

# Chapter 7

## Lives

*What would you do if I sang out of tune  
Would you stand up and walk out on me  
Lend me your ears and I'll sing you a song  
And I will try not to sing out of tune*

(John Lennon & Paul McCartney)

In response to the query, *What's going on?* the participants in this study told their histories. That is, how they were and how they came to be ill. Their talk of the past was quite distinctive and therefore relatively easy to recognise in the texts. However, the more one appreciates the influence and constituting effects of history upon a life story the more difficult it becomes to compartmentalise a narrative into the past, the future and the present. The present can become insignificant wedged between (or swirling amid) notions of the past and the future.

Following Gelven (1989, p.182), the key to the present as represented in the text was to ask the question, *What is being done?* When examples of what the participants did each day were explored, that is, their actions and their situations, it became apparent that the texts were revealing the 'present'. What the participants could do now demonstrated accommodations in their lives for their illnesses and the struggles they had, to maintain their preferred lifestyles. For the sake of clarity in this chapter the 'present' ways of being chronically ill are re-presented in the following sequence. They are presented through the things that each individual does to contribute in life (eg going to work, controlling the illness and being part of society) and through the things whereby the person receives in their lives (eg receiving treatments, taking medicines, being given medical advice, being given a pension or being given help).

As examples of 'ways of life' resulting from chronic illness there are two stories taken from the texts that I will re-tell. These stories illustrate the difficulties that two chronically ill people experienced. Both incidents are useful for considering the ideas of 'contributing' and 'receiving' and they are extreme examples of emotional situations. In a startling way they are reminders of the difficulties that chronically ill people can face and they partly explain the tendency there is for the ill to reside in contracted worlds where lives are easier to manage. While these two examples are 'out

of the ordinary' experiences, to an extent they do represent some of the difficulties that chronically ill people can face and they serve as evidence to substantiate the fears that some chronically ill people have of getting into predicaments which are hurtful.

Throughout the chapter there will be reference to the perceptions of both 'time' and 'space' chronically ill people adopt. It was interesting to note how the illness, to more or less an extent, affected and changed their perceptions of both time and space by either enlarging areas or making them smaller. For example, Ruth lives in a house which she and her husband have planned together. It is open plan and the sense of space within the house is impressive. Yet when she explained how she was confined to certain areas it assumed smaller and less impressive proportions. While her work in the house is laborious and slow she has the time to work slowly because other activities are not possible (fdnte:1.66). Some people's perceptions of their world of space become smaller because it becomes difficult to move, making places and things further away. Pam describes graphically her contracting world as she becomes less mobile. Colin's case study has already been used to illustrate how days could become longer when filled with fewer activities. Perception of time has also changed for people whose lives have become punctuated with regular rituals like taking tablets, measuring blood sugar levels or doing exercises.

As in the previous chapter there is also a strong theme of care; that is, the people's actions reveal what matters to them. In the last chapter concern or care was for things that were revealed in their accounts of the way they were in the past, even though they were still real and affected the person in their present and future. In this chapter the actions available to the person in illness demonstrate different and emerging concerns. These are new concerns which in instances just begin to hint at areas where perhaps new values emerge and perspectives develop which have enriching elements to them. I mean they may be the spaces and places for the start of a reconciliation with one's lot and where some form of peace may be found at times.

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### **Central Station**

In the last chapter Pam was introduced. She is a great storyteller with a vivid memory. She told this story with a mixture of humour and rue. After her diagnosis of rheumatoid arthritis she spent the remainder of her youth in hospital. Eventually, at the time of this story, as a young woman, she lived in a hostel in one of the large cities in Australia. The hostel was hardly more homely than the hospital and she told me the following story to illustrate how difficult it was to maintain tenuous links with her family and her rural home town. It is with hindsight that she sees how unfair the

situation was. As she tells it she describes the naive young girl who had not yet thought to rail against her lot in life.

This story impressed me because Pam shared with me an emotional glimpse of how it can be and feels to be chronically ill. It is a story that conjures up exactly what it was like for her to be chronically ill at that time; it also symbolises some of the tragedy of her life. Although it covers a short period spanning only a few hours of time, there are, packed into the story, rich examples of the insecurities and pains she suffered through her illness. So although the story is about years ago it has a great deal to say about the 'now' experience of chronic illness. She begins:

*I can tell you a story about Central Station (Sa:871)*<sup>1</sup>

She was living in a women's hostel, sharing a room with five other girls. By this time what little schooling she had been given was over and each day was spent at the hospital having physiotherapy. The hostel was strange because Pam was so different from the other girls. There was no privacy in the room which added to her discomfort; it was just like a dormitory or ward. At the time she was made to wear '*revolting plaster casts*' to sleep in. Her bed clothes were lifted by a monumental cradle reminding her and the others that her real place was hospital. The casts were large, heavy, '*spooky*', replicas of her legs. She wore those horrible things because she believed—'*If I was good I would get better.*' She told me, '*The splints never did a damn thing for me, to be honest,*' but I wore them because '*I was so good at behaving*' well (Sa:886–887).

This week the doctor surprised her by talking to her<sup>2</sup> —'*I called him Dr Flash because he would come in, say, "Hey", look at your charts and go, that was all the attention*' he gave you. Anyway this day '*... he said, "You know I'm going to have to re-do that hip—you're in for another operation." Just like that, no sort of preparation for it, he just said, "I'm going to have to change that hip again."*' As his way of softening the blow of the impending surgery the doctor thought that she should go home for the weekend. He did not appear to consider that it would be more reassuring if he was to sit and tell her what was going on. Her parents had no more idea than Pam what was happening and would be unlikely to calm her fears. However she dutifully prepared to go home for the weekend as instructed by the doctor.

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<sup>1</sup>The italics in these stories denote direct quotations from the participants' transcripts.

<sup>2</sup>Pam says that the catch phrase of her early life of illness was 'tell me'. The medical details of her earlier illness and treatment were never discussed with her. She can only make sense of what happened by slowly and incompletely patching her memories together to form speculative pictures.

There was a hesitation for one moment over the plaster legs. How could they be transported home on the train? Walking was painful and difficult as it was, without added encumbrances. Despite the problems it might cause she decided upon a compromised rebellion and chose just one cast. Wrapped in brown paper it assumed a bizarre semblance. Leaving the building with her burden tucked underneath her arm, she presented a queer sight—little and limping, covertly carrying a body part. Passers-by studiously ignored the peculiar sight.

The cab dropped her at the station entrance. The walk to the country platform through rush hour pandemonium was exhausting and painful. Although used to constant pain, this discomfort was exacerbated—she was breathless and anxious about where the train was and how to get herself and the leg on board and periodically wondering, ‘How could I could face more surgery?’ The mass of humans to-ing and fro-ing was a chaotic contrast to the dull life in hospital and was frankly frightening. Then, looking down, she noted her sore, booted, little feet and watched horrified as blood oozed up through the lace holes and between the stitching. With eyes clenched to stop tears, she wondered, ‘How come I’ve got both ingrowing toenails and arthritis?’ She did not want people to see her bleed—‘You can bleed in hospital, but not in public,’ she thought, despairingly. In that split second she would have given anything to be back in the hospital. It was a place where one could bleed without shame.

The woman in the ‘Ladies Waiting Room’ barely noticed her. Pam had fleetingly wondered if she would notice the ‘poor, pretty little thing’ and take care of her. ‘Please may I leave this parcel with you while I telephone my mother?’ She didn’t want to say, ‘While I clean this blood from my foot.’ The woman looked at the strange ‘body part’ and at the bleeding foot and said without a flicker of sympathy, ‘Yeah, if you’re quick.’ Pam hobbled away to sort herself out.

And then—Oh God! How mean! When she returned—no woman, no leg. Turning, she limped back down the platform to find another sour faced woman handling change for the toilets. ‘I said, “Look, have you seen a leg of plaster, part of the leg covered in brown paper?”’ “Oh yeah,” she said, “We put it in the toilets.”’ Pam then had to produce identification before they would return it. How pathetic she was. Who on earth do they think would illegitimately claim that horrible, burdensome leg?

Bad enough? She said, ‘I will never forget this. I got onto the train lugging the bloody leg and found a seat.’ ‘It was a late train and full of hoodlums and these boys were being smart, they were probably a bit drunk.’ They started bothering me—I wanted the ground to swallow me up—anything just to get away. But I always

remember one boy said to them, “‘Don’t, leave her alone.’” That train trip was hateful. I was miserable, confused and facing more surgery’ (Sa:871–934).

In mythical terms her journey could be construed as a struggle to return to her family. It was a journey set with obstacles and tests to try her to the ends of her endurance: the station, viewed as a hostile world full of faceless people tenaciously pursuing their own ends; the leg, symbolising the burden of her ill body; and the doctor, the power broker, the wizard, who sends her on a testing journey only to pluck her back to the world of the sick and painful surgery.

Although perhaps less dramatically symbolic, the existential view of this true story is where its immediate power lies. What she was trying to achieve was not an out of the ordinary everyday experience. Probably most people have shared some of the difficulties Pam experienced—an exhausting journey, the insecurity of weaving through throngs of faceless people, felt the pain of being an ‘outsider’ in a group or the embarrassment of being ridiculed. To consider another viewpoint, a good many would also know the feeling of walking, face averted, so as not to see another’s plight because the energy or inclination to help at that moment is missing. The accumulation of Pam’s trials and tribulations give one some sense of the amount of difficulty she had and the complexity of the challenges she faced. It was not just arthritis that made her journeys difficult but also adolescence, physical pain, separation from her family, impending surgery, ingrowing toenails, and so on. Over and over again when talking to chronically ill people they stressed that they still have their share of life’s difficulties to cope with as well as long lasting illness.

Compared to the world of the strapping mountain climber whose life she described earlier, Pam’s world had contracted. Walking the length of a station platform represented a tough challenge to her. From being the leader of the team, she became anonymous in the crowd and subject to bullying from young men her own age. It appears that her struggles and pain went unnoticed. Through this story it is possible to receive an understanding of how she felt and to feel to some degree her experience.

Pam also told me how weird it was that she became comfortable in the cocoon of the hospital:

*I must say that I got some sort of, again, a dangerous satisfaction of being comfortable and I can remember ...[pause]... and institutionalised. You see it, it’s when you are in pain and when you are afraid of the future, and when you don’t know where you are*

*going and when you are young and have no skills ...[pause]... or no identity, it's so easy to be sucked into this comfort of the institution and have other people dominate you.*

(Sa:823–829)

When faced daily with the type of struggle the story epitomises there is no wonder that Pam was afraid of the life she faced in the wide world.

Pam's storytelling does not consist of only her words. She is animated when she speaks and the intonation in her voice reveals impatience, suspicion, incredulity, embarrassment, pain, struggle and loss. Her face and her arms are used to add emphasis to the expressions. While I have adapted the story to a certain degree, it is not done to exaggerate it but in a poor way to make up for what is lost in the plain texts.

### **Pension problem**

Paul was introduced in chapter four—he has backpain. His last job was working with the families of young offenders in the community. This was almost as stressful as working in the prison as he was often abused and threatened by clients or their family members. Eventually his doctor put him on a sickness benefit and he stopped working. Paul is ashamed of being on a pension and in this story demonstrates that collecting the money can be an arduous task.

*Every fortnight I had to go and visit the Department of Social Security and put a form in and they would say, 'Bring it in on a Thursday.' It is twenty kilometres to the office. I would go in sometimes ... on a Wednesday—go to hand it in and they wouldn't take it, [they would say] 'Bring it in tomorrow,' which ... [shakes his head and clenches his mouth in, as a sign of frustration].*

(Oa:430–436)

Anyway, before he was due to go to \*\*\*\* [city] for the operation they sent him the usual letter with instructions to bring the letter to the office 'on 9th April, which was a Friday.' So, wanting everything to be right for the family while away he went into the office on the preceding Monday. Paul found the process of these 'handouts' humiliating experiences. This day he was in the queue with a man who had been a client in the old days; a man who had abused his children. He really believed that he should not be standing in a queue with people who had broken the law and who in his opinion were less deserving than himself. He wanted to appear different to the man but how could he—back pain is not apparent or tangible. Paul resigned himself to the

fact that they looked remarkably similar. 'I am here because I am sick,' he cried inwardly, with enough passion to make his heart race and his back ache.

He shuffled from side to side trying to ease the pain. There were no chairs anywhere; he could not take a walk around because he would lose his place and have to start queuing all over again. After over half an hour which seemed an eternity, his turn came. He held the letter out to the clerk behind the glass fronted counter and before he could open his mouth to give the prepared speech it was snatched from his outstretched hand. It disappeared under the hole in the glass screen like a possum up a tree. The clerk glanced at the letter and with a resigned look on his face said in a pseudo-patient voice, 'This says to bring it in on Friday.' 'I know,' Paul replied mirroring his tone, 'but Friday is Good Friday. There won't be anyone here.' Paul knew he had irritated the man. 'Well, you can't bring it in today.' 'That is okay,' Paul said, 'when shall I bring it in?' The clerk thought about this and said, 'Tuesday.' Now the frustration was beginning to well up inside Paul. He described it, 'The pain in my back was like two hard bricks pressing down, my stomach ached and my teeth were clenched.' He really wanted to cry but that was unthinkable—that, or reach through the glass hole and throttle his tormentor. People were shifting in the queue behind Paul. He explained that he was going to \*\*\*\* [city] on Sunday for an operation so he would not be in town on Tuesday. 'Well take it to an office in \*\*\*\* [city]' the man retorted. 'I will be in hospital,' Paul replied. 'Gotcha,' he thought. 'Can I bring it here on Thursday?' he asked. 'No,' was the man's belligerent reply.

A calm rage descended upon Paul; he thought of Chelle<sup>3</sup> and the kids. 'I'll tell you what, mate,' he said, '*you are here to serve me. That letter says Friday, so I will bring it on Friday and you had better be here to take it off me.*' Then the clerk flipped his lid and started swearing at Paul. Paul said, '*Excuse me, I work for a government department dealing with people too, you can't talk to me like that.*' "*Bullshit I can't,*" he replied and set off again (Oa:466–269). Paul was aware that the situation was getting totally out of hand. He asked for the manager but there was not one. He tried asking for the clerk's name but he would not give it to him. Paul felt that the people in the queue behind were enjoying the scene; he could hear their mumbling. Paul had to give up but before he did he clenched his fist tightly and shot it towards the clerk's jaw. Stopping just at the glass, he opened both hands and placed them flat on the glass which divided them. The man looked scared and Paul was ashamed, defeated, disgusted and so angry. His hands slipped slowly down the glass and dejectedly he turned for home.

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<sup>3</sup>Chelle is short for Michelle, Paul's wife.

He got back to the car and sat with his feet on the pavement and his head in his hands. He thought, 'Poor Chelle.' His hands were empty and his back hurt more than it was possible to describe. He packed his anger in a tight band around his waist and pulled it as hard as he could. The pain was radiant. Surely everyone could see it now.

Paul had tremendous problems receiving a pension. In order to receive he had to stand alongside people he knew were 'undeserving' and he knew their stigma rubbed off on him. He shared the common suspicion that out of work pensioners were largely a 'bunch of bludgers'. Paul longed for the man behind the counter to treat him as an equal, to recognise that he was different from the others in the queue; he really belonged there with him on the other side of the counter. Unlike the typical bludger, Paul wanted to contribute to the family income and he was especially anxious to settle provisions for Chelle while he was away in hospital. Coming home with no contribution was almost more than his pride could bear. He felt himself gradually becoming more alienated from the class of people with whom he formally belonged and from whom he acquired his values and beliefs. This dawning alienation was a frustratingly impotent feeling which frightened him.

The suffering described in both these stories is caused by an accumulation of Pam's and Paul's individual everyday difficulties which are partly attributable to the restrictions brought about by their illnesses and partly attributable to other people's insensitivity. Both Pam and Paul are made to feel different, insignificant and unworthy. A great deal of suffering results from the image of this diminished self. Both their worlds are smaller, because the world has become more difficult to traverse. Twenty kilometres is nothing to most country Australians, but for Paul it means wear and tear on the old car (and there are no savings to replace it), petrol to be paid for and a very uncomfortable drive lying on the back seat while his wife gives up her time to take him. These are all factors that cause him to fear failure—failure to be a good provider, husband or man. Consistently these worries chip away at his self esteem. It did not take long to appreciate these details when talking to Paul, but he feels that no one does know because no one in health or social organisations asks him to tell them what is happening to him. A little flexibility in the system or a kindly waiting room attendant would have transformed both these situations.

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## **Contributions**

Frankl (1985, p.99) has searched for meaning in suffering from his own experience and concludes that meaning in life is derived through people's responsible attitudes towards finding the right answers to problems and fulfilling the tasks which are set for



all humans during their lifetimes. These tasks form the contributions the person makes to life each day:

... they [tasks] form man's [sic] destiny, which is different and unique for each individual. No man and no destiny can be compared with any other man or any other destiny ... Sometimes the situation in which a man finds himself may require him to shape his own fate by action. At other times it is more advantageous for him to make use of an opportunity for contemplation and to realize assets in this way. Sometimes man may be required simply to accept fate, to bear his cross ... When a man finds that it is his destiny to suffer he will have to accept his suffering as his task; his single and unique task. He will have to acknowledge the fact that even in suffering he is unique and alone in the universe. No one can relieve him of his suffering or suffer in his place. His unique opportunity lies in the way in which he bears his burden (p.99).

