight to the airport and fly somewhere interstate. I could just take any flight that takes my fancy. If I don't know where I am going, how could anyone else? Once I got to my destination, I could book into a hotel under an assumed name. Luckily, I have enough money in my account to last me for a while. I could just disappear.

The problem is, however, that I'm not like everybody else. I would have to find a doctor to prescribe my pain medications. Even if I could find a doctor willing to give me what I need, which is unlikely, as I had enormous difficulty finding the specialist I have, the government could track me through the authority prescriptions I require. Maybe it would be possible for me to just hide over the weekend and then go to see my specialist on Monday and ask him to intercede on my behalf? Would there still be consequences?

Because of the way I have been treated by the staff, I am in emotional torment. I am scared of the power the staff have over me, but I am also scared of the consequences of leaving. I have a vision of being locked up in a psychiatric hospital and having seen some of them during my nursing training, the prospect is not at all enticing.

If I leave and get caught, I don't know whether my specialist will be able to have any say in my treatment. He has been contacted regarding my stay here and, even though he is the psychiatrist who I see for pain management, what he says holds no sway as he does not have visiting rights at this hospital. If I have to stay here after Tuesday, I will definitely lose my sense of reality. I already feel like I am in an alternate universe, but at least at the moment I know the difference!

### **The nightmare ends**

It is finally Tuesday. I repeatedly asked to see the doctor yesterday with no result. I don't know why he wouldn't come and see me, but I'm extremely angry that he did not respond to my request, after being told all weekend by the covering doctors *"you'll have to wait until Monday, to talk to your own doctor."*

I've spent the last three days cowering in my room, facing my own 'Chernobyl': pain meltdown, by myself. I've decided that when I see the consultant today, I will do and say anything it takes to get discharged. I honestly don't know how I've lasted this long, physically or mentally. The doctors had better agree to discharge me today, because there is no way I am going to stay another day. I am going to tell him what he wants to hear. It's going to be 'yes sir, no sir, three bags full sir'.

No matter what he says to me, or how frustrated I feel, I am going to force myself to remain calm. Butter won't melt in my mouth!

The way I feel now, I would dearly love to rant and rail about the treatment and 'care' I have received in this hospital. I certainly have valid grievances. I'm sure if I did so, they would consider me totally mentally unstable and discharge would be the last thing on their minds. I dare not risk it because I will not stay another day. If, for some reason, the doctors won't let me go home tomorrow, I have decided that I will escape from here and contact my own specialist to hopefully make things right, and me a free woman. For my own sanity, I've just got to get out of this place.

The doctor who admitted me in ICU has just walked into my room. "*Susan. How are you?*" "Not very happy, or very well, which you would know if you had bothered to see me yesterday. Didn't you get my messages that I wanted to see you urgently yesterday?" "*I did, but we agreed that you would stay until today.*" "No, actually I didn't agree to anything. It was you that said Monday or Tuesday. Besides, all weekend I have been told by the covering doctors 'you'll have to talk to your doctor on Monday'. And discharge wasn't the only thing on my mind. I needed to talk to you desperately about my pain management." He had a somewhat sheepish look, but didn't comment further.

For my discharge review, I was expecting the doctor that had admitted me and his consultant. Imagine my astonishment when a troupe of people walked in. The oldest looking one in the lead walked up to my bed. "*I'm Dr Malman, the consultant psychiatrist. I believe you've met my resident,*" he said, pointing to my admitting doctor. "Yes." So, the unit I was under was not a medical unit but a psychiatric one. That explained a lot! "*These are my two registrars and those are my medical students,*" he said, waving his hand at about 15 people in short white coats.

The consultant hasn't asked me if I mind the medical students staying. I know I have the right to ask them to leave and be seen privately, but I'm worried that he'll interpret this as paranoia. It is so intimidating to be surrounded by 17 people. I am

going to block the group from my mind and just keep eye contact with the consultant only.

*“Can you remember the events leading up to your admission?”* I explained to him that the only gap in my memory now was from the time the ambulance men were in my bedroom at home until I woke up in hospital. *“Did you take an overdose?”* Not this again! “No. I certainly did not. And before you ask, I did not accidentally overdose either. The last injection I had was at 7 p.m., 10 hours before the ambulance arrived and it was my normal dose.”

