

# Chapter 5

## A Selection of People

### Introduction

As explained in chapter four I have chosen to present the people who helped in this study in a variety of ways. In this part of the thesis some of the people I worked with are introduced. These case studies are the first attempt I made when beginning to analyse the material given to me by the participants in the study. I did this exercise with all the people and have chosen this selection. The reasons for the selection included convenience but I believe these stories also fit together well in the context of the study. The selection of people include Peggy and Linda who have been affected all their lives; Colin, Paul, and Peter who feel they have been afflicted in their prime; and Dr Craig who has gradually become unwell as he has become older.

When I encountered the texts as transcriptions I started the analysis by marking things of note, for example, this is about how different this person was before, this is about his relationship with his son, this is about feeling like an outsider. After spending some time with each text I wrote down the most pervasive impressions I got from the story. I reread these, carefully trying to temper my own interpretations for the time being. I looked to see what evidence my impressions were founded upon. Then I began to ask questions of the text, for example, questions such as: *Why was a particular impression very strong when there was only one reference in the participants' text? Why could I use the term 'loss' associated with health for Colin and others' stories but not with Peggy's? Why are they sure they will be stigmatised? Why am I using the word 'stigmatise'? What words have they used surrounding this topic?*

Bearing in mind Heidegger's (1962) general assertion that, as self interpreting beings, the moment we are presented with a fact we are interpreting it, I do not pretend that these stories are not peppered with my interpretations. However in tune with Gadamer (1994, p.292), I was more than willing to listen to the people in this study and allow their words to reach the audience. For this reason I have included large chunks of the participants' conversations to demonstrate some of the inferences I make regarding their perceptions of their lives with chronic illness.

The results are vignettes of the people with a global introduction to the individuals and the ways in which chronic illness has affected their particular lives. At the end of the chapter I try to draw some ties and links between stories, which may transcend the particular situation to represent the social world the people share. Benner (1994b, p.114) asks the following questions in order to draw out this idea: 'What would happen if the context were different? Would the same issues and concerns show up for the two cases?' Besides links and commonalities I tried to tease out the mysteries and incongruences between the stories by asking: *Why is it that Peter refuses to accept his lot, when Dr Craig does so with relative equanimity? Is it more than their different stages in life?* Gadamer's (1994, p.367) conversations with text which seemed a little 'unlikely' in chapter three were beginning to take form.

## Colin

Col introduces himself in the following way—'*I'm Col ... err, farm producer and rural contractor, with Parkinson's disease*' (Ta:1–2). Col lives with his wife, Jill, in a blond brick house set back from the bitumen byway on a rough road which winds past the (woefully short of water) dam and over cattle grids. The dust billows up around the car and casts a haze on the vast views of dry land, dotted with cattle and gum trees. It is not apparent where the garden starts and I was not sure at first if I should park on the patchy ground which might be their lawn. Jill had planted the garden with roses and petunias, a few hardy enough to still bloom in the mid-day sun of the Australian winter. The cattle dogs barked in greeting but did not come from behind the house.

Col usually came out to greet me, while Jill put the kettle on. The three of us sat around the table in the family room adjoining the kitchen. The tape recordings are sparsely scattered with comments from Jill; sparse because on the whole she was careful to let Col speak. The three of us were comfortable together; we are of similar ages and I loved to hear about Australia and I was interested to hear Col tell me about the stocking of the dam with trout, the animals, and the ways of rural living. On one visit the three of us piled into the front of the four wheeler for a tour of the property. I saw the emu who just 'turned up' one day and made friends with an old, old horse on the property. Col imported, at some cost and effort, two other emus from Queensland to keep it company and to remind it that it was an emu! Suffice to say, they were not welcome and the original emu remains constant to the horse, while the newcomers keep a wary distance.

Now he looks back on it, Col reckons the first symptoms of Parkinson's started about five years ago. Little things which, although strange, he ignored. '*I'd be directing hands working for me trying to do a job and I'd be pointing [and] my hand would keep shaking for about ten seconds after I'd finished telling them where to go*' (Ta:6–9), and he found

the newspaper impossible to read because it shook. Once at the cattle market he spent ages trying to get his arm in his coat when it had started to rain; luckily another grazier saw his problem and helped him. Col remembers this friend looking really concerned, but Col just shrugged it off saying that he was stiff. His work and indeed his safety on the property became noticeably affected.