Like Frankl (1985), people in this study all found that, although they were not always alone physically, they were alone in their suffering. All of them at some time or another remarked that no one else, despite his or her sometimes touching sensitivity, could feel their suffering. The ability to be close to someone who is suffering does not depend on the sufferer to communicate their difficulties but upon the other to be able to conjure up some related familiar feelings. Dass and Gorman (1985) explain the vicarious understanding of suffering in this way:

Perhaps we've not experienced the corrosive pain of illness, persecution, starvation, or violence ... But each of us has experienced our fair share of not getting what we want or having to deal with what we don't want. In this, we all know suffering (p.54).

The tasks or contributions in this part of the chapter are the means by which the participants reveal the significance and meaning that chronic illness has in their particular lives. They also demonstrate the shared circumstances in which they bear their illnesses. The tasks or contributions that have been chosen for consideration in this chapter are work, self care and socialising.

## **Work**

Both the men and the women in this study were concerned about the effect that chronic illness had upon their ability to work each day. Some measure of the meaning and significance of their diseases to themselves can be understood in terms of how much it interfered with their ability to work; that is, to work or to consider themselves useful. To be considered by others or consider oneself as useful is to reach to the heart of self esteem. More or less, work fulfils the functions of providing money, filling in time, providing social company and is an outlet for talents. Most significantly, though, work is the means to independence and a source of pride.

Jane describes how she has managed really well with a failing liver. As far as she is concerned she has been able to maintain her work as a mother and housekeeper. Even though it was difficult she managed to keep ahead:

*I'd just quietly take the tablets and keep things at home as normal as possible ... I would take Danny to whatever was going on or umm, I, I don't think he was disadvantaged in any way. Err ...[pause]... probably less so because I made such an effort.*  
(Va:220–224)

*I'd get up in the morning at about seven o'clock, and do what I had to do. I would walk the dog and get Simon [husband] off to the office and Danny off to school. I'd do the basic tidying up of making the beds and doing the washing up and I would be back in bed by nine o'clock and there I would stay, probably until four when Danny came home ... I would only go into town for shopping ... apart from that I just stayed at home—there was a problem that I could go into a coma ... there were occasions when I did go into a very deep sleep and have trouble coming out of it.*  
(Vb:6–17)

It was interesting to investigate why and when paid employment outside the home was given up. This inquiry threw up marked differences between the men and the women in this study. The women were more flexible in terms of what they would do as work. For example, the ones who had not reached retiring age would take on unskilled part-time work (Sky, Pam and Peggy) or start studying (Sallyanne and Ruth). Those women who remained at home found that by making accommodations they could continue the work of housekeeper (Jane, Pauline, and Elizabeth). This was despite the reality that home management was difficult and tiring and took inordinate amounts of time.

*Now, the way I have managed to organise myself is to say—well if it was windows, I would give myself a roster for two weeks and I would wash one window one day and then I would wash the outside of it the next and I would just work around the house and I would do it that way.*  
(Pb:163–167)

The men were less prepared to be flexible, taking the attitude that if they could not do their job as well as everyone else, they were not prepared to do it at all. I saw no signs of them taking an interest in alternative forms of work such as some household work.

Women in rural Australia are quite used to taking whatever part-time work they can because there is not a great deal of choice in these days of economic hardship.

Work in the home can be paced and therefore done in full capacity and to the best standards but done at a much slower pace. The results are rewarding: a clean and tidy home and well fed family are marks of success and tangible signs that the person is 'doing well'. Williams (1993), in a single case study of an elderly woman with arthritis, found that being able to manage and clean her own house were outward indicators that she was worthy and independent.

Paid employment outside the home is different to work in the home because it usually has to be done to certain times and standards. These exactions may be imposed by employers, colleagues or by the person who is ill. When the participants could not meet these standards they gave up work. In the last chapter Peter explained that he left work as a school teacher when his speaking and writing were not to the standard he expected and when he felt he could no longer command the children's respect. For a short time he tutored a child in maths at home but did not really find it interesting and has refused any other similar work since that time. Jim was self employed and soon found that with chronic fatigue syndrome he was not doing a good job and that he was, at times, unsafe.

*I'd get underneath a car, or something like that, to remove the axle or something like that—I'd be dropping the spanners. Err, by the time I [had] a couple of bolts undone me arm would ache, I couldn't hold onto the spanner because I would lose me strength. I would just have to call out for someone to come and help me get back on me feet again ... and when I told the doctor he said, 'Well, we had better have you off work.'*

(Ja:68–78)

While I expected some people to ask the question, *Why me?* when considering their illness, people, in fact, were more often concerned with *Why now?* The *Why now?* was usually asked because the illness interfered with life plans to do with work. Sky started nursing because she had always wanted to be a midwife. The general nursing was very stressful and may have contributed to the onset of ulcerative colitis but it was when she was doing midwifery that it got so bad she had to give it up.

*It [midwifery] was the whole reason I ever went into nursing, that's why I've got all these bloody birthing books, 'cause I wanted to be*

*a midwife ... Oh it was just outrageous—anyway I got sicker and sicker—I mean two or three months into it ...*

(Ua:204–228)

Although disappointed, Sky came to realise that nursing and midwifery were too stressful for her constitution. She now meters her work outside the home carefully and has a much lower key part-time job. She mourns her unfulfilled potential and this sometimes causes her to bemoan her lot.

*... this was the peak of my life, you know, I was—my career was zooming, my house, I'd bought my house. Who wants this fucking illness? No way! I just ... I was going to leave home every second day. It was all Steve's [husband] fault, I hated his guts, you know ... and we lived in this God forsaken climate and it was bloody cold and I hated [it] and that added to my tension ... and I can't work and I'm sick and ...[pause]... Oh it was horrible, Mary, I mean it was just ...*

(Ub:498–514)

Zoe is another one whose work plans were interrupted by her disease, lupus.

*Oh, God, I am going down this road again—of another illness—and I am having a ball. My business is growing, I'm loving my new job. I've suddenly found myself ...*

(Za:370–373)

Work is so profoundly part of a self image that it is hard to compromise or to give up work which contributes positively to that image. The women found that no matter how difficult it was, they could maintain their work role within the house. Ruth even refused some home help she probably needed so that she could retain her control and get her children to do their normal share. She said:

*... they'd [home help] come two or three days if I wanted but I get it once a week. But that's to maybe train the kids to be tidy.*

Mary—Umm.

*'Cause I think you can be prepared to do all the work but it is no good for the kids. And it is no good for me because I need to do a certain amount of work.*

(Ra:347–354)

Sky describes how she can be more in control of her illness, working in the home at her own pace:

*I just sort of thought, 'Well, shit, I'm going to have to look after myself.' So I just stayed at home and looked after myself and just cooked and worked in the garden and sort of just generally enjoyed myself. I really put this amazing effort into looking after myself, you know. I used to get up every morning and just do my yoga and just walk and, I don't know, and just keep the house clean and I led a really peaceful life.*

(Ua:313–321)

The men in this study who were unable to work found their days were longer. They did not find useful roles for themselves in the home, and different, more accommodating roles in the workforce did not appear to be viable options. This was either because they did not exist or the men were not prepared to do them, or they had not considered alternative work. It has already been shown how Colin found time passed very slowly and Peter was far more inactive than he needed to be.

*Well, I get up at about, oh, ...[pause]... quarter to eight, have a shower, go and sit on the back verandah in the sun, where it is a bit warmer, at this time of the year and as it gets hotter I come inside because I can't take the heat too long. Then I watch TV and that is it. Oh, I might take Mum down town, down there you know, to the local shop, local shops, and drive her down and drive her back, she gets out and goes for—and buys everything and I just sit in the car and drive back and then I, I just walk when I come inside and I sit in here and I don't do anything, you know.*

(Ka:143–154)

Holly continued to work despite severe arthritis. She did clerical work at one of the residential educational colleges. She describes how difficult it was in this way:

*... the girls in the kitchen ...[pause]... used to stand at the door. I used to have to go across the dining hall to put the mail in the box for the students and the girls in the kitchen used to stand at the door of the [kitchen] into the dining hall and the tears rolled down their cheeks when they seen me shuffling across the dining [hall]. I said, 'I don't know what you're whinging about.' It was me that should be crying (chuckle) because it was hurting so much. But err,*

*they were most concerned. But umm ...[pause]... I worked all the time.*

(Qa:81–90)

Holly has retired now and although she is still incapacitated by the arthritis she has gotten rid of her cleaning lady and fills her days with housework:

*I just keep it more or less up to date every morning—well, people say to me, ‘Why do you sweep the patio every morning?’ I say, ‘Because it is habit and I like to do (chuckle) that.’*

(Qa:278–280)

She also keeps active socialising with her many friends. She has little time on her own, enjoying company and feeling none of the inhibitions that Colin and Peter seem to have with other people. She is not overtly depressed by her condition and is fun to be around. However, despite her cheerfulness she has had:

*... twenty years at least—that’s seven thousand, three hundred days, and for seven thousand, three hundred days I’ve had pain of some kind or another and some err, worse than others—some excruciating, some dull, some in between, but umm ...*

(Qa:45–49)

There is not one explanation in the texts for the difference between those people who continue to work and those who do not. However, for those who are not able to work, time passes slowly. The people who work have a mission and purpose to rising each day which may be there for the unemployed but it is not so apparent. Colin retreats to the cool side of the house, Jim sleeps a lot, Peter watches TV, and Paul reports: ‘... *my day was spent lying down. My wife was doing everything which was really upsetting*’ (Oa:394–396).

Home can be both a haven for people with chronic illness and it can be their prison. The home can become a small world for people like Peter, a place where he sets aside his problems and is not challenged and where his life is dull. It is rather like the situation in which Pam found herself as a young woman. She knew hospital was unnatural and an environment which was stunting her growth but it was where she had begun to feel at home. The hospital milieu protected her from the horrors of Central Station. This is not so for everyone. Jane has made her home the hub of family life. It is where she works for the family and where she welcomes the outside world in, on her terms (fldnte:3.3). Whenever I went there she would sit with me and concentrate on what it was I wanted to do. There were no distractions like making coffee or tea. Recently she has started to give Bible classes again; the children are delivered on time

and sit around the large dining room table. Their parents are careful to collect the children on time to conserve Jane's energy. The family has also started to entertain again. Usually the party is the 'Aussie barbecue' because it is easy and the friends all bring the food and are careful to clean up before going home. Jane is grateful for her friends' consideration which gives her the confidence to do more and open her house up. In return, she is a calming person who gives her friends her time and attention.

It does appear that the women were able to find work of value in their homes and this was not so for the men. Running a clean and tidy house was really important and considered valuable work. Both Ruth and Peter are similarly disabled with multiple sclerosis. They both just about manage to walk around the house, still. Ruth runs the house and still meets friends in town and goes to hydrotherapy, quite a marked difference from Peter's life of virtual inactivity.

Even Sky, who is of a younger generation than the other women in the study and who might be described as a 'career woman', valued homework and said she would be quite content to stay at home and care for the house and herself. If anything, the men avoided household work, I suspect, because the exchange of conventional roles accentuated their perceived loss of masculinity. I noted the men never made tea or coffee but their wives would bring me one. Dr Craig was slightly different. He mentioned doing the shopping for his wife and meeting his friends while he was in town. Retired men commonly contribute to the running of the household by taking on specific chores which are considered acceptably masculine, for example, shopping or emptying the rubbish. Alan is the only man who helped with the study who is still working. The others are retired and four have had to give up work.

There are still fairly strong social conventions that men go out to work. Loss of work is regarded by many as a failure to provide for one's family. Despite all the changes in modern society, providing still appears to be predominantly viewed as the male prerogative. I suspect that this sentiment is more defined in country Australia; however, Register (1987) talked to chronically ill American city men who had swapped roles with their wives and ran the home. She found there were similar sentiments amongst these men; that is, they found little value in the work and it was not viewed as 'men's work'. One person put it like this:

I get nicknamed "Mr. Mom" now. I'm the one who stays home with the kids, cooks dinner, and tries to keep the place in a halfway decent living condition, and she's the one who works. Actually, we've done a 180 degree role shift. Before the kidney transplant, when I was on dialysis, I had a really rough time dealing with that ... I am just the one at home now. I'm not making the money anymore—she is. I would like to get retrained in computer programming. I look forward to that. But you've got to look forward to something. Otherwise you'd go crazy (p.96).

This is fairly blatant sexual stereotyping, but the women do not appear to suffer so much from the image of being physically weak or sickly. The picture of them struggling on in the house is lauded. Indeed Pam described an almost perverse attachment to her new frail image at one stage, something I cannot imagine any of the men feeling:

*I was losing weight rapidly ... and I can remember the nurse at the end of the ward say, 'Oh isn't that terrible' [referring to her general condition] and I went as white as a sheet [she was severely anaemic] and I had always been a ...[pause]... bit of a fat kid, I suppose, in my Amazonian [days], and I suppose with all [the] sports I was pretty big and I started to be interested in the fact that I was looking pale and you know ... my identity was changing, you see, and I rather enjoyed it because I always hated me being beefy and sort of butch umm, and my skin began to become opaque and I began to be able to sort of wear very slim [clothes] ...*  
(Sa:231–240)

The women were far more likely to find and take on part-time work, which, although tiring, was worthwhile. Peggy quite often takes on part-time secretarial work for short periods. She is used to this type of pattern of working and fits it into periods in her life when she feels well. The part-time work is not prestigious but it is flexible. Although Sky feels she is wasted to a certain extent because she is not nursing, she appreciates the work she has because she can do it at her own pace:

*Some mornings I wake up and I just feel, like shit. I feel absolutely appalling and I really don't want to go to work and I know if I have a hot shower—I always like a hot shower—once I have a hot shower and something to eat I'm generally okay. Some days I don't make it through that, I really don't, you know. There's some days I just think, 'Stuff this,' you know, '[I'll] stay and read books on the couch today.' I take more sick leave than probably what your average person does.*  
(Ub:372–381)

It is rare to find employment where such flexibility as Sky needs is acceptable. Yet it is important for some people with chronic illness to find a place to work where accommodation is made for their illness such as allowing more than average time off sick or where people are allowed to work at their own pace. People fear that if they do not give equal contributions to fellow workers they will be viewed as burdensome. We



have already seen how Colin was afraid his son might accuse him of not pulling his weight on the property and gave up work before this could happen.

Unemployment can have depressing effects upon a person, accentuating their feelings of disregard for themselves and frustration with a life dogged by illness. This is an area of concern and one where people who are chronically ill could be helped.

### **Self care**

Time and effort is expended by ill people in terms of maintaining their health and preventing their condition from deteriorating. They do not differentiate between physical and mental efforts, for when they are helping themselves the right mental attitude is just as important as physical treatments. These efforts include complying with medical regimes, exercising, eating appropriate diets, engaging in some complementary therapies and maintaining a positive attitude towards their lives in general. There is a strong underlying social ethic which dictates that those who help themselves are worthy. Sarah was quite blatant in her denouncement of other people with rheumatoid arthritis who could not or would not help themselves and who therefore took up competitive resources. This piece in the text comes when she is bemoaning the fifty per cent cut in home help she has been forced to accept:

*... there is such a demand for it [home help], I can't understand. You know, there are a lot of old people, really incapable people who should be in a home. But, for instance, one lady who has chronic arthritis doesn't want to get out of bed, doesn't want to try so the home care is there, twenty-four hours a day. And it is up to the doctor to say, 'No, you are going in a home.' But he doesn't and the people who still want to get on with life, they're umm, victimised.*

(Xa:383–390)

There is also a feeling that the expenditure of time and effort may stave off the gradual onset of dependence. Peter who is not prepared to join society, preferring to keep his own company at home, still works hard to maintain his independent status and quotes his motto: '*use them or lose them*' (Ka:189) which he was taught in the city hospital and which is a fairly common expression I have heard in Australia.

The participants used the metaphors of fighting and combating the disease. Quite commonly they referred to 'refusing to be beaten', 'licking it', 'keeping ahead of it', and so on. They referred to their illnesses as if they were something other than themselves that needed to be controlled and that were malevolent. There is a modern critique of these types of metaphors (Sontag 1979; Wilson Ross 1993) whereby these

fighting metaphors are seen to perpetuate the common although undercurrent misconceptions of illness as an evil which is dealt out to people as punishment,<sup>4</sup> as something alien which happens to the body and which must be controlled, as something which can be overcome, given the will to fight. While I accept that these metaphors contribute to the overall unhelpful attitudes towards ill people and ill health generally, it does seem that some participants believe that this combative attitude has been an important means of surviving and living with chronic illness. Jane talked about always keeping ahead of her liver disease and is justly proud of her achievement of living fifteen years beyond medical speculation. Her outlook and attitude towards illness are undoubtedly a part of her 'success'. She said to me:

*... that was the way I decided that I would attack things and that is the way I did ... the thing was that my liver was deteriorating and at that point, I mean, it was going to kill me, sooner or later. Umm, I just assumed that it would be later because it would have to catch me first.*

(Va:160–173)

People did not appear to choose one attitude towards their disease or the predicaments in which it put them. Nor did they describe phases of reactions to their illness—such as shock, denial, anger and so on. Their moods and attitudes oscillated in time, altering the ways in which they behaved and coped with their illnesses. Among the texts collected in this study there were several examples of attitudes which could be applied to the task of living with illness at different times. There was the fighting spirit, the resigned/passive attitude, and there was an embracing attitude. Also in the texts was a mixture of examples of anger, resentment, frustration, fear, sadness, humour and love. These were all emotions born of the predicaments in which chronic illness had placed these people. Broadly speaking, love was more evident in narratives in which the teller at the time enveloped the illness as an integral part of their Being; anger was more evident in the fighting spirit and resentment brewed in those who were helpless. I believe it is significant to note that examples of all three can be found in most people at some time or other. For instance, Sky is incredibly angry some days but she can become deeply introspective, philosophical and peaceful at other times. Colin appears on the surface to be resigned and rather depressed about his condition and altered lifestyle; however, there are times when he is quite animated and obviously interested in the pathology of Parkinson's disease (fdnt:1.99). Register (1987) understands this oscillation of attitudes and emotions towards illness. She writes:

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<sup>4</sup>Sallyanne recalled that when her sister-in-law told an old family friend that she had disseminated cancer the friend replied in shocked tones that she had had no idea Sallyanne had been so sexually promiscuous.