Dr Malman proceeded to ask me some exceedingly personal questions, including some that seemed to have no relevance to my present situation. I was extremely embarrassed when he started asking me about my sexual history including *“have you ever had sex in public?”* I feel outraged and am biting my tongue, so that I don't bite his head off. “NO!”

*“I would really like you to see one of our pain management specialists. We don't think you are on the most appropriate or effective regime at present.”* Hearing that, I nearly burst out laughing and had to mask this by coughing. They are suddenly concerned with my pain management now, when I've been begging for relief all weekend? “I'm happy with my own specialist, thank you.” *“We really think it would be a good idea if you did consult them.”* “Thank you anyway, but I am really happy with my doctor, who I've known for over 10 years, and I have achieved very good pain control with him.”

*“Do you feel well enough to go home?”* Don't these doctors talk to each other? After taking a deep breath, I said very slowly and calmly, “I have felt well enough to go home since I left the ICU.” Thankfully, he seemed satisfied. *“You can go home today then, Susan.”* “Thank you.”

I turned to the admitting resident with a last comment. “By the way, you *promised* me that my back wouldn't suffer from the ward bed and that I wouldn't experience any chronic pain stigma. The bed has exacerbated my pain to such an extent that excruciating doesn't begin to describe my pain intensity. And, not only did I

experience appalling stigma regarding my chronic pain, but I *also* experienced the stigma of having a psychiatric illness, which I do not!" The resident didn't bother to reply and they all walked out of my room. The hairs on the back of my neck are standing up and quivering in anticipation of leaving this hell hole.

A nurse has just entered my room as I'm packing up my belongings. *"So, you're going home today, Susan?"* "Thankfully, yes." *"You'll need to get your stuff out of the room so we can clean it, as we need the bed."* "My girlfriend may take nearly 2 hours to get here to pick me up, so I'll need to be able to use the bed. I can't stand or sit for that long." *"As I said, we need the bed, so you'll have to sit in the chair."* I can't believe it. I've been begging to get out of here for 3 days and now they are kicking me out!

### **Home sweet home – my private paradise**

I am in a state of bliss and joy at being home. Taking back control of my life is wonderful. It feels surreal after having all control taken from me without my consent. I am wondering now whether it was legal for the doctors to hold me and not let me discharge myself. I was under the impression that a patient has to be psychiatrically committed into a psychiatric unit if they are to be detained against their will. I am very angry and shocked at the treatment I received.

Looking at my discharge medication, I notice the concentration of my injections. As the pharmacy has labeled the box, I can finally see the amount of injectable opioid I was having in hospital compared to my usual dose. Now that I have done the math, I am dumbfounded! One injection in hospital was, in fact, one-tenth of my normal dose. Added to that was the fact I only had it twice a day, instead of 3 hourly. In reality, I was only given one-fortieth of my total usual daily dose! Compounding these minimal amounts, I was also not having any of my baseline, slow release oral morphine.

I now realise why I've been having intermittent diarrhoea and stomach cramps that started at dinner time on the day I was sent to the ward. As the first meal I saw was literally nauseating, I had put it down to the hospital food. It is obvious to me

now that I was withdrawing from the opioids as I had basically gone 'cold turkey'. I'm actually surprised that detoxification wasn't as bad as I imagined it would be.

I have spent the afternoon sitting outside in my back garden. It is such a beautiful day and I feel like I need to soak up every minute of it. My spirit and soul have been deprived of even the simplest things in hospital. Listening to soothing, classical music interspersed with bird calls is doing more for me than anything the staff at the hospital managed. After just a couple of days of regular self hypnosis, meditation and a return to my usual medication regime, I feel back to my customary self. I do, however, retain some severe residual emotional issues stemming from this experience.

### **Chapter Summary**

Hospitalisations are, unfortunately, an inevitable part of a chronic pain sufferer's life. Time spent in hospital should be an opportunity for rest and respite. It is impossible to rest, both physically and psychologically, when in emotional distress. When nurses react to the commonly held stereotypes and labels that surround chronic pain sufferers, without taking the time to get to know them as individuals, emotional trauma is usually the result. Stigma regarding chronic back pain as well as treatment with opioids is another unwarranted cause of emotional trauma.