*I used to ride a motor bike, a motor bike for mustering stock—and I had young cattle [who] went bush and I had to place them. I put the cattle out through a fence in the neighbour's [land] and I had to go and get them back out of [there] and I ended up racing around like a ...[pause]... like a ...[pause]... you know, really fast in the paddock and which I had [done] for several years, but I couldn't work out why I had six busters ...[pause]... that morning with these cattle. Here you know I never had [a] buster in me life.*

Mary—*What is a buster?*

*Fall off the bike ... and I'd be racing around and I'd go, I'd go to sort of stop or turn this way, [shows me—his arms and hands steering the imaginary bike] as I turned I was right beside a rock, I wouldn't miss the rock, I'd ride right into it—and then I would get a buster, but I didn't realise at the time that it was all me co-ordination ... looking back ... and I actually bugged the bike—I bent the forks and the handlebars and everything. Now I'd been riding that bike for ten years.*

(Tb:365–393)

Col was eventually diagnosed with Parkinson's disease by his general practitioner. He was visiting the doctor for something else but by this time his shaking and hesitancy were quite apparent. The general practitioner was confident enough of his preliminary diagnosis that he called Jill into the surgery and told them both that Col probably had Parkinson's disease. Col went to see two neurologists in Sydney before deciding upon the one he now has. They are sure that they have the right physician as he has a good reputation and some neighbours who are medical people recommended him. This specialist appears on television occasionally and Col and Jill recorded him. They are pleased that he is regarded as one of the leading specialists in the country (fldnte:l.98–99).

Col has stopped working and given the management of the property to his son, Martin. It was the practical thing to do; it was not a difficult decision but it is hard to live with. Col talks of the classic father/son problems that occur in farming; but it is made worse

because he feels useless and rejected because of the Parkinson's. So when his son does not take his advice it is a reaffirmation of his changed status in life. One day Col's father dropped in for a coffee; he was a talkative man and it was interesting to note Col's simmering impatience with him. Perhaps he feels that Martin is as irritated with him as he gets with his father. The following excerpts from Col's story are quite illustrative of how he sometimes feels about his working relationship with his son and his attitude towards himself; feelings that make him quite depressed.

*... he likes to think he—he likes to do it his way and then when he finds out after he argues with me for ten minutes that my way is the way that—I've got to the stage now where I let him do what he wants to do, virtually—not always ... but if I want to do it my way and he wants to do it his way, well I just sit back and let him do it his way.*

(Tb:36–45)

*... but yesterday the son-in-law was over, you know, [we were] going to pull the shed down and I forgot to take me tablet and I was half an hour late and I just had to come inside, I just got sick of it ... yeah well I had mostly done what I wanted out there and they—I thought, 'Oh blow, I don't care if it all fell down and blew away in the wind'. You know when you feel like that you, well you do what you want to do, 'cause I wanted to shift it and they didn't want to shift it, and I, well I let them have their way because we were undecided ... I came in and sat over by the cool side of the house for a while ...*

(Tb:256–309)

Col's speech is affected. He describes his tongue as 'thick' and the dryness caused by the madapar compounds this feeling which distorts his speech. The first time we recorded him he fiddled with a pencil on the table in front of him, rolling it in his fingers and tapping it on the table. Suddenly he saw what he was doing and flung the thing away, impatient with himself, so that he could not touch it again. It was not possible to hear his speech on the tape recorder and I could only make notes. Col was disappointed and apologetic when I told him. He believes these affects of the disease (speech and fiddling) cause him to be stigmatised—an idea he detests.

*... sometimes I get an awfully dry mouth and I get slurred speech and fuzzy in the head and every word you say is an effort to get out and every thought you have is an effort to think. And to try and have a sensible conversation, it seems like you are rattling on and ...[pause]... and trying to make sense out of something you are saying but you feel like you're not, you know, like ...[pause]...*

Mary—*Yeah.*

*you're talking with [the] intelligence of sort of somebody ...[pause]... well, not a spastic but I mean like err, ...[pause]... err, like intellectually handicapped sort of, or intellectually slow or whatever, you feel like you've got that sort of conversation going rather than a lucid umm, ...[pause]... intelligent sort of a conversation.*

(Tb:262–283)

Col described an incident when the family were all together, including his daughter's parents-in-law, and he just did not feel a part of the group as he did not have the energy to participate any more.