I learned a lesson which the experience of illness teaches over and over again: No matter how sophisticated your intellectual acceptance of illness, your emotions always lag a bit behind (p.86).

The emotions and attitudes appear to propel these people through life: anger and fighting conjure up strong, determined, quick movements—they spend days filled with purpose. Resentment and resignation conjure up stagnation with still, but slowly poisoned, lives, and the rare, but rich, embracing, loving attitude towards both oneself and the illness conjures up peaceful, flowing movement.

When Sarah read the first transcription of her talks with me she commented on how angry she was. She had not realised how palpable and recognisable the anger was in her demeanour (fldnte:1.54). Her anger is like a force which propels her through life. She sometimes feels she needs to fight for all her comforts—from her family's attention to support from social services. Even though she voiced some surprise at the amount and force of her anger she recognises it as an integral part of how she copes with life. She has had a life full of tragic loss<sup>5</sup> and she is used to railing against her lot; this reaction to life's incidents is one of her mechanisms for survival. Her antidote to the anger expressed to others is a world of music where she can distract herself from the frustrations, worries and pain that rack most of her time.

Sarah has studied pain management and teaches other people distraction and relaxation therapy. Intellectually she accepts and teaches others that illness is an holistic concept. However she finds this way of living difficult and tiring:

*As you know, arthritis is a progressive disease which flares up at the most horrible, inopportune moments ...[pause]... so what I have trouble with now, despite all my methods (rueful chuckle) for control and management of chronic pain, is the progressive incapability of my body ...*

(Xa:141–144)

*That is not self pity, it is just a matter—a fact—it is a matter of fact. And I think the mere fact that you are so tired, you think, 'What the hell, I am not doing it anymore.' So you stay home—you are not going to the concert, you are not going to this, that and the other thing.*

(Xa:508–512)

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<sup>5</sup>Sarah's family was imprisoned in a concentration camp during the last war. On their return to Europe all their savings and possessions were gone. Sarah's husband was killed in a car accident and only a few years later her son sold the farm which she had entrusted to him.

Self help and a ‘fighting spirit’ mean to Sarah that she needs to be resourceful and expend vast amounts of her very limited energy, sometimes more than she thinks she has. She also feels to a certain extent that to be resourceful and self sufficient is to allow others off the hook. She is irritated by how inconvenient her illness appears to be to others who are required or requested to help her, whether they be her family, friends or members of the medical profession. The following excerpt from Sarah’s transcript relates to the help she used to get from her home help; it reveals her anger and frustration with both the authorities and her daughter-in-law. She believes that part of the reason that her home help’s hours were reduced was because she tried to make herself look good each day. She dresses immaculately and she always wears makeup.

*I have a home care err, daily umm, who I have six hours a week who used to do my grocery shopping. That is now out [clipped voice]. They are not allowed to [do] my shopping anymore, so I am stuck with that. And now my daughter-in-law does it, under sufferance uhh, which makes me feel uncomfortable, not guilty, but uncomfortable. I cannot [louder] go and stand in queues. I cannot go and shop and reach for things because I drop things and that’s one—and I am on crutches that’s two [reasons].*

(Xa:291–299)

Sarah’s anger is directed at the people and organisations which she feels have let her down rather than at her illness itself. This anger does energise her to face the authorities and people and demand what she needs. She attends to her illness in the ways she has learnt (distraction, relaxation, and the self administration of narcotics) and she contributes to the welfare of fellow sufferers through teaching and by being an official of the arthritis group. On the day that I attended this meeting she helped to arrange and advertise an outing to the local museum and ensured that everyone who wanted to come would have appropriate transport. She did this in an efficient and kind way. Her anger is not overwhelming, rather it is a part of her life which she manages to express. Lois Keith (1994a, p.1), ‘a wheelchair user paralysed from the waist down’, reminds me a little of Sarah—her anger is not directed at her disability or herself but at the injustice she experiences. She uses this incident to explain and demonstrate some of her anger:

*After our meal I was getting into my car when the all-too-familiar happened. In a busy road, with cars parked on both sides, I kept the traffic waiting whilst I folded my wheelchair into the nifty mechanical hoist which stacks it on the roof of my car. A thirty-something, City banker, BMW type approached, offering much-unnneeded help, and tried to close the door, which clearly wouldn’t shut what with the hoist very slowly moving its way up.*

I was pleased with the way I dealt with this one, uttering a pithy phrase like 'Leave my door alone, you stupid idiot, can't you see you'll just have to wait' and at the exact moment slamming the door shut. Furious, his face now scarlet, he swore at me through the closed window, insisting he was only trying to be helpful.

What can you expect? I turned to Sall, expecting solidarity, sympathy. Hadn't I for once been AMAZING, dealing so adeptly with one of the pillocks of this world? Silence. Sally did not approve. She was upset and thought I had been unfair. She wasn't proud of me.

We began to talk about the unspoken layers of difference between us. Her dislike of aggression, my feeling that it is sometimes the only way I can deal with the world. Her feeling that in rejecting genuine help, I was rejecting her. My feeling that she had to accept my definition and understanding of the world. I lived it. I knew how thinly people disguised their patronage, fear and dislike of people who were different, people who were disabled. Her feeling that there was more rage here than she could deal with. We both cried. We made up. I respect her for wanting to talk about it honestly, but it hurt us both (Keith 1994b, p.68).

Keith (1994a) describes this anger or rage so well and has encouraged other women with chronic illness and disability to write and express their rage. The thinly disguised '... patronage, fear and dislike ...' of people who are different is something she has learnt to recognise, it is not some prejudice that she makes up—it is borne of experience in the world as a disabled woman. However, she does not live this rage all the time; it is something that erupts during bad weeks, or crops up when she is treated unfairly. However, there are other views which can exist alongside sporadic anger. In response to Lois Keith's call for more anger to be expressed, Maria Jastrzebska responds this way:

... I also want to put another view to you, partly to play devil's advocate but also because I believe it. Surely feminist/women's creative writing doesn't all have to be overtly militant, explicitly angry with strong heroines and neatly wrapped up triumphant endings. You seem to have a blueprint of how you'd like us to write but maybe we don't all fit into the mould!

I hope there will be some room in your book for sadness, loss grief, frustration which are also part of our experience (1994b, p.201).

It appears when I turn to the texts to examine the participants' ways of resisting the disabling effects of chronic illness, I find examples of *struggle* more than fighting. There are extreme examples of struggle (as in Pam's story at the beginning of the chapter) using every ounce of precious energy to remain a part of society, to retain control of life and to have a role (Jane's perseverance to maintain her role as mother in a Christian family is another). There is also the unremitting struggle of just 'keeping going' from day to day in order to maintain as much independence as possible. Elizabeth puts it this way:

*Sometimes I think it is because you haven't got any choice but to cope.*

Mary—*Yeah.*

*You either give in to it and you lose what goodness you have in your life, or you cope. You know you haven't got any choice.*  
(Ib:825–829)

The struggle is generally considered essential by those who engage in it, but their stories reveal that it is hard work. On searching the text for examples of what the people did to resist or combat their diseases, most of the revealed behaviours involved energy and self discipline. It is about the struggle involved in working to maintain a social life, a positive attitude, a healthy body, control in life, and so on. The people in the study found the struggle involved in everyday life very tiring:

*The fatigue is incredible and it is just as if you're going through a rice pudding, sometimes, pressing yourself to do things and to shift the system.*  
(Xa:504–507)

Sarah, a struggler par excellence, wrote this poem about the relief she feels when the responsibility of keeping going is taken from her for a while. This generally occurs when she is admitted intermittently to hospital.

### ***Hospital***

*A sense of relaxed trust  
In blurry faces poised over me,  
A sense of powerlessness  
Lying prone in the blue bed, and  
Noises of caring floating around me  
A giving-in to the tiredness and pain,  
Of holding myself erect  
For the world and for myself—  
Hospital; A last resource for me  
To shed responsibilities—and rest.*

(D.C. TvB)<sup>6</sup>

Those people in the study who were depressed<sup>7</sup> found maintaining the everyday struggle extra hard. They had less inclination emotionally, physically and spiritually, to struggle. Anti-depressants could make them feel lethargic and unable to motivate themselves. Elizabeth referred to depression as '*this heaviness*':

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<sup>6</sup>Personal communication—'for Mary: with your understanding and perception, may your ideals come true'.

<sup>7</sup>Recognised by their doctor as clinically depressed and receiving anti-depressant tablets.

*I can't explain this feeling inside of me, like it is in here, it's a heaviness and things that mattered to me before don't matter. Umm ...[pause]... and the energy I had before, it's just not there, and I just can't get up and go.*

(Ib:263–267)

Jim found that it was at times difficult to discern the symptoms of chronic fatigue syndrome and the side effects of his anti-depressant tablets. In one examination at the technical college he was disappointed to get only a mark of fifty per cent. He complained to his doctor that he found concentrating and remembering things difficult. The doctor looked up his list of medications and said there was no wonder he had problems:

*... when he looked at my file and he said, 'Err, no wonder you had problems. You've been on seventy-five milligrams of prothiaden.'*  
(Ja:959–961)

Until then Jim had presumed that chronic fatigue syndrome was the sole cause of his fatigue and lethargy and it was the fatigue that confined him to the lounge in the sitting room for a large part of each day. In the last chapter it was noted how denying that depression caused him to be ill, was an important factor in securing a tangible diagnosis of chronic fatigue syndrome in the first place. However, now it is important for him to recognise the part depression and the anti-depressant medications plays in his condition so that he can begin to work or struggle to correct their effects.

Pam has become good at assessing her own moods. During the time we worked together she decided that there were problems from the past which were affecting her emotionally now and making her feel depressed at times. She arranged a series of counselling sessions for herself—'to sort herself out emotionally' (fdnte:1.83). Colin began to recognise how debilitating depression was once it began to lift. He was noticeably improved when I spoke to him six months after the initial tape recordings. His depression was recognised by his neighbour and friend who happens to be a doctor. Colin was handed his first course of anti-depressants over the back fence (literally) and he found them so helpful that he now gets a regular prescription from his own general practitioner (fdnte:1.99).

Most of the people I spoke to got depressed about their condition at varying times and found that this would affect how they managed their lives. Nine of the people were depressed enough to require medications or, as in Pam's and Sky's cases, counselling. There appeared to be little in the way of help offered to people with depression besides anti-depressants which sometimes exacerbated their feelings of

lethargy. It is extremely hard to struggle on when depression hits and more attention to people's moods could be a key to helping them. Continually picking oneself up and carrying on becomes wearing and is a lonely business.

The old maxim—'laugh and the whole world laughs with you, cry and you cry alone' has a ring of truth. Holly, who remains remarkably cheerful on the surface despite years of pain from arthritis, explains that her cheerfulness is her normal facade. It makes her popular but this popularity does not make her life significantly easier to live. She puts a great deal of effort into her cheerfulness and is sometimes disappointed by people's responses to her:

*... if people say to me, 'But you never complain,' and I said, 'Well, what's the point in complaining, people don't want to know about it,' and err ...[pause]... and sometimes, you know, somebody will come along and they will say 'Oh, how's your arthritis?' [I reply], 'Oh, still there, you know, still with me, it's lovely.' (laugh)*  
(Qa:115–120)

*I'm not blowing my own trumpet, [but] somebody said [to me] once, 'Everybody loves you,' and I said, 'Yeah, well, I love everybody.'*  
(Qa:306–309)

This is not always true and it is at home where Holly is apt to drop the facade of cheerfulness:

*I am fairly placid, well, I'm so placid I'm stupid, you know, and somebody once said, 'Do you ever get annoyed?' I said, 'By Jove I get annoyed, sometimes I get really cranky (laugh)'—'Oh when?' [they asked] 'Only with Steve [husband], he gets up my nose sometimes.' But, umm ...*  
(Qa:355–359)

Frank (1991, p.64) describes two types of emotional work that are involved with being sick. The first is the work of trying to work out the meaning of the experience of illness. This is hard work with people who care and who are prepared to hear about frustrations, fears, sadness and so on. The second is the work done to maintain an emotional appearance which is socially acceptable, which coincides with what is viewed as good behaviour for ill people and could be any behaviour, as being cheerful, brave, uncomplaining and so on. For the chronically ill this is not always just a facade or appearance, they can genuinely behave in these ways sometimes.



However, the hard work of facing emotions and coming to understand the meaning of experiences is too often neglected.

The temptation to retreat from the struggle in the social world is felt by most people at times. In some instances it can be quite restorative, as in the days Sky occasionally takes off work and spends reading books on the lounge. There is some relief to be found away from people and a society that advises how one should behave. Brody (1987, pp.102–103) gives two literary authors' views on this phenomenon. Virginia Woolf (1948, p.14, cited in Brody 1987, p.102) writes:

Human beings do not go hand in hand the whole stretch of the way. There is virgin forest in each; a snowfield where even the print of birds' feet is unknown. Here we go alone, and like it better so. Always to have sympathy, always to be accompanied, always to be understood would be intolerable.

Lamb (1962, p.216, cited in Brody 1987, pp.102–103) explains how the only company he looked forward to in his sickness was the nurse because this was someone who was prepared to help without taxing the sick person to reciprocate. I would liken this to Peter's comfortable and untaxing relationship with his mother, or Colin's with his wife. In their changed states as sick people they wanted as little company as possible with the exception of a comfortable and undemanding partner. However, both Woolf and Lamb were writing about short term illness. Long term retreat and solitude is not so restorative.

The third attitude and emotion towards chronic illness I noted among the texts was an embracing attitude—one where the person accepted the illness as a part of themselves. This is how Sky intellectualises her ideas which originate in Japanese philosophy:

*... for something, even if, if it is an illness, attacks you, you go with that energy to a certain extent—you have to flow with it. If you try to stop it, it's just going to knock you right over. You're going to eventually get rigid and get knocked right over. If you don't make any response, if you're completely flaccid to it, you will get knocked right over, too. But if you stay nimble and aware and on your toes and you move with that energy, like you move with the energy of your attacker, you move with the energy of life, then you can sort of stay on top of your illness, or stay on top of your life, you know. You're, you're in balance, your life is in harmony, sort of thing.*  
(Ub:46–59)

Sky tries to live by this philosophy. She is not always successful but she is satisfied that she does the best that she can. She does believe that illness, while it has brought

some misfortunes upon her, has also taught her: 'I try to be happy, you know, and I think that is something that a chronic illness teaches you' (Ub:70–71). When reading this text I see a glimmer of value being placed upon the experience of illness. Sky shared this philosophy with me again in her narrative when she recounted the following dream she had:

*... a dream that I was standing across a dam, I was sort of spread eagled across this dam like the kid across the dyke and there was this little crack that I sort of put a finger in, this little crack, and then there was another little crack and I put a finger in that little crack and then another little crack and then another little crack [speaking faster] and soon there were all these little cracks in this dam and I was sort of standing there and [louder] desperately, desperately, desperately stretched to the utmost, sort of, to hold back this dam and it burst. There reached a point where I just couldn't do anything more. It just completely burst and I was washed by this dam down a river, and, and, as I was going down the river I was sort of initially floundering, completely floundering and going under and coming up and eventually it got just sort of quite nice. I realised that I could ride with the flow of the river and it all felt very, very nice, you know, and that I could, I was just sort of floating along with the river and just really enjoying it. The water was warm and it got calm, sort of thing, and I was washed up on the shore and it was a very nice place and there were animals and, and, these animals basically sort of almost rescued me. Sort of, my love of these animals ...*

(Ub:78–102)

Her analysis of the dream is that:

*... a realisation that you can't control life, that life is bigger than you. That you've, you've desperately tried to hold your life together and you couldn't and, and that by remaining rigid and static and trying to confront things in life, you can't do it. You've got to go with the flow, the river is the flow of life and you've got to [go with it] and sometimes you will go under and sometimes you will get washed ashore but you have got to keep going. You have got to follow the river and you can actually enjoy it and you can master some of the, sort of, the processes of life, you know.*

(Ub:105–114)

Pauline was the other person who revealed an acceptance of her illness and a peace like Sky's. She too talked of a progress to a point of acceptance and also that it was a peace that is not always with her. She too, in her dawning contentment, finds value in the experience of illness.