## **CHAPTER SIX**

### **CONCLUSION**

This study explored the experiences of people living with severe chronic nonmalignant back pain. Five people were interviewed and their experiences, along with my own, are illustrated in story form. I knew from the moment I decided to pursue this research that a qualitative approach was the most appropriate because I knew that I would be able to gather rich, descriptive data. I initially chose to use grounded theory as my methodology. My original purpose was to investigate only the hospitalisation experiences of my participants. It was my participants who expressed a need to talk about all aspects of their lives, including their hospitalisation experiences. Had I not initially been using the grounded theory method of analysis, I would have missed this wonderfully rich data and my study would have had a much narrower focus.

After a period of time had elapsed I was introduced to autoethnography and decided that it was a more appropriate methodology as I could incorporate my own experiences. Deciding to adopt an autoethnographic approach was not without some fear and trepidation. Writing up the data as a series of stories or narratives at first felt foreign. It was also incredibly challenging. I think and hope, however, that it has worked as a means of informing nurses and healthcare workers of the life lived by chronic nonmalignant pain sufferers.

Before commencing this research, anecdotal evidence suggested that other chronic back pain sufferers had had similarly traumatic hospitalisation experiences to mine. I therefore wanted to find out whether there was evidence to support this contention. Following a review of the literature, I found that there was evidence to support the anecdotal evidence gathered, including studies of pain patients' perceptions and expectations of nursing care, and studies reporting that nurses did not have an appropriate knowledge base to effectively care for chronic pain patients. Labelling, stigma and disability theories helped to explain why there was a disparity between chronic pain patient needs and the care they received, as well as explaining some attitudes within the community. The literature review, while

updated, remained little changed in content from when I switched from a grounded theory approach to narrative autoethnography.

After interviewing five participants and reviewing my own experiences, I discovered our lives following injury were startlingly alike. What I discovered, which is represented in the stories, was that each of us endured referrals to specialist after specialist, seeking a cure and way back to our previous life (*'The merry go round: searching for a cure'*). We all went through a grieving process, grieving for the body and life we once had and we all felt misunderstood while we came to terms with our reality (*'Mourning the loss'* and *'Walk a mile in my shoes'*). Our hospitalisation experiences were so similar; they could have been carbon copies (*'Here we go again'*). While the final story, *'We're not in Kansas anymore'*, was mine, it is not inconceivable that it could happen to others and more than any other story illustrates stereotyping, stigmatising, labelling and above all a failure by healthcare professionals to listen and care.

This study, the results of which are presented in narrative form, has the potential to illustrate the tremendous impact chronic back pain has on sufferers. Stories, as already noted, are powerful education tools as they allow the reader into the world of a chronic pain sufferer. These stories can dispel the myths surrounding chronic pain behaviours. Stories can demonstrate that when someone living with chronic back pain enters hospital, they bring with them all their past experiences and the issues they face in the outside world. They also carry the remembrance of all of their previous hospitalisations. This means that they are not entering the hospital with a 'clean slate', unlike most acute patients. The literature indicates that most nurses also carry a recollection of their experiences with previous chronic pain patients and therefore, they too are not functioning without bias (Burckhardt, 1990; Ferrell et al., 1991; Gardner, 2003; Griep, 2003; Moss, 1988).

*'The merry go round: Searching for a cure'* is a story that indicates to healthcare workers that chronic pain sufferers are likely to be heartily sick of the medical system and have a history of their pain not being validated, by being told that their pain is "all in their head". When, as patients, they face nurses that disbelieve either

the existence, or the severity, of their pain, they are reminded of their previous experiences and this added invalidation multiplies the trauma.

*'Mourning the loss'* is a story that can educate people that sufferers have undergone, or may be in the process of going through, a transformative experience that leaves the person in a vulnerable state and in need of empathy and compassion. *'Walk a mile in my shoes'* asks the reader to appreciate that journey so that they can truly understand the life a sufferer must lead.

*'Here we go again'* outlines a 'typical' pain management hospitalisation and demonstrates the labelling, stigma and stereotyping that regularly occurs. *'We're not in Kansas anymore'* reinforces those issues. This study has the potential to inform nurses about the way sufferers may experience a traumatic hospitalisation and the role they can play in minimising or maximising the emotional distress felt by sufferers.