*You know you can't switch on and off, if you're switched off by the disease you can't bring yourself back, until it—whatever [the] chemical [which is] imbalanced [or] out, corrects itself, there is no way you can show interest in something until your body is ready for it sort of thing, you know ... half the time your mind is as blank as ...[pause]... a sheet of paper ...*

(Tb:311–321)

While talking to Col his watch usually alarms and Jill gets up and gives him his tablets. He feels the effects quite quickly if he misses one of the two-hourly doses. Sometimes if he is talking to someone he will turn the alarm off and then forget to take a tablet.

Although he and Jill try to fill the days, life is distressingly different from how it used to be. Col's life was full of hard 'manly' work on the property and the change is a stark and constant reminder of his illness. He describes proudly how he used to do *one hundred sit ups* and could *out do* all the men on the farm. His son is strong, as he used to be. Before he was ill the two of them used to compete. Now he calls himself a '*weakling*' (Ta:101–106).

He says that, '*One of the worst things is other people's reactions*' (Ta:35–36). He feels he is on exhibition, he does not look 'crook', it is just his mannerisms. He describes laboriously writing a cheque in the bank which, when he presents it to the clerk, looks like a child has written it and this embarrasses him. For this reason he prefers to avoid people in the town. Neither Jill nor he liked the support group. Col disliked seeing people with worse symptoms than himself and he particularly disliked being with one person who discussed his recent neurosurgery.

The days are long—much longer than they used to be, even though he rises later.

*My day generally starts around four o'clock, 'cause that is when I wake up. I can't go back to sleep ...[pause]... I lay there counting the hours off until it is time for the morning medication which is six o'clock ... I used to get out of bed at five o'clock ...[pause]... and now I don't like to be out before eight o'clock because I just ...[pause]... You've got a lot of time on your hands ... as soon as you get up you've got to start using the time, whereas if you stay in bed, it sort of passes a bit of the day by, you know, and you haven't got so long to have your breakfast and it's not so long to lunch time.*

(Tb:5–29)

I visited Col and Jill again about five months after the first series of visits. It was really good to catch up on their news. Col looked and said he had improved markedly. They had seen the neurologist in Sydney and the Parkinson tablets had been changed, his speech was clearer and he looked brighter and more alert. He also said he had been taking different anti-depressants; his neighbour is a doctor and he gave him some to try. Now he gets them on prescription from his general practitioner.

## **Peggy**

Peggy telephoned me in response to the advertisement that I had put in the local newspaper. I could tell she had some breathing disorder on the telephone as she spoke in short gasps. That afternoon I went out to visit her at home, about fifteen kilometres from town. The property looked 'unfinished'; there was rubbish on the veranda and no steps up onto it. Peggy let me in. She was flushed and breathing in short gusts. She apologised for the mess—the house was a mess, there were magazines and papers everywhere and food and washing up lying around the kitchen.

Peggy launched straight into her plight. She answered my advertisement because she wanted some help. She was not interested in the research—what she wanted was someone to notice how ill she was. I tried to calm her and get her to tell me how she was feeling. She was angry and disturbed that she was home, unwell and nobody was helping her. I suggested that she rang her doctor and see him, but she had only seen him the day before and he had said she was slightly better than the last time he saw her (what he did not realise was that even though she was recovering from a chest infection she was now exhausted and less able to cope than when her medical condition had been at its worst). I asked her if he realised what it was like for her at home. She said, '*No one knows, I wish they would come and see*' (fldnte:3.8). She wanted me to telephone the doctor and tell him how ill she was.

I persuaded her to telephone the doctor's surgery for an appointment that afternoon (this is the specialist in town rather than the local GP she had visited the day before). She wanted to tell him that I had visited and had said that she should see the doctor because in my professional opinion she looked so ill. I said I would prefer her not to use me in this way and we rehearsed what it was that she wanted before she telephoned. Quite clearly she thought my opinion would be more credible than hers. I found the number for her, placed the phone on the table and sat her down where she could lean her elbows and breathe a little easier. When she got the receptionist on the telephone, she asked to see the doctor that afternoon. The receptionist asked, 'What about?' (The receptionist has known her for years as a severe asthmatic.) Peggy replied, 'My breathing' and was told there were no appointments free for that afternoon. Peggy said, 'I need to see him this afternoon.' (By this time I was standing behind her with my hands on her shoulders trying to give her strength and support.) The receptionist asked if she was worse and Peggy's voice broke in reply: she said she was coughing a lot, she just could not breathe and she could not manage any more. The receptionist was then quite kind and gave her a time to see the doctor that afternoon.