*And I believe that God very graciously has shown me umm, how to get from a position of great loss to a state of contentment or growing contentment ... I have been taught how to get from here, a place of here as I would call it [of] growing despair and resentment, to a place of contentment, which I call there—so [I have progressed] from here to there. Umm, so all of what I do, whether it be thinking, whether it be physical, has to be dispersed with a lot of rest and a lot of umm, and there is a lot [of] time involved in that and it seems—it can seem at times, very futile because it just seems wasted. But part of what has been very blessed to me even in doing this umm, exercise of looking over my history, the thing that I thought about after I umm, did my first session was to see where God has brought me ... a lot of things in my life that have been very joyful, there have been a lot of things when you look at it that have been very, very difficult and umm, and I think and—here I am and I am here, because God has brought me that way, ... there will be benefits umm ...[pause]... but I don't always know—most of the time I don't know what they are, but I can just be glad that I am there umm, with a fairly content spirit and umm, and I think that that is a considerable thing.*

(Pb:108–130)

Others sometimes display this attitude but they have not thought it through as thoroughly as Sky and Pauline and they are less likely to identify it. Jane recalled flying into Sydney<sup>8</sup> before life-threatening surgery and described this experience:

*I do remember as I went in over the city and umm, ...[pause]... it, it was so lovely with all the lights and so on and umm, I sort of looked out and I thought, 'Well I might be dead in a few hours but err, what a way to go.' You know—it was a lovely sight.*

(Vb:563–567)

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<sup>8</sup>I have made this one exception of naming a capital city because I think it is relevant. The aerial night view of the Harbour Bridge and the Opera House is magnificent. Most people who have shared this view will be able to understand Jane's awe and spiritual experience.

There is no intention in this study to compartmentalise people as either ‘strugglers’, ‘embracers’ or ‘retreaters’. It appears when the texts are searched that there are times when each type of behaviour is the way chosen. I would not suggest that one attitude is more appropriate than another. People sometimes behave as they feel they have to. Colin or Peter would find explanations of flowing with a river and embracing their illness as strange. Yet I do believe that they still see some good in their lives and could be encouraged to explore these notions themselves with beneficial effects; that is, they could engage in some of the harder emotional work and explore their experiences in order to find some purpose and meaning.

### **Social contributions**

There was an anxiety revealed among the texts that chronically ill people might be considered a burden upon people, socially. There were many examples in the texts of participants being most comfortable socially when they were contributing in some way to social groups. For instance, Peggy will only join groups that require her help. She likes to help with the makeup at the local amateur dramatics society, has been a committee member for the parents of asthma sufferers, and is actively involved in the parent/teacher association of Floyd’s school.

As an active member of his nearest support group for people with chronic fatigue syndrome, Jim is proud of the help he has given to a man who was very depressed. Both Jim and his wife attend the meetings regularly and regard them as helpful (fdnte:3.15). Holly and Sarah are committee members of their respective support groups and regular attenders at the monthly meetings. At these meetings they are busy and spend some time talking to all the people who attend (fdnte:1.21–23).

It was apparent among the other people in this study that attendance at support group meetings was not particularly valuable. Out of all the people who helped with the study only Jim, Holly and Sarah go regularly to support group meetings. These three people have official parts to play in the group and receive feedback that they are needed. Holly has tried several times to retire from her committee position but is always persuaded to stay on because she is needed.

Elizabeth, who was eligible to be a member of a few support groups (coeliac, arthritis and Crohn’s), explains that she prefers the company of people who are well. She does not want to spend her leisure time talking about her illness. A number of other people who helped with the study agreed with her. Colin found it particularly difficult to go to meetings and see people with advanced stage Parkinson’s disease. It is not something that he is prepared to face yet:

*... and they talk about their disease, climbing up the walls ... and one woman talks about her husband hallucinating and all this nonsense and I am not interested in all that. If that is going to happen to me, I would rather not know about it until it happens, you know.*

(Tb:587–592)

Colin went to one meeting because he wanted to get more information about Parkinson's disease. Most people I talked to found the printed information that is sent out by the societies and support groups is important. They want to keep up to date with advances in the treatment and understanding of their illness. In some cases the associations offer a range of gadgets which are helpful.

Elizabeth, to a certain extent, displays contradictions in her attitude to socialising which are also apparent in other people's texts. While she says she does not want to mix with people with the same disease as herself at the support group meetings, she is pleased to be considered helpful by the hospital when teaching people with coeliac disease to cook special meals. She also gives descriptions of how difficult it is to be with people who have no idea what she goes through. This is just one brief episode:

*I went on a bus trip with some friends to \*\*\*\* [city] to see 'Joseph and the Technicolour Dreamcoat'. Well, I was sick three times on the bus and then the head pain started and I was a real mess and I didn't want to spoil anyone else's weekend and I thought, 'I can't do that again.'*

(Ia:792–797)

Along with a number of the other participants, Elizabeth enjoyed going to the hydrotherapy pool not only for the therapy but also because it is a social event. There is a pool in both Armidale and Tamworth. Elizabeth, who avoids support groups for her diseases, explains why she appreciates the hydro group:

*One of the things I get out of going to the pool, there are a lot of people up there and of course we've all got problems and we are all having physio. And it is the social contact with these people.*

Mary—Umm.

*And some days we even joke about our disabilities and laugh about it—laugh at ourselves and what we can and can't do and err, and [we have] a little chat, because we are supposed to go and have coffee too after we have been in the pool. Men and women—we*

*seem to mix really well, and even the men will come out and talk a little bit about themselves, but not straightaway.*

(Ib:1013–1024)

For the success of groups there appears to be a fine line between the extremes of being too illness focused or unrelated to illness at all. Elizabeth feels comfortable enough to talk about some of her problems with the people who join her at the pool but she is relieved that that is not the purpose of the group and she appreciates that often other things will be discussed and laughed about as well. The Northcote Hydrotherapy and Massage Group (McDonald 1992) are a group of older women who have successfully maintained a hydrotherapy group after their physiotherapy was withdrawn. Their success is put down to the commitment of the members, the fun they have together, and the contribution they all feel they make to the group. Reading about the formation and conduct of the club reveals a sense of pride amongst the members; this is one of their most valuable assets and will ensure the continuance of the group (McDonald 1992).

The people who live alone have to make some kind of social life for themselves or they would become very isolated. Sarah prefers to entertain in her own home but she feels more confident if one of her daughters is there to help. Only good friends are invited for they can be relied upon to bring a contribution to the meal and will help with the serving and clearing up. There are a couple of friends who have come to Australia from Europe. They visit once a week, enjoy a cup of coffee and a chat in their native tongue with Sarah before they fetch any shopping that she needs. Peggy, on the other hand, is not confident enough to entertain in her home. The only person who regularly visits her at home is the friend from the women's refuge. She is a friend who has shared her story and who also has asthma. One of the reasons why Sallyanne chose to live within a community following a long and radical course of chemotherapy for Hodgkin's lymphoma, was so that she did not become a burden upon her brother and sister-in-law.<sup>9</sup> Within the community she can mix with people when she wants to without a great deal of effort and she can choose to join in a range of social activities. She is under no obligation to reciprocate hospitality but enjoys having a few people to her room now and again to share a bottle or two of red wine.

The people who were most successful at socialising (that is, they did it and valued it) believed that they were worth being with and that they had a contribution to make to groups and other people. Peter is the most extreme example of someone who thinks that he has nothing to contribute socially. He believes that the people whose

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<sup>9</sup>There was never any hint from her family that this might ever be the case. However Sallyanne wanted to be independent and relieve them from some of their obligations to her. She and her family enjoy her regular visits home.

friendship he would value will not want to be with him. Colin does not enjoy socialising; it is a strain because he feels that he is not connecting well. He begins to feel left out quite quickly:

*You can sort of fool yourself and pretend and join in the conversation but half the time your mind is as blank as ...[pause]... a sheet of paper. And people are talking—‘Ah, yes, yes’ [I say] and you wouldn’t [you are] not listening to a word the ...*  
(Tb:319–325)

Jane never particularly enjoyed socialising anyway and really does not have enough spare energy:

*I’m not into socialising any, anyway. I find it is more fun out in the kitchen doing the washing up while everybody else parties and poses in the next room. It’s not really my scene ... I think probably we should entertain more at home with Simon, in the position he was in ... but umm, I was really too tired—it was an extra thing.*  
(Vb:459–468)

The factors revealed in the texts which affected people’s sociability were their personal inclination to mix, the contribution they could make, the amount of energy they had to expend, and the amount they enjoyed or valued the experience.

## **Receiving**

Receiving is something that most people with chronic illness have to learn to accept. That is to say that to some extent they all need some help because they are ill. The amount of help they require is unique to each individual and bears more relationship to their total makeup than to their specific illness or the type of disability it inflicts upon the person.

It is sometimes apparent to people who are chronically ill that they have to do more taking than giving in their lives of illness. On the whole this imbalance is a strain for them. There are social pressures that expect social relationships to be based upon the unwritten, but generally shared, rules of reciprocity—I scratch your back, you scratch mine, as it were. The people in this study who felt uncomfortable about the amount they had to receive were aware they had broken the social rules. This realisation results because they understand how the system works and therefore they expect people to tire of their needs. The sick know this, too, because in their experience people generally cannot, in Pauline’s terms, *last the long haul* (Pb:249) with an ill

person who needs help and attention. Indeed, Pauline has the insight to recognise that she could not herself, when she was well and impatient, get things done quickly:

... [I] *had to look at myself and I had to say, 'Well, how have I, how have I done this for others [people who were ill for long periods] in the past? Have I been about to go the distance with people?'* and the answer was, in the end, 'No'.

(Pb:263–265)

## **Medical attention**

Medical attention can be both a rewarding and extremely frustrating experience. There are plenty of anecdotes in the texts of both types which will be included in this section. The relationship between the chronically ill person and the doctor is a professional one and therefore people do not meet the same problems of an imbalance of giving and taking that there are with friendships. The doctor is rewarded for attending to patients, therefore it is considered to be her or his duty to give a service. However it is apparent that there are times when the patient's view of their 'due' is quite different to the doctor's view. As money changes hands in the doctor's surgery in Australia this 'due' is more apparent than I, as an English person, am used to. In England there is still a residual, although inaccurate, feeling that the service is given freely because payment is not at the point of delivery.

The relationship between medical practitioners and those with whom I spoke was very important. When the relationship is good, doctors are immensely helpful. They can make the person feel better even when medical treatments are not significantly affecting the disease process or symptoms of the disease. When the doctor/patient relationship breaks down the participants describe feeling bereft, anxious and often angry.

When examples of what were considered good experiences and poor or bad experiences with doctors were examined, I began to question, *how long had the patient and doctor been working together?* It occurred to me that the one thing that chronically ill people have is time to establish a rapport with doctors—often over a period of years and I wondered what, if any, the benefits of this luxury might be.

I looked in the texts for continuity of relationships between the chronically ill and their doctors. It seemed to me that these people should be well known to the general practitioner and the surgery staff, because they are regular attenders over a long period of time. Continuity of care would ensure that doctors understood the person's story which, we have already established, is such an important part of their being and welfare. I found only a few long established relationships with doctors that the



participants referred to. The long relationships are some of the examples of good work between the patient and the doctor.

Elizabeth has gone to the same practice for years; she always sees the same doctor<sup>10</sup> and she really appreciates his care and attention. He will visit her at home if she is in pain. He is honest with her both when he knows something and when he is not sure. Above all he treats her like a fellow human being and is welcoming. These are some of the things she said about him:

*When we went up to see my friend in [name of local GP practice—the visit took place after she had seen a specialist who said she complained too much, see chapter six] and he talks to me and he is up front and there is no mucking around with him and he said, ‘Elizabeth, you are difficult to treat, you are a difficult patient.’ He said, ‘You are not a difficult person, you get all these unusual things wrong and that is what makes it difficult’ ... I think he understands what is going on because he treats my everyday little aches and pains, I get phlebitis a lot, especially in my arm.*

Mary—*For no reason?*

*For no reason it just comes, he treats that. He treats all these little unusual odd problems that I get and he knows what happens in my day to day life. And I feel he is the one who should be getting the specialist fees because he is the clever one and he is the one who knows a little bit of everything, whereas if you go to a specialist who only knows one thing and can’t connect one problem to another.*

(Ia:626–647)

Her doctor maintains a relationship with Elizabeth no matter how difficult to treat she becomes and she really appreciates this (he stays with her). She feels that he likes her and that he genuinely feels for her suffering. He likes her because he knows her. He listens to her and he has become her friend over the years; he knows what she has gone through. Other doctors appear to regard her as a list of unsolvable problems and they view her with frustration which is sometimes manifest as irritation. Building this kind of professional relationship with a doctor can be one of the benefits of being chronically ill. Elizabeth enjoys visiting this doctor, although she is careful with his time:

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<sup>10</sup>She has seen this general practitioner since he was so helpful in securing her diagnosis of coeliac disease over fifteen years ago.

*You don't want to bother him too much, you don't want to be nagging at him all the time either.*

(Ia:728–729)

*Umm, but he really is a funny doctor. I went one day and I walked in the room—he had called me in—and I went in and I couldn't find him, I thought I must be in the wrong room and he went 'Boo' from behind the door (both of us laugh) and he said, 'Oh, I knew Elizabeth was coming, so I hid.' (more laughing) See, you can handle that ...*

(Ia:729–735)

Pauline also has a good long term relationship with her general practitioner. He knows her husband through professional organisations in town and he treats the rest of the family too. She feels that because he knows her well he always believes her. This trust in her integrity was tremendously important to her when she was searching for the diagnosis of chronic fatigue syndrome and this is a part of their continuing relationship. I draw the contrast again between her relationship and medical treatment and that experienced and received by Jim. Jim has stayed with the same group of general practitioners since he became ill but does not necessarily see the same one each time he visits the surgery. This diversity of medics could be one of the reasons why he was left on such high doses of anti-depressants for too long. Jim has only lived in the area a short time. He has not established a network of social contacts and when he does they are not likely to be in the same social circles as Pauline and the general practitioner. As I mentioned in chapter two, his pre-diagnosis care was remarkably different from Pauline's. Perhaps if he had enjoyed the rapport with one general practitioner like Pauline had, he would have had a different and better experience.

People who are newly diagnosed do not necessarily know their doctors well. In the early stages the patient can be quite easily upset. Zoe recalled that her general practitioner remarked that she should not relate all her symptoms to lupus. This careless remark really upset her. As it happened on this particular occasion she was proved right (ie her symptoms were attributable to lupus) and she planned with me to confront the doctor and tell him that she had felt demeaned when he had said that to her. She wanted him to accept that they were both learning about her disease together and that in the future she would like him to show more respect for her feelings (fldnte:1.13; 1.17). This is a good example of the patient staying with the doctor. I believe that with this kind of candour the two of them may have a good partnership over the coming years and that they will work well together to make Zoe feel better through the ups and downs in her health which they both anticipate.

However, some of the people in this study saw different doctors and even changed practices for a variety of reasons. Sarah moved practices recently because the appointment system was tardy and the seats in the waiting room were not conducive to sitting and waiting in pain. She gave the surgery no reason for moving nor did she attempt to remedy the unsatisfactory situation. I thought this behaviour was rather out of character for her as she usually stands and fights such battles. The reality was she wanted to try a new doctor. Within Sarah's text there is a familiar pattern where she finds that after a while, general practitioners can think of nothing new to offer her in the way of treatment or consultations with specialists. Usually the last ditch effort is to refer her to the pain clinic or to suggest that she needs psychological treatment. This is when the parting of the ways occurs.

*... yes, and don't say, 'Oh, well I had better refer you to the pain clinic,' because to me that is doubt you know—to me that is, 'I have given you up.' And then you think, 'Okay, I am not trusting you any more.' And then you get to doctor shopping. So I am going to the next doctor and the next and the next—I haven't been doctor shopping a lot because I have put my cards on the table but it is very hard to be assertive all the time, if when you are in pain, feeling down and so on and so forth.*

(Xa:467–476)

Changing general practitioner means that the gradual process of getting to know each other has to begin again. Sarah does have some notion of this process for she says at one stage:

*I have changed my GP recently and he hasn't got the full umm, picture yet, but yes, I think he could, yes [referring to his ability to represent her to a specialist].*

(Xa:479–481)

She reveals in this passage that really neither of them knows the other. It is a shame that one of the advantages of chronic illness, that is, the ability to have the time to be known by and know the doctor well, is lost in these cases and substituted by short term, generally unsatisfactory relationships.

Rather perversely, Linda demonstrates the difference between long term satisfactory relationships with doctors and short term unsatisfactory ones. In fact, she avoids doctors nowadays. She manages her own diabetes and does not want anyone to find out about her epilepsy. She describes medical attention she has had:

*... I think this has been a problem, the first seven years, from when I was five. When I was twelve, I was at the Children's Hospital in \*\*\*\* [city] and err, [interruption] and at the diabetic clinic you had the diabetic specialist and you had a dietitian and you had—well you had the specialist and the dietitian. They were the two that were there so that you could ask questions of either of them umm, and then ...[pause]... when I was twelve I was sent to the \*\*\*\* [name of the hospital] and I was under a specialist there, he was the one that got me into [names the profession she entered]. And once again you had a dietitian and a chiropodist you know, it was a clinic and you could get information there. And then, when I was eighteen and I started at uni, umm, I transferred from the clinic then and I went to the private specialist ... I think in a way that was a mistake because I was cut off from all the other information. You only saw him in his rooms, twice, three times a year, so you were cut off from everything else.*

(Ha:532–550)

It is speculation, but it is worth suggesting that if Linda had still been going to the more familiar clinic during her first year at university, when the fits started, her specialist might have helped her more than the unknown person she did go to. Perhaps the team she described in the clinic would not have allowed her to bury her head in the sand and ensured she understood why treatment was necessary.