With a greater understanding, nurses have the capacity to fulfil the expectations of the chronic pain patient. Contrary to what nurses believe, chronic back pain patients, including my participants, don't expect nurses to be able to completely relieve their pain. All chronic back pain patients ask is that their nurses spend time with them and get to know them as a thinking and feeling person, as they would with any other patient. Taking this approach also has the potential to reduce nurses' feelings of frustration and helplessness as they interact with their chronic pain patients in a therapeutic nurse-patient relationship.

The patient also has a responsibility in the nurse-patient relationship. They must try to enter each hospitalisation with an open mind, by trying to put past emotionally traumatic hospitalisation experiences behind them. By giving chronic back pain patients a voice, this study can assist them to do this. All of the participants remarked that when a nurse was caring and kind, they felt validated and reassured and commented that these nurses "were like gold".

I hope that on reading this, healthcare professionals and others will have a greater understanding of what it is to *be* a person living with chronic intractable

nonmalignant pain. Chronic back pain sufferers are often misunderstood, sometimes by family, often by friends and usually by healthcare workers. My aim is that when nurses and others read this research they will begin to understand some of the reasons why chronic back pain patients act as they do and why nurses react to that behaviour in the way that they do. Living with severe pain without significant relief in the foreseeable future is difficult. However, having to live with the stigma and labelling attached to it is harder still. After reading the participants' stories nurses may understand this on an intellectual level, however I hope that they will share a connection on an emotional level as well and truly empathise with their chronic pain patients.

A new understanding and empathy by all healthcare workers will facilitate change in organisations, in the way hospitals organise wards to accommodate the needs of chronic pain patients. Chronic pain patients would benefit from having dedicated wards, staffed with nurses who choose to work with chronic pain patients. Patients would then receive the care they deserve and their nurses would have an increased sense of job satisfaction.

It is not only healthcare workers that believe the myths surrounding chronic back pain. Society subscribes to the same myths. The media, a major source of (mis)information, perpetuates the labelling of, stigmatisation and stereotypical view surrounding chronic back pain sufferers. This is most notably seen on current affairs programs that frequently air exposé features on people who are receiving compensation payments for supposed back injuries and are seen lifting heavy objects or performing manual labour. Fraudulent behaviour such as this is extremely rare. The regularity of these programs, however, gives the viewer the unrealistic impression that most people claiming to have back pain are frauds and the stigma is reinforced if that person is a compensation claimant. This research, through publication of the stories, may alter the perceptions of the general public and thereby ameliorate the false impressions created largely by the media.

The literature supports the contention that nurses label chronic pain patients and do not have the knowledge base to adequately nurse chronic pain patients. This study has not sought to interview nurses that care for chronic pain patients and

establish their perspective on their beliefs and attitudes that affect chronic pain patients. Nor has this study examined in depth current undergraduate nursing curricula. This study reflects the participants' experiences of the nurses they have encountered during their hospitalisations and corroborates the literature.

Undertaking this research has been a journey for me. On a personal level, it has given me the opportunity to reflect on the impact chronic back pain and its treatment has had on my life. While there have been many negative consequences, there have been some positive ones as well. As Leder (1990) highlights, pain brings the body to the forefront of one's mind. I have come to know my body intimately, as never before. I now trust my instincts implicitly. For three months prior to my open heart surgery, I was continually saying to my doctors "something isn't right". I had no specific symptoms, yet I knew that something was very wrong. My doctors assured me that I was simply experiencing side effects of long-term pain, so I didn't insist on any tests. Two days before I collapsed at home, I saw my local doctor as I was becoming really concerned and he assured me that I just had a "flu like virus". That experience taught me that I am the one who knows my body better than anyone else, including doctors. I now have the confidence to express my concerns and ask for what I feel I need.

I, like the other study participants, have also developed skills to manage my pain that I would never have thought possible. My mind is my strongest and most important defence against pain. Pain has taught me that my mind is a powerful ally if I use it offensively, rather than allowing the pain to overwhelm and dominate my thoughts. The stories illustrate the obstacles pain causes in our lives, but cannot convey the intensity of the pain that I and the participants feel. It is sometimes difficult not to feel totally overwhelmed and encompassed by the pain. However, a positive and hopeful attitude is an important strategy in learning to live with chronic pain. All of the participants expressed a need to have a meaningful life in the present, by participating to the best of their abilities, as well as maintaining hope for a better future. Without that hope, pain becomes soul destroying.