During the time I had sat and talked to Peggy I could see that she was upset and near the end of her tether. She kept saying, 'This isn't right' and 'I can't manage' and, 'Oh dear'. I did not want to speak for her on the telephone—I did not know enough about her. I explained this and said I would help her get what she wanted now for herself. What she wanted was to see the specialist. I suggested that when she was better and felt stronger we should talk about doing something about longer term problems and make contingency plans for when she was ill (fldnte:3.9).

Besides not being able to breathe well in the day she worries and dreads night times for she is sure that one night she will die. Her house is in a fairly isolated area and she lives with her sixteen year old son. Her asthma frightens him and she says he hates to hear the sound of the nebuliser in the night. This puts her under added pressure to just keep still and concentrate on her breathing. She is aware that she is getting better from this episode but when she looks at the mess around her and feels so short of breath and exhausted she just cannot carry on. It appeared to me that besides medical treatment for her chest she needed some other support. She had been feeling unwell for about six weeks. She was behind with everything, doing anything around the house was just too much effort (fldnte:3.10).

Peggy said that she was able to drive to the doctor so I left her, promising to telephone her in a few days to see how she was. At this stage I thought that she would not help with the research as it had hardly cropped up in the conversation as she had far more important

concerns. She just kept saying that she needed a nurse and that my advertisement had come just when she was desperate.

When I next telephoned Peggy she was quite cheerful and invited me over as she wanted to tell me what had happened after our first meeting. When she had visited the specialist he had agreed that she was ill—her peak flow recording was only 100—and he decided that she should be admitted to hospital. She then drove herself to the local emergency department to be clerked in by a doctor. After two or three hours a nurse came up to her and told her which ward she would be on and requested her to take her notes with her. Peggy made her way to the lift and waited for it to arrive. She crouched down on the floor leaning her elbows on her knees and thought—‘*Why bother? They won’t do anything I can’t do at home and they certainly aren’t going to help me. They haven’t noticed how ill and desperate I am feeling now*’ (fldnte:3.9). She picked herself up and drove home again feeling desolate.

In two days when she was feeling slightly better she went to her general practitioner and told him the story. She told him about me and said that I was surprised that no one saw her at home. She said he changed completely: altered the dose of her drugs and said she was not to feel she was struggling on her own. He would come out to visit anytime she wanted. She at last felt he was taking some notice of her. She said she felt more assertive with me on her side.

The house was tidy as a friend had come over and done it for her. She felt so much better when it was presentable. The friend, Wendy, is an older woman and fellow asthmatic she met through the women’s refuge. She feels comfortable with her because she understands her and she is sure she is not repulsed by her coughing.

Peggy and I chatted and she invited me to come back with my tape recorder and she would tell me about her experiences. She was not confident about being able to help but I think she looked forward to me coming again. In the following weeks I went back five times. We made three tape recordings but after reading the first transcription Peggy decided that she wanted to write her story herself. I always made notes after I had seen Peggy because most of our conversations (off record) were about her experiences of illness. She was a great talker and impressed me very much.

... as I said, my health has ruined my life in lots of ways.  
(Na:618–619)

Peggy starts her story with a long history. She has had asthma all her life, and her earliest memories include wheezing and being breathless and exhausted from the slightest physical effort. She missed so much time at the local school that she was sent to a



children's home in the city (eight hours by car from the rural town her parents had moved to). The home was for country children who required regular attention in the city hospital. In the home, education was not a priority:

*... in those days they never had teachers. I'm going back in the 19 ...[pause]... late 1940s ... in those days we didn't have teachers in the school, we had one woman there, err ...[pause]... and over a period of two years, on and off for two years, umm ...[pause]... I learnt how to colour in very well and I learnt how to put icing on biscuits.*  
(Na:35–42)

When she returned home she had to repeat sixth class three times. She made it to high school for only six months but by then, at the age of fourteen, it was time to leave school. In sixth class, where she was by far the eldest, she was constantly humiliated. When she left school she could not read or write.

*... I left then 'cause I figured I was dumb and stupid and even in sixth class in those days, umm—I don't know if you have it over in England, I hope not—but in those [days] they used to have what they call a dunce's cap with a big D on it and I can remember quite clearly in ... I was always just stuck in a corner on a stool with a big dunce's cap on. So I always used to get the dunce's cap and even, umm, and even in the first year, I knew that I had the ability to learn but I just didn't have the opportunity you know. So I left school ...*  
(Na:69–78)

Her lack of schooling still bothers her today. She does not usually tell people how long it took her to read and write.