On the whole, it would appear that a long term relationship with the doctor is beneficial. The general practitioners who provide this long term, good service are not fixed within the biomedical model of health service delivery. They relate well to the person and are concerned with the social character of their lives because they understand its impact upon health and wellbeing, generally. When they provide this kind of service they are not usually rejected when they admit they do not know what the best course of treatment is next:

*Or he will say to me, 'Oh, gosh, Elizabeth, this is a real problem.'  
He'll say, 'Look I'll get me books out tonight and I will give you a ring tomorrow.'*

(1a736–738)

However, it is not always the rule that long term relationships tend to be good ones between the doctor and chronically ill patient. Peggy has stayed in the area more or less all her life. She is well known as a severe asthmatic, has had numerous admissions to hospital and has two children who are asthmatic. Indeed one of her children died

in the local hospital.<sup>11</sup> Yet I have witnessed how ill she can become at home and the trouble she has getting attention from either her specialist or her general practitioner. Peggy could not be described as demanding but she does complain that neither she nor her special needs seem to be recognised by the health care professionals with whom she comes into contact over and again. When I first met her she was exhausted and in my professional opinion required medical attention and help. Yet she had only visited the general practitioner the day before and she had been sent home with nothing—no comfort, no advice, no new medications, no offer of social help, no domiciliary nursing visit, no referral to a specialist. From Peggy's perspective her long term acquaintance with caring health professionals who know her past experiences and suffering appears to count for nothing (fldnte:3.6–10).

Chronically ill people tend to know a lot about their disease and symptoms. They are kept up to date by their various support groups and associations and they will go in search of any available information. It is often the case that they know as much as their general practitioners. Their experiences with chronic illness make them increasingly aware that medicine is fallible. While there is still a respect for medical knowledge, like Thorne (1993), I have found that various incidents serve to foster a growing scepticism of the power of medicine. Thorne writes:

In ongoing situations such as chronic illness, medical truth rapidly changes. Thus, over time their exposure to the frank subjectivity of diagnosis, labelling, prognosticating, and intervening leads those with chronic illness to reinterpret medical science as anything but logical (1993, p.216).

It is with the specialists that these people invest most of their hope and trust for an improvement or even a cure for their ailments. Elizabeth's general practitioner likes her to go to her specialist in the city regularly because the specialist is the one who has the expert knowledge and directs her treatments. One of the disadvantages of living in rural Australia is that the number of specialist physicians is limited. Most of the people I talked to prefer to see a specialist in one of the capital cities. The only people who saw specialists exclusively in the local towns were Peggy (asthma), Jim (chronic fatigue syndrome), Holly (rheumatoid arthritis), Sky (ulcerative colitis), and Zoe (lupus). Travelling to the cities always involves quite a lot of planning and expense. The trips are often arduous and little regard is given to the travellers' special circumstances. Even though Jane had to go regularly to Sydney and they knew how far advanced her liver disease was, neither the specialists nor their staff took this into account.

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<sup>11</sup>She told me that the specialist she now sees was the houseman who attended her daughter before she died.

*We don't just appear in the waiting room. There is sort of ...[pause]... a lot of work and a lot of organisation and a lot of disruption that goes into it.*

Mary—Umm.

*And it is all very nice for them to say, 'Well, that's fine. You are here, now, but I think you should come back in three days time, and umm, and we'll admit you and we will do certain tests.' Simon used to jump up and down and bang heads together and get pretty, pretty uptight about the whole thing, which didn't do me a lot of good.*

(Vb:340–346)

Their response to Simon's complaints was insensitive:

*A few words were spoken of fair volume, and then, and then things got—sorted themselves out, umm ...[pause]... I think they really said to Simon, 'Well, umm ...[pause]... we're talking about your wife's life here,' and that's what made him sit back a bit and then he said his piece and I think that made them realise—'Ah, yes, well, you know, they are going through a fair amount of strain.' And I was piggy in the middle thinking, 'Well, thank God we only come from New England and we are not in Perth.*

(Vb:353–361)

Alan had similar problems when he went down to the city to see a cardiologist and found that instead of one appointment he was booked in for three days of tests. He was alone in the city; he had had an unpleasant quarrel with his brother; he felt very unwell; and no one inquired where he was staying or how he could travel into the hospital each day. While his story was different to Pam's (as related at the beginning of this chapter), it has similarities. It may be worth remembering that Alan is the participant who constantly plays down the severity of any of his symptoms.

*I went up to the motel across the road from the hospital and stayed the night and was shunted off into town early in the morning to find somewhere else to stay for the rest of this week, which—I didn't know I had to stay really. (sigh) And I felt really terrible that morning, really terrible. And I think that probably goes back to what was dislodged the night before or the day before [Alan had had a cardiac catheterisation the day before and it is suspected that he had a small cerebral embolism as a result]. I thought I was going*

*to fall over in the train because I didn't have any seating. I had to stand all the way into the city in the morning rush hour, and I was feeling very, very miserable, very well down on that one.*

(La:268–278)

Elizabeth recounts one trip to the city—by the time she got to the specialist's rooms she had a headache and started to vomit. There was nowhere in the rooms she could lie down and the specialist told her to be sick in the wastepaper basket. He also said he could not see her in her present state. She ended up being sick in the flower beds in the hospital grounds where she was tended by a kind passer-by. On the way home in the car they stopped at a health centre where a sympathetic doctor, who had never seen her before, gave her an anti-emetic and a shot of pethidine. This story has the kind of desperate chain of events similar to Pam's trip. For most ill people the journey to the city from New England is too far and arduous to do alone. It requires considerable planning and resources to accomplish with the minimum of discomfort. As Jane noted, it appears that doctors just expect patients to appear in their rooms; they take no responsibility for how they got there.

It may well be that making travel arrangements, and allowing people to express negative emotions, are not within the usual sphere of general medical practice work. It is hard to see how they could be fitted into the fee for service organisation in Australia. The longer the patient spends in consultation the more the service costs. This is hardly conducive to therapeutic communication. Nor are surgeries the best place to do this type of unhurried work. These are two of the things chronically ill people in this study needed from the health service and were not getting from their general practitioners. The time that chronically ill people in this study have to attend to their health is seriously mismatched by general practitioners who are classically busy and have little time to spare. These needs are not directly expressed by people because they have little idea that they could be provided for by the health service.

### **Medicines**

Jane sums up the prevailing attitude to medicines: '*Oh, a necessary evil, I think*' (Vb:195). On the one hand medicines can hold back a disease, relieving some symptoms, but on the other hand they bring a mixture of side effects and give the person the strange impression that they are poisoning themselves. They have to be carried around and punctuate the day, reminding the person they are sick. Colin's watch alarms every two hours from six in the morning until ten at night. As the number of drugs taken increases, understanding of each one's effect becomes more complicated and it is more difficult to recognise and control what is happening to the recipient.

There is a general reluctance to take drugs and quite a few people stress that they would not usually take drugs. Paul voices the underlying association of medications with drugs and addiction:

*I didn't want to take medication, drugs, you know. I have always been a person where I don't want drugs. I don't smoke, I don't drink.*

(Oa:77–79)

This is a fairly old fashioned attitude and Sky demonstrates the difference between the generations when she tells me quite candidly that she will take whatever it takes to make her feel well. She smokes dope in the early hours of the morning when she wakes up with a tummy ache and nausea. She finds it gives her great relief. Her general practitioner approves of this while the specialist does not. She is not particularly impressed by either of them and will continue to do what feels right for her.

*... horror of horrors, I hate to admit this on tape but umm, I'm going to say this truthfully, you know this. At four o'clock in the morning I smoke a joint and it is the best thing that I find I can do to kill nausea and to make me feel like a reasonable sort of person (laugh). It is just the best thing I can do ... and I mean, my GP (laugh) because, well, everyone knows that my GP smokes \*\*\*\* (laugh) he umm, he's fine. He says, 'Look Sky, if that is what it takes, I wish I could prescribe it for you, you know.' My physician (specialist) thinks that I am mad. He [says], 'Oh, you know, you're stupid. You know, you should take valium.' He really wants me to sort of take valium and umm ...*

(Ua:130–149)

Jane takes a range of drugs with as many side effects as benefits. She knows that some of the doctor's explanations for side effects are illogical and that the truth is neither of them are sure which drug or combination of drugs is causing which effect. The most likely source of such information is a combination of the doctor's pharmaceutical knowledge and Jane's knowledge derived from her illness experience and understanding of her own body:

*My skin is very fragile, this is from the prednisone, imuran. Umm ...[pause]... I bruise very easily and that's more so since the operation, as well. Err, and they, once again, they say that ... as with the [poor vision] yes, well it [is] caused by the prednisone. But*



*I didn't bruise as badly as that in the err, over [the] twenty years that I have been taking it [prednisone]. So I imagine that it is the combination of the cyclosporine thrown into the cocktail as well ... The eyes are blurry. I have to see an eye doctor next week to see whether I can get some glasses now. Err, I couldn't do anything about that because umm, the level of prednisone was varying and err, if I got a pair of glasses six months ago I would have needed another lot a couple of months later and so on ... So hopefully I will be able to see again in a couple of weeks, that'll be nice (chuckle) ...[pause]... I find umm, I am very hairy ... the hairdresser thinks it's wonderful. She thinks I have got the loveliest head of hair of anybody that comes into the shop. Trouble is it's all over my face (laugh) and arms as well.*

(Vb:228–251)

Other side effects she has to contend with are recurrent infections, nausea, peeling nails and skin eruptions. On top of the symptoms she gets from hepatic failure, these added problems are like thorns in her side—they make life that much more uncomfortable. She refers to her trail of ailments as the '*continuing saga*' (Vb:84)—she has put up with them for years and she knows the future holds more in store for her.

Within the texts there are examples of drug reactions and overdose. In one extreme case, Sallyanne was comatose and almost died (fldnt:3.16), and the less dramatic results are distressing symptoms or excessive lethargy. Dr Craig is perturbed by the number of drugs he takes for gout, arthritis and diabetes. Twice he has had to point out to his doctor that the prescription needs to be changed because he has either been on a drug too long or because the combination is wrong. It annoys him that he has to watch out for this. He feels he should be able to trust his doctor to know these things. He is disturbed by the doctor's rather cavalier attitude:

*I have got—I am on a whole cocktail of tablets sometimes, six, seven, eight, nine perhaps. And err, although you can get books that tell you that you shouldn't take one with another you really haven't got any information about a complex number like that and really you only have to work on a hit and miss thing. You go on taking them until there is some adverse effect and then you try and discover what is causing that adverse effect and I think it is fair to say that doctors work like this as well.*

(Wb:72–83)

*... and these [drugs] two couldn't be taken with one of the others that I was taking and eventually I said to the doctor, 'Look my book says I mustn't take these two together,' and he said, 'Oh well, leave one off, then' ...[pause]... (rueful chuckle) that's how we handle it.*

(Wb:88–93)

Poisoning was a term used by some participants to describe the effects of their drugs. Elizabeth is taking methotrexate and has read that it can cause cancer. She asked her general practitioner about this and got an honest but not particularly reassuring reply.

*I took my methotrexate today and I feel like I am poisoning myself every time I take it and of course that is why I am easily sick because of the methotrexate. Oh [resigned sigh] I have heard that that causes cancer, between five to seven years, and when I asked my doctor [GP] he said, 'Yes that's right.' But he said, 'We give it to you in hope that in a few years' time we will have something better to give you.' And umm, the fact is he said, 'If I was you, I would take it because, without it, you would be living the life of a vegetable. You would be stuck in bed, you wouldn't be able to move.' Umm, so that is one reason why I take it.*

(Ia:816–827)

Elizabeth appreciates his honesty and accepts that this is just another thing she has to put up with. Neither of them see that perhaps this is a problem that, even though they cannot solve it at the moment, they should continue to discuss. Elizabeth is not critical of him because she does not expect him to do more than give her information and to monitor her blood levels so that the correct doses are prescribed. This is a doctor who does his best to provide an individualised service but even he does not have the time or inclination to stay with this problem and support Elizabeth through her fears. She has taken anti-depressants for years and valium occasionally. She feels that these drugs contribute to her feelings that things do not matter any more and contribute to some distress in her life. Perhaps if some of her fears were dealt with (eg like the fear of cancer induced by methotrexate) the anti-depressants and valium could be reduced. However, this type of work is time consuming and not regarded as usual medical practice. This next extract is an example of a doctor failing to appreciate the information that Elizabeth is giving him about the effect tryptanol has on her body:

*And I kept saying to the specialist, 'Tryptanol doesn't agree with me. It seems to do something to my muscles and it really doesn't agree with me.' And then one day I had to get some shopping and*

*I collapsed in the middle of the main road and there were cars going everywhere and my groceries went everywhere and they had to pick me up. And it was because of the tryptanol that this happened to me.*

(Ia:134–139)

In this instance the doctor made a decision to ignore Elizabeth's remarks and keep to the dominant perspective among doctors that drugs have *certain* independent actions. This perspective means that some doctors, as in this case, fail to appreciate that each drug reaction with a particular person has the potential to be different. It is prudent to listen to the person taking the drug when they describe how it makes them feel. Considering only the drug's independent actions, that is, their therapeutic actions and recorded side effects, and disregarding or failing to solicit a patient's view, means that valuable information is lost.

Some of the participants titrate the medicines and their doses themselves. This can be good as it means that the drugs are used to their best effect. For example, doses are increased as soon as symptoms appear and reduced again promptly when things improve. This control saves quite a few visits to the doctor; however, it is not always beneficial. Peggy feels she could do with more advice and support about the doses to take and the legitimate reasons for taking them:

*... normally I regulate my own cortisone which I don't think is a good idea. I think I should have more regular check ups of that ...[pause]... but the one thing about the cortisone, it gives me energy, it helps me to get things done ... when I was at the show last year, I had dosed myself up [with steroids] for weeks to get myself right for that.*

(Na:9–18)

It may or may not be right for Peggy to use steroids in this way. She needs to discuss the practice with a person with more knowledge than she has about pharmacology. Sky does what she likes with her medicines by choosing which of her doctors to go to. However, she knows this is not really in her best interests.

*So yeah, so yes, I came off it [steroids]. I didn't tell the physician [specialist]. I told Mick [name of general practitioner] I'd come off it and Mick said, 'Well, you know what you are doing.' I think Mick sort of trusts me. You know because I have worked with him and he says, 'Oh well you are a registered nurse, you know what you are doing.' I didn't really, not for myself, that was the thing.*

(Ua:340–345)

The drugs which people have the most ambivalent attitude towards are the steroids. They can negatively affect moods and appearance but they also offer feelings of wellbeing which the person finds hard to resist. Sky tried hard to be well without the prescription of steroids; she stopped working, relaxed, meditated, ate well and exercised. However, in the end she has acknowledged that she needs them, especially when the pace of her life quickens.

*... and I sort of, then, came to accept medical help too, I sort of came to the understanding then that, I don't know, you could use whatever you wanted at various times, you know. You just, if I wanted to work full-time, well then, maybe I was going to have to take medication and umm, so I went back onto the prednisone and got, felt, really well until I started reducing it and then I got sick a couple of days ago. But now I'm going to start taking this other stuff, this other stuff called imuran which also has side effects. You know, it's not good for the liver.*

(Ua:567–578)

Ruth chooses to accept the side effects of steroids in order to reap the benefits of walking better. She has learnt to recognise the symptoms of steroid side effects and copes with them.

*Occasionally I go on prednisone which is ...[pause]... it helps me walk, which is great. but I hate to give it up. See, your body gets used to it and umm ...[pause]...*

Mary—*Do you get side effects?*

*Uhh ...[pause]... bit of a puffed face, a bit of weight and umm ...[pause]... other than that [a] depression it puts me really into for a couple of weeks, but I have learnt to umm, control [it] when I'm on steroids ...[pause]... knowing that I am depressed because I'm on steroids and umm ...[pause]... it's mind over matter. You've just got to tune yourself into where you are going. I stay on them for three weeks. Within that time I'll ...[pause]... I'm a bit icky and things like that, but that's ...[pause]... at least I know I'll walk afterwards and I don't complain.*

(Ra:433–451)

Steroids change people's appearance and that is really upsetting—*horrendous*, in Sky's language. People (eg Elizabeth) resent putting on weight when they have not been overeating—it is not their fault:

*I am always smart ...[pause]... my face and I have put on weight and although I hardly eat, and I am on the healthiest diet because of the coeliac diet, I still can't lose weight so I have gone from seven stone to ten stone ... and err, I am afraid that I will just keep putting on weight, and I try and cut the cortisone down and then the pain is too severe so I can't.*

(Ia:832–839)

The distress caused by a change in appearance is underestimated. Most people at some stage would look at their lot with illness and say, 'Well, at least it could be worse.' Usually they would say, 'At least I am not disfigured or in a wheelchair.'