## **A personal reflection**

This research has caused me to be totally immersed in chronic pain. I have been reading about it, interviewing other sufferers, writing about it and at the same time having to live with it. I have now decided, as this phase of my life comes to an end, to approach my treatment differently. At present I have more trouble coping with the all-consuming fatigue that is the main symptom of chronic fatigue syndrome. My specialist has told me that my chronic fatigue syndrome is a consequence of having very long-term chronic pain. I am unsure whether this is the case or whether it is, in fact, a side effect of all the medication. I have decided to listen to my intuition and come off the medication. I have made this decision because I hope and believe that it may be possible to control my pain by using the sophisticated form of self hypnosis that I have taught myself. At the moment, I cannot use this method effectively because the fatigue saps my concentration and mental acuity.

Reducing, and ultimately ceasing, my medication is an unsettling thought because I feel the pain could be so intense it would be unbearable. I know, however, that recommencing the medication always remains an option. I plan to commence this new phase as soon as I have completed this thesis. Fortunately, I have found a new pain management specialist who believes he can perform a procedure that should greatly reduce my pain. He has had patients who have gained significant pain relief lasting between 9 and 24 months and it is possible to repeat the procedure as often as necessary. He says I may need some medication for breakthrough pain, but I am hoping that I will be able to manage without it. There are, of course, no guarantees. However, I am extremely optimistic that at last my future is looking up.

# Appendix 1 Human Research Ethics Committee Approval

Australian Catholic University  
Brisbane Sydney Canberra Ballarat Melbourne



## Human Research Ethics Committee

### Committee Approval Form

**Principal Investigator/Supervisor:** Dr Carmel Seibold Melbourne Campus

**Co-Investigators:** n/a Melbourne Campus

**Student Researcher:** Susan Ward Melbourne Campus

**Ethics approval has been granted for the following project:**

HOSPITALISATION EXPERIENCES OF SEVERE CHRONIC  
NONMALIGNANT BACK PAIN SUFFERERS.

**for the period:** 1998 to 2003

**Human Research Ethics Committee (HREC) Register Number:** V1998 53

The following standard conditions as stipulated in the *National Statement on Ethical Conduct in Research Involving Humans (1999)* apply:

- (i) that Principal Investigators / Supervisors provide, on the form supplied by the Human Research Ethics Committee, annual reports on matters such as:
  - security of records
  - compliance with approved consent procedures and documentation
  - compliance with special conditions, and
- (ii) that researchers report to the HREC immediately any matter that might affect the ethical acceptability of the protocol, such as:
  - proposed changes to the protocol
  - unforeseen circumstances or events
  - adverse effects on participants

The HREC will conduct an audit each year of all projects deemed to be of more than minimum risk. There will also be random audits of a sample of projects considered to be of minimum risk on all campuses each year.

Within one month of the conclusion of the project, researchers are required to complete a *Final Report Form* and submit it to the local Research Services Officer.

If the project continues for more than one year, researchers are required to complete an *Annual Progress Report Form* and submit it to the local Research Services Officer within one month of the anniversary date of the ethics approval.

Signed: ...  ..... Date: 30/04/1998  
(backdated).....

(Research Services Officer, Melbourne Campus)

(Committee Approval.dot @ 31/10/06)

## **Appendix 2      Participant information letter**

**AUSTRALIAN CATHOLIC UNIVERSITY**

[On university letterhead]

**TITLE OF PROJECT: HOSPITALISATION EXPERIENCES OF SEVERE  
CHRONIC NONMALIGNANT BACK PAIN SUFFERERS**

**NAME OF SUPERVISOR:            MS CARMEL SEIBOLD**

**NAME OF RESEARCHER:        MS SUSAN WARD**

The purpose of undertaking this research project is to discover and describe hospitalisation experiences of people suffering from severe chronic back pain not related to cancer, treated with long term narcotic therapy, for example: morphine, pethidine. I am especially interested in exploring the interactions between chronic back pain patients and their nurses, and hope this project will be useful in describing what patients feel are the most important issues for them in hospital. If you agree to participate, individual in-depth interviews will be conducted, and in addition, I will be asking you to complete a short history regarding your back pain and treatment.