*At least I'm lucky it is not something which disfigures me.*

Mary—*Umm.*

*Or makes me really ugly because I think it is really difficult for a woman in our society who has some sort of disability, you know.*

(Ub:185–188)

When people explained how they felt about putting on weight with the steroids there was sometimes almost an apology because it was felt they were being vain. Despite the tendency of most people to continue to take the steroids (this is because their potent benefits do outweigh the negative effects of the many side effects), the distress they cause by changing people's appearance does tend to be dismissed. This is another problem that people like Sky and Elizabeth are left to deal with alone.

Taking medicines may be difficult and fraught with problems for chronically ill people. However, these problems are not usually great enough to make the person refuse the treatment because of the associated benefits of the medications but they do contribute to the general discomforts that chronically ill people have to put up with. There are problems of side effects of the medications, fears about possible complications and changes in appearance. After prescribing the medications the medical professionals described in this study did not contribute to supporting or encouraging people to continue with their treatment. Nor did they actively look for individual responses to medications beyond what they expected therapeutically.

## **Help**

When Sallyanne was critically ill in hospital, a circle of friends from the Cancer Foundation sat with her continuously. She is most appreciative of this help and is sure that one of the friends/volunteers brought her back from the brink of death (fldnte:3.19). Now she is cured of cancer, she is left with residual ill health; she tires

easily, she has some peripheral neuropathy in her legs which prevents her walking far, she has no sight in one eye and glaucoma in the other. She has turned from a person who was terminally ill to one who is chronically ill. She did not expect the supportive circle of friends from the Cancer Foundation to stay with her now her needs have changed so much. Indeed Sallyanne chose to take up university study and to live in a residential college precisely so that she could release her family and friends from the *obligation* of helping her on a day to day basis. It was a deliberate ploy to maintain her independence and preserve the excellent relationships she has with her family and close friends. She remains popular because she is 'no trouble'. This is not behaviour for the sake of appearance and popularity, as described by Frank (1991, p.65), but how she chooses and wants to be.

The help that people in the study required ranged from company, lifts in a car, and shopping to physical care. The distinguishing feature is that chronically ill people require help over a long period of time. In the participants' words the commitment from helpers that is required is to be able to *stay the distance, last the course, or go the long haul* with them. It is not so much what helpers do but that they are able to be constant in their attention. Pauline describes two good friends who live far away in the city; they telephone and chat with her. Their calls are not regular but she knows they will not fail her (Pb:249–253). Sarah described to me how over and over again, she will meet people socially who say they would like to help, perhaps by giving a lift to choir practice or into town. After a while they begin to make excuses and it begins to dawn on them that they have committed themselves to something they do not want to or cannot continue. This rejection is difficult for Sarah who wearily starts looking, with a heavy heart, for someone else to help (Xa:159) (fldnt:1.54). Pauline has worked through this kind of behaviour by people and thinks that she has come to understand and accept it. She describes how when she was first ill she was almost overwhelmed by people's concern and offers of help. She admits that she in fact enjoyed the attention and this took an unpleasant edge off the experience which could have been very frightening and depressing. However as time went on and she did not improve, she was very hurt when the attention waned:

*I believe, at that point, in response to how people were with me, I had a rather umm, immature and umm ...[pause]... unrealistic expectation [of] umm ...[pause]... What was given to me at that time was enough to keep me going in a way that people would perhaps have seen me as being a very brave patient umm, good and kind and bright. It was as if really nothing had happened, I guess.*

*Umm, but that was really riding on the euphoric umm, nature of a lot of attention that would not last.*

(Pb:215–222)

*... when it did start to dissipate and when people couldn't go the long haul with me, then again I knew, that there was bitterness and there was resentment. There was within me, a crying out, I believe, of, and a judgemental approach to other people. I felt that it was— umm, all of a sudden I had gone from somebody who really was fairly notable to somebody, over a period of time, who really became quite umm ...[pause]... unnoticeable.*

(Pb:231–238)

Some of the participants in this study were already aware that this was a potential pattern of human behaviour and they avoided it by keeping away from people as much as possible, thereby avoiding the eventual pain of being made to feel unnoticeable.

There was a clear distinction in the texts between the people who lived on their own and those who had partners, or, as in Peter's case, lived with a parent. Those who lived on their own had no choice but to rely upon friends' and family members' goodwill. They feel an uncomfortable stress that these people's goodwill may be temporary. Without help from friends and family the single person is in a very difficult position. Peggy is reluctant to ask for help and when she is ill she is stranded in her isolated home and surrounded by mess she cannot clear up (fldnte:3.6–9).

The parents in this study tended to be careful with the time and resources of their children. It is quite easy for relationships to become strained. Sarah has an uneasy relationship with her daughter and daughter-in-law. She admits that her daughter-in-law makes her feel *uncomfortable* when she asks for help with her shopping once a week. Her eldest daughter lives in town and tends to meter time to her mother carefully. I have been in her house when her daughter has parked across the street and sent one of the children in with something and a message that she is too busy to come in—she has to dash. Sarah on this occasion told me it was the first time that her daughter had called at all for over a week. She was disappointed she did not come in but excused her, in some measure, by saying that her daughter had agreed to help her give a dinner party. This was considered by Sarah as a generous gift of her daughter's time (fldnte:3.77). Dr Craig mentioned several times through his story that he did not wish to ever become a burden to his children.

Being able to maintain independence is important to the chronically ill person. Trying to find and organise people to help one is tiring and often disheartening. Sarah demonstrated the need for paid help by being so distressed when social services cut the number of hours and the type of things a home help person could do. The person who is paid for helping is being rewarded and therefore the chronically ill person is relieved from having to be grateful and of thinking how they might reciprocate in some way. Pam is very assertive with the social services and now interviews her own helpers (fldnte:1.61). She requires a lot of physical help and insists upon having someone with whom she can get along and who will do exactly what she wants. She hates it when someone she is used to leaves for some reason. It means she has to start showing new people all over again how to help her.

One of the attributes of good friends, besides being constant, was that they were the people who knew what to do without being asked. Long term friends would just come in and do things without making a fuss:

*I [have] very few friends left but the friends I have are very good because they can handle me, they see me for what I am ... they say okay, I'll help you with the coffee or just cheerfully do things as a matter of fact. Not, you know, 'Oh dear,' you know, 'What can I do for you?' ... they see what I am not good at and they just do it.*  
(Xa:197–205)

This ability to know what needs to be done and doing it is related to *lasting the distance*. It is the people who are thoroughly familiar with each other who are most likely to know what is helpful in a particular instance. Jane talked of the number of acquaintances who say in passing:

*... they say, 'Oh well, if there is anything I can do' ...[pause]... err, and you don't say to them, 'Well, there is a basketful of washing there.'*

Mary—*Umm.*

*(laugh) So you just say, 'Oh no, we're fine thank you' ...[pause]... 'There really [is] nothing'—'Oh, well, if there is anything we can do' and emm, they really, oh, they really mean it, but err, you, you don't ask.*

(Vb:435–442)

I asked Jane how she would feel if someone just marched in and did her washing, and she laughed and acknowledged that she would not like that either. Getting help just



right is quite a tricky process. I once mentioned to Colin that I was unsure how to greet him after he had complained about the number of people who say, 'G'day, and how are you?' and are not in the slightest bit interested. Both he and his wife laughed spontaneously and said that it was okay for me to use that greeting. There is room for some of the chronically ill people in the study to understand how difficult it is for friends to get offers of help just right.

Asking for help can be tedious and, to an extent, demeaning. Holly and Elizabeth get exasperated with their husbands when after years of helping them they still have to be asked each time:

*That is the worst thing of all and I can never understand why people, I mean I ...[pause]... I have asked my husband to do so many things. He'll do them quite willingly but he never thinks to say the next time, 'Oh, I'll do that' (rueful chuckle) and so they just don't seem to think.*

(Qa:216–220)

One morning Holly's husband was up early and had left the house before she could ask him to zip up her dress. In her words, *he got away*. She tells an amusing story of having to nip out onto the street to find someone to do the honours for her. However, behind the amusement is a hurt that he did not remember that she would be stuck without him (Qa:289–307).

Help which is required is not always physical. Zoe recalled a time when her husband was away on business and he called in the evening. They talked about what he had been doing and she longed for him to ask about her health but he did not. Eventually she told him she had not been well but it was not the same as if he had thought to ask her first. Elizabeth makes this same point about her daughter:

*And I will talk to her on the phone and she will say, 'Mum you are not good today.'*

*Mary—... and how does that make you feel?*

*Oh, pretty warm inside because I think, 'Oh, she knows me well enough.' I haven't got to say, 'Oh, I feel sick today.'*

(1a:762–785)

There is a hesitancy among people who are ill to ask for help and yet it appears that busy people will not notice, they have to be asked. Register (1987, p.67) coins the phrase, 'I'm free to ask for help if they're free to say no.' This kind of frankness is

necessary so that a lot of the energy that goes into finding help can be conserved. It also might reduce some of the anxiety and hurt associated with having to find help. However Sarah was the only participant in this study who lived by this maxim and she did not fare any better than the others who displayed hesitancy.

I would like to say that I found within the texts an understanding that to help others is a blessing and that the participants in the study saw themselves in a positive light because they afforded others the opportunity to do something worthwhile. None of them displayed this type of positive attitude in anything they said or did. Needing help is generally a demeaning pastime and is fraught with anxiety and shame. Ellie O'Sullivan writes about this in a most moving way when she describes the differences between cancer and her chronic condition, arthritis:

The second difference links with the first but is in some ways even more painful and that is how one comes to be defined publicly, socially quite simply as a burden. Over and over again in media coverage of 'invalids' the overwhelming emphasis is on the carers and *their* burden, and *their* difficulties. No voice is given to the 'invalids'—the complexity of their relationship to their families or loved ones—and it acknowledges nothing of what they are still able to offer which is needed and necessary to those around them. The assumption is that carers have wasted lives, are overburdened, are saints sacrificing themselves to this non-being.

... I don't want to reach a stage where people are happy to tell me how lucky I am to have Pete but no longer believe that he is lucky to have me. Nor do I want all that I have meant to Charlotte and all that she has meant to me to be reduced to the image of invalid mother, put-upon daughter. None of us can survive such images of ourselves (O'Sullivan 1994, pp.209–210).

Apart from a few instances of strangers spontaneously doing the right thing, the people who can be most helpful are the ones who care enough to stay with the person over the years and learn how to help. A friend who gives this kind of consistent help automatically sends the message that the person is valuable and worth being with. The situation is different with partners and family because loyalty and duty are intermingled with love. Although I have given examples of partners having to be asked, there are also many examples of unspoken care and consistency in these close relationships which can reinforce feelings of being loved. As is usual, these relationships do go up and down though. Indeed, Ruth is so driven by her love and concern for the rest of the family she sometimes fleetingly wonders if she would find life easier on her own, in a space where she could just concentrate on her illness and how she was feeling rather than on how her illness was affecting her family (fdnte:1.68).

## Summary

On the first occasion that I met Pauline she remarked that being chronically ill does not excuse the person from all the rest of life's hassles. Indeed, they come just as thick and fast and are usually more difficult to manage and cope with (fldnte:3.2). Like the stories at the beginning of the chapter, lives of people who are chronically ill are full of one problem or difficult situation after another and at times appear to be impossibly unfair.

Being treated as people who still have a lot to contribute ensures that people who are chronically ill remain involved in society, whether it be at work or helping to run and organise groups. Having a purpose to get up and contribute each day is an important motivator when life is difficult. However, being able to maintain such functions means that people with chronic illness are involved with a lot of tiring struggles each day. To balance the struggles they need time to recuperate, as well as time alone and away from responsibilities of keeping themselves going.

In order to find some peace and meaning to their illness, people need time to be introspective and to work through their hardships and grief. It is probably in this last area that the chronically ill people in this study are receiving the least help from the caring professions. It is already well established that people who are dying or who are passing through acute illness or problems need support and time to come to terms with what is happening, and to try and find some meaning from the experience. Indeed, people who have chronic illness may experience some of this help and support when they are first diagnosed. Zoe (lupus), Pauline (chronic fatigue syndrome) and Colin (Parkinson's) certainly did. The problem is that the help does not seem to last as chronicity sets in and the excitement of the initial diagnosis dies down. People and their families and/or friends are left to sort things out by themselves. Ironically the general maxim is: once you accept the disease you will be better. Holly's general practitioner said to her after years of suffering with arthritis:

*'You've come to terms with it at last, Holly.' And I said, 'Yes.' He said, 'Once you come to terms with it, you're much better.'*

(Qa206–210).

He was right to a certain extent; it is just a shame that he did not realise that perhaps she could have used some help to get 'there', and indeed that 'it' is not a static state. Acceptance, peace of mind, call it what you will, has to be continuously strived for.

An understanding that people feel and act in a range of ways at the same time may seem obvious, but it is relevant. While people who are chronically ill often require a

great deal of help from friends and relatives, this does not preclude them from still contributing—their lives can still be valuable and friends and family can still receive a great deal from them. Sometimes they are able to offer more because they are ill, for example, they may be able to offer friends their time.

*Friends*

*other times  
they're the ones  
who seem tired  
they seem to find relief  
in this quiet room  
they move  
into the huge, uncluttered spaces  
in my diary and like it there  
they can relax  
knowing there's no need  
to perform*

(Maria Jastrzebska)

These things of value need to be found and celebrated, just as the things that are difficult need to be investigated:

*I had to take a long hard look at what I had lost and look at my responses umm, the bitterness that was growing ... and when I got through the process of anger and all the rest of it and then when I started to look at myself and see ... I knew a new way to be helpful to others.*

(Pb:276–280)

## Chapter 8

### Futures

*Time will say nothing but I told you so,  
Time only knows the price we have to pay,  
If I could tell you I would let you know.*

*If we should weep when clowns put on their show,  
If we should stumble when musicians play,  
Time will say nothing but I told you so.*

*There are no fortunes to be told, although,  
Because I love you more than I can say,  
If I could tell you I would let you know.*

*The winds must come from somewhere when they blow,  
There must be reasons why the leaves decay;  
Time will say nothing but I told you so.*

*Perhaps the roses really want to grow,  
The vision seriously intends to stay  
If I could tell you I would let you know.*

(W.H. Auden)

### Introduction

Heidegger (1962, p.378) in a poetic yet typically difficult phrase says that ‘to be’ futurally, is to awaken the present. That is, to authentically view the possibles that lie ahead is one of the most important ways human beings exist—to be aware of the future is to enhance existence. Human beings are aware of and affected by the possibilities that lie ahead. Indeed some of the most difficult, yet arguably rewarding work that people who are chronically ill have to face are the things they see in their future. How they deal or do not deal with these possibilities affects their everyday experiences. For example, Elizabeth’s knowledge that methotrexate may cause cancer in the future is something that worries her now and upsets her life.

According to Heidegger (1962) the most significant possible to face is personal mortality, the certainty that we are moving towards our own death. Heidegger believes that this concept has to be faced in order to anticipate the future with authenticity (being authentic is to be aware of what it means to exist); that is, to be able to make decisions and plans with resolve.

Looking for glimpses of the future in the participants' everyday accounts of their lives with chronic illness is the last part of the interpretation I undertook in the study. The story that follows shows how deep understanding is embedded in everyday actions and situations. It also shows that meanings which relate to future possibles may be found in unexpected places in the texts.

As with the other two chapters relating to the past and the present the understanding that is revealed in this chapter throws up paradoxes and differences residing in a person simultaneously. There are no defined ways of being chronically ill, but there are experiences which chronically ill people share and emotions and behaviours they all feel. These experiences are not neat; they do not come one after the other in sequential stages. They are felt and displayed to different degrees and at different intervals during lifetimes. It is quite possible for one person to be angry and then resigned to their illness within a short space of time.

I found reference in the text to a mixture of potential fortunes, of fears and hopes for the future. There was reference to more struggle, to death and loneliness, to worries about impending loss of independence and to fears of losing loved ones; I found hopes for improvements in health, for a recovery and for peace of mind.

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## Story

This story is a different one from the others, so far, in the thesis because it is my account of some time I shared with Sarah and some of the members of her family. I told the story to Sarah over dinner one evening and she gave me permission to use it in the work.

Three of us drove away from a chilly Armidale August at six in the morning. We set off north following Sarah's son Patrick, his wife June, and their family of three girls. The traditional Australian stop for morning tea was in a charming clearing on the edge of a rainforest. We boiled the billy<sup>1</sup> and ate homemade cakes while natural entertainment was provided by lyre birds in the forest. After three hours of driving, of which a significant proportion was over rough road, Sarah was stiff and walked around the cars with difficulty, leaning heavily upon her crutches. The children looked after their grandmother, taking her the first cup of tea and arranging things within her reach on the side of the ute. The whole family chipped in to tell me things about the forest and native Australia. I began to feel the family's familiarity with the country.

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<sup>1</sup>An Australian term for making tea in the bush.

In another four hours we turned off the dirt road and drove into the bush. Myra, Sarah's youngest daughter, lived with her two girls in their dream home. It was a wooden settler's cottage perched on the crest of a steep hill which rose out of the bush. The house is surrounded by circles: first a continuous wide wooden veranda, then a lawn and scented garden planted with roses, honeysuckle, and jasmine. In the next circle this extends to become a native garden with banksia, banana trees and eucalypts. The garden then drops down all around the hill to merge with the surrounding bush. There are no gates, walls or fences. The views from the veranda are of hills covered in thick eucalypt and then hardwood forest—blue grey turning to rich dark green and brown. The sounds were of cousins playing happily in the sunshine and birds calling and singing in the wild.