To minimise inconvenience, and to promote your comfort, pain control and privacy, interviews will be conducted in the participant's own home, at a suitable time. As necessary, respite breaks will be offered to maintain your comfort and pain control. While interviews will be audiotaped, strict confidentiality will be maintained. Access to data will be restricted to myself and my supervisor. Your name, or any other identifying information, will not be published with the findings of the study. In the event of your feeling any anger or distress during the interview, the interview can be suspended at your request, and steps taken to alleviate any distress experienced.

It is anticipated that interviews will not exceed a period of two hours.

It is hoped that participants will benefit from participating in this research study by having the opportunity to explore and vent their feelings in a supportive environment. Once the study, or a part of it, is published, participants may have the potential to feel empowered, by being given a collective voice. It is also hoped that participants will benefit in the future from a greater understanding of their hospitalisation experiences by hospital staff. Discovering and describing the chronic back pain patient's perceptions of nursing behaviours will benefit both the participant and the nursing profession, as it will generate knowledge and will potentially influence the care behaviours of the nurse. As a group of patients, chronic pain sufferers often require frequent hospitalisations, and if the needs of



these patients and their relatives can be better served, this may result in shorter stays, fewer hospitalisations and a resultant decrease in health dollars spent.

The participant is free to withdraw consent and to discontinue participation in the research study at any time without giving a reason.

Any questions regarding this project can be directed to the Researcher:  
**SUSAN WARD** on telephone number: **(03) 9370 5235**

and/or to the Supervisor:  
**DR CARMEL SEIBOLD** on telephone number: **(03) 9241 4477**

in the department of **PROFESSIONAL NURSING DEVELOPMENT** at:

AUSTRALIAN CATHOLIC UNIVERSITY, MERCY CAMPUS  
412 Mt Alexander Road, Ascot Vale, Victoria 3032

This study has been approved by the University Research Projects Ethics Committee at Australian Catholic University.

In the event that you have any complaint about the way you have been treated during the study, or a query that the Researcher or the Supervisor have not been able to satisfy, you may write care of the nearest branch of the Office of Research:

*Chair, University Research Projects Ethics Committee  
c/o Office of Research  
Australian Catholic University  
412 Mt Alexander Road  
Ascot Vale, Victoria, 3032  
Tel: 03 9241 4513  
Fax: 03 9241 4529*

Any complaint made will be treated in confidence, investigated fully and the participant informed of the outcome.

If you agree to participate in this project, you should sign both copies of the Informed Consent form, retain one copy for your records and return the other copy to the Researcher.

---

Endnote: My surname changed in 2003, so this participant information letter reflects my name at the time of signing.

### Appendix 3 Consent form

TITLE OF RESEARCH PROJECT: **HOSPITALISATION EXPERIENCES OF SEVERE CHRONIC NONMALIGNANT BACK PAIN SUFFERERS**

NAME OF RESEARCHER: **MS SUSAN WARD**

I ..... (*the participant*) have read (*or, where appropriate, have had read to me*) and understood the information provided in the Letter to the Participants and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realizing that I can withdraw at any time.

I agree that research data collected for the study may be published or provided to other researchers in a form that does not identify me in any way.

NAME OF PARTICIPANT: .....  
(block letters)

SIGNATURE: .....

DATE: .....

NAME OF RESEARCHER: **SUSAN P. WARD**

SIGNATURE: .....

DATE: .....

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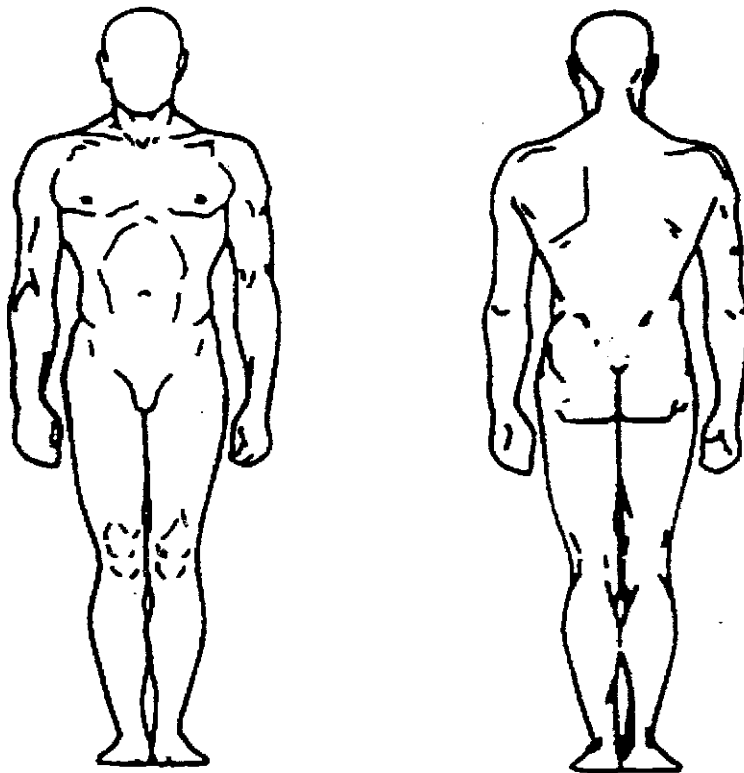
Endnote: My surname changed in 2003, so this consent form reflects my name at the time of signing.

## Appendix 4

### Chronic Pain Profile

Using the key, please mark on the drawing where you experience chronic pain.

Key: Pins & needles = 00000    Stabbing pain = /////  
      Burning            = XXXX    Deep ache        = ZZZZ



**From:** Uden, A., Astrom, M., & Bergenudd, H. (1988). Pain drawings in chronic back pain. *Spine*, 13(4), 389-392.

## **Appendix 5**

### **Personal and medical history**

Please answer the following questions. All information will remain confidential.  
Thank you.

#### **Personal Profile**

1. Year of birth:
2. Marital status:
3. With whom do you reside?
4. Are you currently employed, and if so, how many hours per week do you work?

#### **Injury / Disease Profile**

5. How long have you suffered from chronic back pain?
6. How did you injure your back?
7. Please list the type and number of investigations you have undergone in relation to your back injury.
8. Please list the surgical treatments you have undergone in relation to your back injury
9. How many hospitalisations have you had since the onset of your injury/disease?
10. How many days have you spent in hospital in the last twelve months?

#### **Pain Profile**

- 11 Rate your pain where 0 = No pain and 10 = Extremely intense:
  1. Right now
  2. At its worst
  3. At its best
- 12 Is your pain constant or intermittent?
- 13 What pain management techniques do you currently use to help control your pain?
- 14 How long have you been taking narcotic analgesics (e.g. morphine, pethidine) on a daily basis?
- 15 Who prescribes your analgesia?
- 16 Please list all the medications that you currently take to help control your pain.

## Appendix 6

### Original interview schedule

Opening question: Describe your experiences of hospitalisation and the care that you received.

Probe questions:

1. How would you generally describe your relationships with your nurses and doctor(s) during your hospitalisations?
2. Concerning your last hospitalisation for pain management, would you describe:

How you feel the nurses related to you as a person

How you feel the doctor(s) related to you as a person

How the nurses responded to your pain

How the doctor(s) responded to your pain

How the nurses responded to your pain medication regime

How the doctor(s) responded to your pain medication regime

Doctors' and nurses' knowledge of chronic nonmalignant pain, addiction and dependence, intrathecal pump regimes [in Allison's interview]

Did you encounter any stigma about your chronic back pain or your long term use of narcotics?

How did your pain respond to the medication regime?

What criteria did you use to determine the effectiveness of your medication regime?

Did hospitalisation raise any issues for your family, and if so, were they addressed?

Do you feel that discharge planning was done satisfactorily?

(areas including:

- physical impairment (eg. home occupational therapy assessment, RDNS, council assistance, walking aids etc.).
- psychological requirements (eg. counselling for yourself and family/caregivers).

- sexuality and sexual needs (eg. counselling, practical suggestions).
  - recreational and social needs (suggestions, support groups, group meetings – eg. crafts, hydrotherapy/water aerobics)
  - basic life support needs (sleeping, eating, breathing etc.)
  - financial counselling
3. Was your last hospitalisation a 'typical' experience for you?
  4. Is there anything you would like to see changed, to improve your hospitalisations?

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