In the late afternoon Myra and the five children promised to find the wild orchids for me. As we set off Myra warned her mother she could not come as it was far too steep and rugged for walking with crutches. Myra was afraid her mother might fall. The kids skipped down the hill, vying with each other to show me this or that wonder of natural Australia. We found a wombat hole, and looked at various droppings which proved that marsupials and other animals came close to the house. We said g'day to the cockies making a noise and a mess in the gums.<sup>2</sup> We found the orchids growing out of a large grey boulder and all of us stood around and just looked at the plants, appreciating their delicate hardiness; they were not in flower yet. Myra broke the silence by saying to me, 'I know so much, and love so much of all this because my mother taught me. She found beauty and wonder everywhere in the bush.' I looked up the hill and saw Sarah standing on the edge, leaning on her crutches trying to see us. I felt the most extreme sense of her loss. She seemed to be longing to be there with us, loving the bush and teaching us still.

When I told Sarah the story months later she reached for my hand and we shared a single reserved Western European tear as she simply said, 'Thank you.' I told her I wanted to use the story to convey the sense of loss an illness can bring. She replied, 'Do you want to know what it means to me?' 'Yes,' I said. 'It means my daughter's love endures all this,' she sighed.

It means that Sarah meets the future, which is packed with difficulties, knowing that she is loved and appreciated by her daughter. This is a profound sense of reassurance to her because her relationship with her family can be fairly feisty. This sense comes not only from what Myra said, although it was deeply touching, but from the way the children have been shown Sarah's ways and the acknowledgement of her contribution to their wealth. Myra's beautiful home which is in harmony with the

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<sup>2</sup>The cockatoos sit in gum trees eating the flowers and throwing the leaves all around them.

land is a testament to her mother's considerable contribution to her life and will be there in the future. This story will not always sustain Sarah, but she will relish it sometimes and use it to give her strength to carry on with her daily struggles.

If she chose to, Sarah could agree with me and use the story to depict and feel her loss. She could remember the times she had with her growing family before tragedy struck and compare them with her present lot. Instead she looks to the future and uses the emotions generated in a positive way.

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## **Loneliness**

The loneliness of the ill person was expressed in three ways. First, people said that their experience was theirs alone. Other people, no matter how close or how sensitive they were, could not know exactly how they felt. Second, Zoe and Pauline spoke with considerable insight and described the difference between loneliness and being alone in their illness. Third, loneliness was described in terms of not being with people, either because they could not get to see people or people did not come to see them anymore. When a person is lonely or alone, others feel distant and the space between them enlarges and the world of the ill person resounds to their own reflections and emotions.

### **Only I can feel this**

No matter how articulate the person is or how perceptive the attender, the chronically ill feel there is no way that they can accurately convey how it is they feel ill. They are therefore ultimately alone with their most excruciating experiences. This will always be the case, although some people may come nearer to sharing their feelings than others. A closeness may arise when others have some similar experience of their own to relate to or they are able to spend time with the person. Elizabeth recalls the reaction of a woman who had encouraged her to share a long bus trip with her. During the bus trip Elizabeth was sick several times:

*I think she probably understood a little bit and umm, she said, 'Oh, Elizabeth how do you cope with life?' she said, 'I had no idea you go through all this.' ... they don't have any concept of what it is really like.*

(Ia:540–544)

For Sarah the inability of others to comprehend her pain has meant it is not always believed. This causes her to feel demeaned and effectively distances her from others.



She is relieved when the doctor (in the extract below) shares her experience, to an extent, but she is still frustrated by people who do not try to understand her pain.

*The main thing is that chronic pain cannot be communicated. It's, it's ...[pause]... [inexplicable] to those around who haven't got it. Even a GP here accused me of malingering and said, 'Oh look, you know your back is fixed up now, stop ...[pause]... stop, you know, complaining about it.' Until he crashed his car into a tree and got backache himself and he literally came from behind his desk and put his arms around me and said, 'I am so sorry I accused you of malingering.' And I said, 'Right, John Smith, the next time you will, you know, yeah, you will know that we are speaking the truth.'*

(Xa:69–76)

The doctor's movement to come closer to Sarah from the other side of the table was significant. She had felt that he was far away from her and her suffering. When he began to understand the experience of her pain he moved nearer, physically and emotionally.

There is sometimes a longing for the other person to know what is going on. Elizabeth wishes that for just a short time her husband could feel her pain. She said, '*I have often said to my husband, "I'd hate you to have this, but I wish you could just feel it—just for five minutes"*' (Ia:1074–1077). Holly recalls that her mother suffered terrible pain from arthritis for years but that it was only when she got arthritis herself that she began to realise the extent of the pain and thereby the difficulty that people who have not had a similar experience have in comprehending it.

There are also times when people do not even try to understand the ill person's experience. Elizabeth was hurt when a friend of her husband said—'*Who do you think you are, Robinson Crusoe? We all get a bit of that*' (Ia:547–549). Holly, who is twisted and bent with arthritis, tells an amusing yet, at the same time, irritating story of the people who come and show her what might be their own arthritis:

*Umm, they say, 'Oh yes, I'm sure I'm getting it in that finger.'*  
[Holly holds up the tip of her little finger] *(laugh) One finger! But you see they don't realise, I mean nobody ...[pause]...*

(Qa:122–124)

Jane was touched when one family came to her and told her that they were nearer to understanding some of the trials and tribulations she and her family suffer. She was particularly pleased for Danny's sake:

*... earlier this year, I think it was. Err, a friend of ours went into hospital to have something fairly minor done and it all turned out to be major and she was flown off to \*\*\*\* [city] and err, the family went through a fair amount of trauma. I was talking to the husband, well actually the husband rang me up and err, he said, 'We knew when you were in \*\*\*\* [city] what the family was going through and that it was very difficult for you, but we really had no idea. We really didn't understand what it was really like until, we've been there [and] done that now.' And umm, he has a son the same age as Danny and the son said the same thing to Danny, 'When you were away from school we knew, you know, that things weren't good, but we didn't, we didn't really have a clue what, what it was really like.'*

(Vb:608–622)

Peter finds it exasperating that his mother attempts to understand how he feels. He is sure that she cannot possibly understand and it drives a gap between them both:

*I mean, my mum and I, we have arguments about this, you know. She says she knows what I need and I say, 'Look!' and then I'll say, 'I wish I didn't have this MS.' And she'll say, 'I know, I know what you must be [feeling]'—they always know and I get cranky with that and I fly off the handle.*

(Kb:286–291)

Part of the problem is that Peter cannot share his problems with his mother. He is sexually frustrated and feels that this is a subject he cannot raise with her or anyone he is in contact with currently. Although his mother is with him constantly and she does pay attention to him and listen to him he cannot talk to her about his frustrations. Whenever he talked to me about this he used to look around to see where his mother was or speak in a whisper. He is painfully alone with this problem and sees no relief in the future (fdnte:3.11–14).

To an extent Linda is like Peter because she does not share her experiences and so those close to her have difficulty appreciating her. The advice Linda's parents gave her at the age of five was—'Well you have got this now, err, you have got it for the rest of your life, and that's it' (Ha:54–57). It was hers and she was advised not to make it other people's problem. She has shouldered diabetes and epilepsy most of her life and she shares the experience with no one because it is hers and she feels that it is hers alone (Hb:555–563). In the future she has the possibility of making a new decision and perhaps learning to share the experience of her illness with more people.

However this decision will be hard for she has had a lifetime to learn to keep her experiences to herself.

Sometimes people show that they do understand or at least are trying to understand the nature of the illness experience but then at another time the same person forgets and goes on with their busy life, forgetting to make reference to the ill person's experience. Zoe finds this so with her husband; he appears to be living a much faster pace of life than she can and this makes her feel desperately lonely at times. She feels that if he really understood her pain he would not forget. However, at the same time she also knows that this is an unrealistic expectation and she resigns herself to more loneliness in the future (fdnte:1.42).

This type of loneliness is inevitable. There are some places you cannot, and like Elizabeth, would not really want to take people. However, people who have shared similar experiences do have a better understanding than most. Peggy chose to expose her vulnerability to her friend from the women's shelter. This person may not experience the same severity of asthma as Peggy but she shares the experience of being a single mother and needing shelter too. Peggy chose her because she feels that through her experience she understands her predicaments, is helpful, and is not judgemental. Register (1987) and Keith (1994a) both seek the company of other people who are disabled or unwell. They need to be members of a 'new community' and see the value of fellow sufferers' company:

As I began to make sense of the different world I now seemed to inhabit, I found that while I could describe and explain my new life to my friends if I wanted, I couldn't learn about it from them. Sometimes I didn't want to talk about these new experiences and sometimes when I did, they found it hard to listen. I realised that to survive and make sense of my new life, I had to find the support of people like myself. I had to become a member of a new community (Keith 1994a, p.2).

There are few instances in the texts of this study where the company of fellow sufferers is sought or valued. It is perverse that this avoidance serves to double back upon people who feel they are less socially acceptable as people with chronic illness. There is the potential for chronically ill people in this study to compound their own feelings of unworthiness (that is, they can feel they are devalued people whose company is not worth seeking anymore). They achieve this by displaying similar views of other chronically ill people themselves. These views are spawned in the culture and picked up through accustomed ways of doing and being. It is only Jim and his wife, Peggy and Holly in this study who really appreciate the company of other people with the same disease. Jim likes to go to the support group for people with chronic fatigue syndrome. He finds it most reassuring that there are other men

who are going through similar problems to himself. He is eager to learn more about the course of the illness and he is quite prepared to contribute and help other members through problems which they face (Ja:996–1018). Holly valued the company of people who also have arthritis. Although she regularly goes to the official Arthritis Foundation branch meetings in the town and works for the group she remembers fondly the small, less formal meetings they used to have:

*... but before this Arthritis Foundation was formed we had a little support group which was held—I was introduced to it by a friend of mine there. [At that time there] was only about a dozen of us—we used to meet at this woman’s place umm, one Monday a month. That was excellent because the people who went ... we talked about what ...[pause]... where we’ve got a pain this week, and where we think we might have one next week, and how our medication is going just [now], and one of the women, her husband had just developed a nasty cancer and, and I mean, it psychologically, it, it’s a great help ... I feel this Arthritis Foundation branch is, is much the same. It’s a little bit more official, you know?*

(Qb:206–225)

While it is true that no one feels the same experience as the person who is suffering, there are people in the world who have a better understanding than others. These are usually people who have had a similar experience and people who have spent time with the sufferer, paying attention to their suffering. Frank (1991, p.49) sums this up:

*Terms like pain or loss have no reality until they are filled in with an ill person’s own experience. Witnessing the particulars of that experience, and recognizing all its differences, is care.*

I have searched these texts to find this particular type of care given by health care professionals and sadly it appears to be missing.

## **Alone**

*Alone, alone, all, all, alone,  
Alone on a wide, wide sea.  
And never a saint took pity on  
My soul in agony*

(Samuel Taylor Coleridge)

Both Pauline and Zoe talked about aloneness. They are Christians and to them the experience of aloneness is both exquisitely painful and spiritual. It is the space where no person can go with them and where God touches them:

*... so I have known an aloneness that umm, err, that just cannot be touched by another person. But that, I guess, is the place where God has met me the most, and the fact that God alone is the one who can touch that place ... the sweetness that comes from feeling the extent of your aloneness and then knowing a God who is all powerful, has made everything, and rules everything, cares about [me]. It is just extraordinary and nothing can touch you like that does.*

(Pb:354–360)

Somehow this experience of aloneness has helped Pauline to come to terms with loneliness. She believes that she expected too much when she wanted people to understand her experience:

*I've been wrong. My expectations have been invalid and I have been demanding and I know now that in those ways God alone can do for me what people can't do for me.*

(Pb:362–364)

Zoe described being alone after she was given the diagnosis of systemic lupus. She was driving home through the Moombi Mountains<sup>3</sup> and the rain was pouring down:

*... as I was saying to you before, it was another time I became so aware—there have been certain times in my life that I have felt this incredible aloneness and it is quite different from saying, 'Oh, I feel alone.' It's your entire being feeling on, on an island, and you are the only one who really knows what it feels like. How it feels umm ...[pause]... all the gut feelings, the fear and being distraught ... and I really, I felt God's presence, it was amazing. I just knew that there he was, that I wasn't on my own, that I was—I don't know, I just felt a surge of strength.*

(Za:384–400)

While Sky does not interpret the experience in quite the same way as Zoe and Pauline, she does describe a similar experience. Her experience of aloneness started with incredible hurt and loneliness and turned to a spiritual bathing and calming. It was at the time she had the dream (described in the last chapter) where she learns to ride with the river. At the time she had taken to her bed, depressed and sick, and the only time she got up was to visit the counsellor. She spent her time *alone* and her new puppy started to comfort her:

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<sup>3</sup>The mountain range that reaches up to the Tablelands from Tamworth towards Armidale.

*I was utterly miserable all the time ... but I kept her in my bed (laugh) ...[pause]... she was really spoilt, completely rotten as a puppy. But that was very healing that was uhh, a lovely thing.*

Mary—Yes.

*And umm, and that, that taught me a lot about gratitude, at the time, I think. I was very grateful to have Sally [name of puppy], really, really grateful. I didn't want to see anybody—didn't want to see any friends or anything like that. I used to marvel at her like a baby, I guess it was very much [like] having a new born baby. The marvel of life, you know, of watching this little thing grow. And life began to feel very precious ...[pause]... and to me I felt ...[pause]... very grateful for being alive, you know, and being so sick for so long. When I did start to feel better, there was this ahh, very, very intense sense of the preciousness of life for some time.*

(Ub:119–135)

The three people described these strange experiences beautifully and I find little to add to them. They were deeply poignant and personal to each woman and contributed a great deal to their strength, peace of mind and acceptance of their illnesses. It was as if in the depth of their souls, reached by suffering and far, far away from others, was to be found a spirituality which is enriching.

### **Where is everybody?**

This feeling is hard to bear. It relates to the speed and space used by well people which is incompatible with keeping the company of people with illness. For ill people often do not have either the energy or the ability to go with them. There are often times when ill people just cannot keep up and therefore get left behind. Sarah's story is an example of this. We all went down the hill, at a speed she had no hope of keeping up with, to a place she could not reach.

The future may appear to be full of people disappearing at a pace and to a space the chronically ill person cannot hope to keep up with or stay in. Molly Holden's (1994, p.60) poem gives expression to this feeling. There is not a wish to curtail other people—it just is painful being left behind:

*Along the lane...*

*Along the lane go two of almost  
equal height, her arm  
through his. She takes my place, so sweet  
a surrogate no harm*

*enters my mind. Yet I can hardly bear  
to watch my daughter  
on her father's arm. Salt in the wound.  
Fate gives no quarter.*

(Molly Holden)

It is good to have loneliness relieved by people visiting at home. Here the person is more likely to be comfortable and able to enjoy company. My visits to participants in the study were appreciated; I was welcomed and entertained wherever I went. After my first visit with Peter he said that he would welcome me back and be part of the research because it would be good to talk to someone new (fldnte:3.13). Peggy always came onto the veranda to greet me when she heard the car draw up and she made elaborate preparations for my visits, usually pikelets, jam and cream. Linda spent ages one day showing me the most exquisite embroidery that she does and we both enjoyed browsing through her collection of books (fldnte:3.21). Sarah liked an excuse to open a bottle; whatever time in the afternoon I would visit she used to look out of the window and say with humour, 'I think the sun is over the yardarm by now.' People who are prepared to alter their pace and space in order to be with chronically ill people are generally appreciated.

#### *Friends*

*thank god  
for the small procession of friends  
who knock on my door  
bringing me flowers and newspaper  
cuttings  
interesting books  
or the wrong kind of apples  
because I've forgotten to explain  
which ones I like*

(Maria Jastrzebska)

However, ahead of chronically ill people is the possibility that they will have times of loneliness as 'well people' bustle along with their healthy lives.

## **Loss of independence before death**

The repercussions of chronic illness which people who helped with this study were most likely to experience, was creeping inability to look after one's self rather than premature death. Future loss of independence was mentioned more often than death as a matter of concern. However, there were a few people who talked about death. Those who did talk about their attitude to death were the ones who had conditions which were more life threatening. It was reasonable that they were preparing for and considering death.

## Independence

There is a range of things that may occur to the chronically ill person which makes life for them more difficult. What they fear most are the symptoms which will cause them to become dependent upon others for their care. A range of symptoms will ultimately affect the person's ability to move and purposefully help themselves. People who are chronically ill have plenty of time to study their diseases and to appreciate the difficulties that they may well face in the future. Dr Craig knows what his deteriorating eyesight means—the doctor will probably prescribe insulin and he will not be able to give his own injections. He will have to rely on someone to help him and this really bothers him.

Coupled with the notion that it is demeaning and embarrassing for any adult to require assistance with daily living activities, dependence is feared because one may then become a burden upon others. Dr Craig really would not mind too much what is happening to him, physically, if only he could be sure that he will not become disabled. He says:

*So ...[pause]... the thing that's threatening me, to me, in the [future] umm, ...[pause]... disabilities increasing, is umm, ...[pause]... that I am going increasingly to have, to have, to give up control of my own life, really, and rely on other people umm, that's a scary sort of ...[pause]... situation.*

(Wa:197–203)

He does not want either his wife or his children to be inconvenienced by his disabilities. The prospect really worries him:

*It raises uncertainty. You just don't know what is ahead of you. Err ...[pause]... the future is uncertain, you just don't know the degree of disability again. Err, you don't know the amount of help you will need or whether it is available or whether you can afford to get it if it is available. Umm ...[pause]... I would not like to impose on my wife who really doesn't like, she had a, a stint of nursing during the war and really didn't like it and she wouldn't like giving injections and she wouldn't like carrying bedpans and stuff like that ... I would also not like to look to my children to look after me. I think that's imposing on them too much, on them ... the future is uncertain, you just don't know.*

(Wb:196–209)



It is these worries that spur him on to try and comply with a medical regime of medicines and diets which he hates and makes him quite miserable at times. He feels guilty if he does not try because of the repercussions for his family rather than himself.

It is interesting to note how Colin's refusal to look at the future has affected his life now. Colin recognises, and is quite interested in, some of the things that he has difficulty with now and his ways of getting around them. What he has found in time is that the drugs that he is taking for the Parkinson's are helping him. It has taken some time to get the doses right but in some areas there is improvement:

*It's like when I put me socks on, you stand on one foot and put the other foot in the sock and you lean a bit and you fall over—you [addressing me] might sit down to put your sock on.*

*Mary—Oh, I definitely sit down to put my socks on, Colin. I wouldn't try putting them on standing up.*

*Standing on one foot, I used to stand on one foot and just drive the other foot into the sock, but, you know, if you lean out of plumb well, you fall, you have to grab something. I, I had, I had to sit down for a while but I sort of try to put them on standing up, now.*  
(Tb:493–496)

What he cannot face or even think about is how his condition might deteriorate. This is one of the reasons that he avoids the Parkinson's support group and prefers not to think about more disabilities yet:

*If that is going to happen to me I would rather not know about it until it happens, you know ... I might be worse I don't know, and ...[pause]... as I said before, ignorance is bliss and if you don't know what is going to happen (bleep bleep) ... [rather ironically Colin's watch alarms at this point to remind him that he should take more medicine]*

(Tb:594–601)

In his avoidance of the future he did not seem to appreciate that there could be improvements or good things in store. In responding to his unexamined fears he may have given some things up before he strictly needed to. Perhaps a more candid view of the future might have helped him to postpone some of the radical decisions he made about the property and the business.

Sarah does not wish to rely upon her family when she is no longer able to walk. In contrast to Colin, she examines the future and wants to know what will possibly happen to her, as the arthritis gets worse. She has made alterations to her unit now, to ensure she will be able to manage independently, for as long as possible. With pride she shows me the drawers in the kitchen which slide open with a touch from the little finger, the wide door ways and accessible bathroom. She feels good about these alterations as they help her to stave off some of the worries she has about the future (fldnte:3.108).

Dr Craig may consider euthanasia rather than become a burden upon his wife or children. It is one of the possibles that lie ahead. It is an option which he has which will allow him to continue to control what happens and could prevent him from becoming dependent. However, he acknowledges that this way out may be fraught with problems for his family (Wa:253–267). At the moment it pleases him that he is not faced with an inevitable situation of dependence and there are decisions he could make to extract himself.

Thinking of the future and the possibility of growing dependence is not a wholly pessimistic affair. Although there are grim facts to be faced by some participants, those, like Sarah, who can realistically look to the future for the various possibles, appear to be able to relieve some of their fears and worries. However, those who are disturbed and worried now about the possibility of future dependence do not seem to be getting any reassurance or help to face the future. The support groups are helpful in terms of providing information about appliances and means of adaptations for increasing disability. However, these are not very useful when the person is still not ready to face the future.

## Death

*My father used to grow vegetables down the back and I used to see my mum and dad down the back and they would be worrying. And I would be inside wheezing and just—because there was no machine [nebuliser or ventolin] you just had to wheeze ... and I was such a burden to them. I was sixteen and I used to pray to God every day to let me die.*

(Na:288–295)

In this short passage Peggy is one of the few people in the study who described the struggle of chronic illness as making one 'world weary unto death'. She has had little relief in her life from the struggle to breathe, herself, and to help her asthmatic children breathe. Yet, as an adult with responsibilities, she struggles on because she

still has things to do and Floyd to look after. She no longer prays to die but she is sure she will die prematurely and I think she may be right (fldnte:3.12).

**Song**

*'Tis true our life is but a long dis-ease,  
Made up of real pain and seeming ease.  
You stars, who these entangled fortunes give,  
O tell me why  
It is so hard to die,  
Yet such a task to live?*

(Katherine Philips)

Sallyanne faced death when she was so ill with cancer. Following an overdose of chemotherapy she was semi-comatosed for days in acute pain and left with peripheral neuropathy. She speculates that the overdose of chemotherapy is probably what at last sent her into remission and improved her prognosis. Before the chemotherapy, her doctors doubted she would live three months. Her body bears many scars where tumours were removed. Now living with chronic illness she is sanguine about death—she believes that it is not such a frightening prospect as she once presumed:

*After my experience I have absolutely no qualms of dying—  
absolutely none.*

Mary—*Now how does that make you feel?*

*Umm, really peaceful actually. I have, I mean, you know, okay, I don't want to be in all that pain again before I die. I don't want to have that extended length of pain ... prior to all this I think I hated the thought of dying, I didn't want to [die] ... Now it [is] just there ... I have no qualms at all that movement from this life, this life that we see to the next ...[pause]... to the next one.*

Mary—*You're quite pleased with this peace that you've found?*

*Oh yes.*

Mary—*Because you're smiling.*

*It's so peaceful that sometimes I wish that I could get there quicker. It was just so peaceful, it was such a beautiful experience that I can feel my body sort of tingling.*

(Ga:185–197)

Nowadays when life is too much of an effort she sometimes wonders: *'If I could go tonight'* (Ga:207). She believes that death is not far away, not that she thinks she will

die soon but that she could call it up: '*A couple of times when [life was particularly difficult] I would think, "I don't think it worries me if I don't wake up in the morning," and I can remember once I woke up in the morning and I was really disappointed*' (Ga:212–214). Sallyanne's experience and the meaning she derives has something in common with Frank (1991, p.137) who also faced near death: 'Some part of me still knows where it was going. I wait to finish the journey my body now knows is inescapable. I hope to wait a long time, but not forever.'

Jane has lived with the fear of death since she was found to have chronic hepatic failure when Danny was a baby. She explained that she always kept a few steps ahead of death and bargained hard. She used to hope and pray for just enough life to get Danny through each of his childhood and adolescent stages. The story of her struggle is fascinating. It is now, when Danny has reached university and she has had a liver transplant, that she can afford to marvel at how close she was to death. She even remembers sleeping on the edge of hepatic comas during some days when she was in bed during the afternoon before Danny and Simon came home. Although the stages in Danny's life gave her tremendous strength to carry on, she says she will not give up now that he is ready to leave home and is no longer the subject of her bargains—'*but then I am not sort of contemplating carking it at this stage so...*' (*chuckle*) (Va:186–187). The liver transplant has given her new hope for living longer although she pays a high price for her life. The side effects of the medications and numerous other complications stemming from the transplant plague her. She admits that thoughts of death are never far away because she is constantly reminded of her illness through the unpleasant symptoms and the regular activities like taking medicines and going to pathology for regular blood tests—'*It's there all the time, you couldn't forget it*' (Va:198–199).

Most of the participants in this study will not die prematurely because of their chronic illness. These people are no more occupied with the subject of their deaths than 'well people'. Indeed, death was not something that they talked about when telling me of their experience of chronic illness. The calm way that Jane and Sallyanne view death has some similarities with the spirituality experienced by Zoe, Pauline and Sky through aloneness. This type of spiritual state is born of deep introspective suffering and it appears to render the person a calm which is valuable and which gives them a great deal of support to continue on with their lives. Frankl (1985) through his theory of tragic optimism explains:

... tragic optimism, that is, an optimism in the face of tragedy and in view of the human potential which at its best always allows for: (1) turning suffering into a human achievement and accomplishment; (2) deriving from guilt the opportunity to change

oneself for the better; and (3) deriving from life's transitoriness an incentive to take responsible action.

It must be kept in mind, however, that optimism is not anything to be commanded or ordered. One cannot even force oneself to be optimistic indiscriminately, against all odds, against all hope (p.162).

Optimism, he explains, cannot be pursued; it must ensue. There needs to be a reason for optimism (p.162). I think that the people in this study who have learnt to face death and being alone with such equanimity have found a reason to be optimistic in their tragedy. They all, to varying degrees, still need to work at creatively turning their negative experiences into something meaningful but they are progressing. For example, Sallyanne said with confidence:

*... I'm more open to believing what will be, will be, and what is ever out there, with my name on it, sometime it will come to me, or I will get to it, and that'll be fine. I also believe that, I really believe this, that I did not go [through] what I went through for nothing, so ... I am meant to be here doing what I'm doing at my age to enable me to get to that thing out there with my name on it. Whatever that thing is, I don't know what that thing is. I have no idea what that is. Whether it might be—that I stay in academia or whether it might be that I write a book, ... maybe [I am] to use my illness to help other people.*

(Ga:101–110)

## Hopes

The hopes that people expressed were characteristic. What I mean is, they reflected where the person was in terms of understanding their own experience. For example, the self-professed egotist Peter, hopes to be cured of multiple sclerosis; that is all he wants—anything in between is not worthwhile: *'I want to be cured, then I can do all those hopes for myself'* (Kb:198). He looks to the future in an unrealistic way and plans holidays in the Far East; nothing which will improve his lot in small ways interests him. He wants to be the 'man about town' again or have nothing; he does not really face the future. Paul hopes that the back surgery will mean the pain will be controlled and that he will be able to be the father and husband he was before he was incapacitated by pain: *'Well, next year I will be better still and we will go places, we'll go camping'* (Ob:484). Jane, with typical modesty, just hopes that—*'one day all these little bits and pieces will sort themselves out and we can really get on with things'* (Vb:169–171). Colin hopes he will not need brain surgery (Ta:99).

A persistent hope is that their illness will not get worse too soon; that is, rather like Jane (living from stage to stage), until they have been able to accomplish this or that. Zoe wants to make a trip abroad with her husband without any ‘flare ups’; Elizabeth hopes she can just help her husband get started on a business venture before she needs to go to the specialist again. Linda hopes that she can reach the age of sixty before either of her diseases catches up with her. Then the children will be off her hands and she says she will not want to work:

*Yeah ...[pause]... I mean, you know, things would, would—will significantly change by the time I am sixty ...[pause]... err*

*Mary—So you are thinking, ‘Just keep me safe until then.’*

*Yes, and then we will see what happens then.*

(Hb:491–498)

### **I know I will get ...?**

A person’s prognosis is their medical prophecy. Arriving at a prognosis is, at best, an uncertain art of prediction. Dr Craig has worked this uncertainty out for himself. He knows that his illness is not as clear cut as some would suggest. He is sceptical about the causes of his troubles. He is told that being overweight is the cause of his diabetes but he wonders if perhaps there may be another unknown factor that is influential:

*So I think that they might, well, eventually [find] that there is a third factor that causes both diabetes and obesity and err, until you find that, you are really not getting far.*

(Wb:118–121)

His scepticism of the cause of his disease extends to his medical prognosis. He would quite like to argue his way out of the predicament he is in. He hesitates to tell the general practitioner about his retinal deterioration for he fears that in order to stave off more damage to his eyes the doctor may advise him to take insulin to lower his blood sugar—‘*I would hate to have to go onto insulin*’ (Wb:184). He would like to reject the forecast of worsening eyesight but his rational and fair mind will not let him. It is a pity that he and his wife have not discussed these fears with someone. At the present he is only given advice—advice to stick to the diet and control his own blood sugar but to date he has not been able to do this. The advice is not really helping him at all.

Pam can remember how difficult it was in the days when people were not given information about their prognosis. Her adolescence was spent loitering in hospital, waiting patiently to get better and get on with her life:

*And they used to say to me, 'Righto, your therapy can be taking umm, de-shelling the hard boiled eggs,' and I did this [incredulous tone] week after week, month after month. And after a couple of months I was with this really nice therapist called Clarky, Anne Clark. And I said to her, 'Hey, Clarky ...[pause]... I'm really sick of it, when am I going to get better?' And I remember looking at her and she put down what she was doing and sort of disappeared and honestly, Mary, that is when I realised I wasn't going to get better. Nobody said to me, 'You know you've got this disease. This is what is going to happen, this is, [can] be, your contribution to stopping the progress of it ... I realised though from Anne Clarke's ...[pause]... umm, reaction, she just made herself scarce and I never got an answer to that.*

(Sa:507–527)

Pam really resents the fact that she was never directly told what was the matter with her and she was never included in making decisions. She marvels at her own passivity at the time but understands that that was how she was expected to behave and how she had learnt to behave. She believes that some of the deformities that she has today might not have occurred if she had been told why she had to do certain exercises and been motivated to help herself. In effect they stole some of her future by not sharing what they knew with her.

In contrast, Ruth is pleased that the information was kept from her. She says that multiple sclerosis was suspected years before she was given the diagnosis:

*I mean when I was twenty I went blind in my left eye, completely blind and my sight came back within two months ...[pause]... and err, they must have suspected it then ... but they didn't tell me, thank goodness.*

Mary—*Are you pleased they didn't tell you?*

*Absolutely pleased [firm definite voice] because I wouldn't have had two more kids ...[pause]... and I was so active.*

(Ra:50–62)

The relevant point here is that both these women needed to be given information in different ways. The decision whether to tell them or not about their illness or possible illness and its likely course was taken by a doctor. This patriarchal policy is outdated now; however, it demonstrates quite well the implementation of a policy without reference to the individual concerned. More recently, in this modern climate of truth,

Sallyanne was given her diagnosis (Hodgkin's lymphoma) and prognosis (barely three months) by a surgeon standing up on the ward round. The nurse came back to offer Sallyanne some support but not until she had finished going around with the surgeon (fldnte:3.17).

In these two examples it would be hard to propose that there has been much improvement in service from Pam's time to Sallyanne's. The decision whether or not to give either of them information was based on current practice at the time, not on who they were and how best to handle the individual situation. It could be argued that neither of the doctors involved (Pam's specialist or Sallyanne's surgeon) could have made a prudent judgement regarding the information or help they needed because neither of them knew their patients as people.

Just as with medicines, an illness reacts differently with separate people and therefore can run unpredictable courses. Part of a prognosis must include the person's entire response to date, not just the information available in the medical text books. In chronic illness the prognosis is something that can be reassessed regularly over the years. It is of great interest to the person suffering the illness and something people would like to have the opportunity to talk about regularly with their doctors.

Some of the people do not face the future with the possibility of continuing deterioration. For example, Holly has found that although her joints are creaky and stiff the pain is not as vicious as it was (Qa:70). Joint replacement surgery has given her some relief too. Paul still has backpain but he expects to continue to improve (Oa:343). Alan's heart failure has responded well to diuretics and calcium channel blockers (Lb:681).

## **Summary**

*How is it possible to view the prospect of chronic illness in the future?* The texts have shown that the future for most of the participants is full of more illness, struggle, loneliness and creeping dependence. However, when it is faced with candour, it is possible to glimpse means of gathering support to lessen the struggle—ways of keeping company and plans to maintain independence. This chapter began with Heidegger's (1962) proposal that to be aware of the future is to enhance the present. The experience of the participants in the study is that this is a difficult thing to do and superficially, at least, it is not a particularly 'enhancing' pastime. Life is a struggle and it is hard to contemplate a future with the potential of more struggle and suffering.



Those who do face the future and consider what may be the means of dealing with the obstacles and problems which might be theirs, have at least the opportunity to make plans and feel more at ease now. Their option to face the future can be related to Heidegger's (1962) notion of 'anticipatory resoluteness'; that is, an ability to meet possibles with candour and thereby to live authentically or, in other words, to be aware of one's own existence.

To view the prospect of more years of chronic illness means, for most of the participants, more loneliness. There will be times when the rest of the world will speed ahead and leave them to their own devices and their inaccessible places of pain and suffering. For some people it means facing the prospect of increasing disability and dependence upon others. For others it means going forward with more confidence based on an authentic review of their existence and the influence chronic illness has on their lives. For a few it means moving forward towards their own death or more difficulties with some peace, for they have found the strength which can be felt within themselves.

Frankly, facing the future means more difficult work for people with chronic illness. By the very nature of chronic disease it is likely that their illnesses stretch far into the future. However, dealing with the possibles now can lessen the stress and worries uncertainty causes. It is only possible for people with chronic illness to face the future at a time which is right for them and preferably with some help and encouragement from family, friends or health care professionals. The participants who have been most candid in their relationship to the future were helped by their religious faith or spiritual attunement. The only health care worker who has been a significant support through this type of work is the counsellor to whom Sky referred herself.

The participants in this study showed different attitudes towards facing the future. I would not propose all of them should be helped to look honestly to the future immediately. Some are not ready and others are already masters at it. What I do propose is that they all need time and space to discuss what the future means to them now.