*... I still didn't feel a normal person ... No one ever knew. As a matter of [fact] I don't think I told anyone until I was about forty-six or forty-seven ... I never told a soul. And even my kids growing up [said], ... 'God, you're dumb Mum, you never learnt to read and write.'*  
(Na:177–182)

However besides missed opportunities, being ill gave her the opportunity to be sponsored to go to an expensive college in the city. At this college she learnt very quickly and was able to get a job, after some initial hiccups.

*... Mother thought I should try out for Telecom ... but in those days if you went for a Government job you had to go for a medical test—of course I failed that in the first five minutes.*  
(Na:86–91)

She had to struggle to be accepted because of physical problems and intellectual problems. She did not feel normal and felt more comfortable with other disabled people.

*... we went to this place [work assessment centre] in \*\*\*\* [city] and it was a big floor and everyone on the floor had something wrong, they were crippled or, I can remember that quite clearly, they were crippled or had something wrong with them, and I thought I would feel comfortable working there—it was funny, I felt I belonged there.*

(Na:109–114)

This feeling of being seen as different and not fitting in has persisted for Peggy. Now, when she is not coping she feels more comfortable asking her ‘asthmatic’ friend Wendy (whom she met at the women’s refuge) for help rather than turning to her neighbours.

*... ‘cause that is why you don’t tell people because—‘That’s all she talks about [is what they think]. That is all you talk about, your health.’ Well I don’t want to be like that. Except my friend Wendy who I can talk about things like that [to] ...[pause]...*

Mary—*She understands?*

*Yes, she was the same, and I don’t feel embarrassed, and she might say, ‘Ah I’ve got to go and have a cough’, or something like that, ‘I am real wheezy, I’m coughing up’, like, [if it was] anyone else, that would make you sick.*

(Nc:134–139)

Yet Peggy does know she is worthwhile and capable; she gives me examples of friends she used to work with calling on her after thirty years. She says that her office skills have been appreciated and she was asked to teach at one stage. She sings (she sang for me) and a national women’s magazine included her in an article they were running about an asthma support group for parents and she has done the make-up for the amateur dramatic society. Yet she still prefers not to tell people about her asthma. When the amateur dramatic society offered to sponsor her to do a make-up course she declined even though she would have liked to do it.

*No, I just said to him, ‘You might be better off getting someone younger to do [it] or you know—someone who is a regular member who can teach it to other[s]’ ... I didn’t say the real reason is because I am not well enough and I am sick and everything else.*

(Na:26–30)

She can pick up insincere people quickly—a sense learnt early in the days of the home.

*... I was aware of and got very cynical about—we always used to have famous people [who] used to come and visit there and have their pictures taken and off they would go ... we used to laugh because we weren't stupid ...*

(Na:231–239)

She has met with similar behaviour from people many other times in her life. She describes the senior nurses in hospital and how they come around and make pleasant but superficial remarks.

*... and the senior sisters would come down on their shifts and say, 'Hello, youse back again?' and I am in bed there—'Oh those are lovely flowers, isn't that a pretty nightie?' They wouldn't stop and say, 'How are you coping, do you need any help?' And I used to think, 'Silly bloody bitches, why don't you stop and sit down and ask—just talk to me?'*

(Na:526–532)

*... and her job is to dismiss, err, discharge people and she comes around—it's a stupid job she has got—and she said to me 'Ah Peggy now you're,' [as] she just rubbed my toes, 'now you just look after yourself won't you, now you're right, aren't you, you don't need any help when you get out?'*

(Nc:88–96)

*When I was on the [ward] the asthma clinic sister came around—'Ah Peggy do you want any magazines or anything?' ...[pause]... I was half dead and on a drip.*

(Nc:57–63)

Besides the physical problems of wheezing and shortness of breath, Peggy's chest is deformed.

*... I have that deformed chest. I never ever let my chest show. [She uncovers her chest through layers of clothes to reveal a large indent in her chest.] That's from the asthma, some people have got the pigeon chest that comes out ... well, I had a few boyfriends but no one ever got past first base because I never would have let them know what my chest was like—and they used to think I was pure and innocent but I was just like other girls, but ...*

(Na:208–226)

She has little respect for professionals, basically because they have never really helped her and in some instances have hurt her. When she was small her family moved from the city to the town because they were advised she would be better in the country; then she was sent to the city because she needed to attend the hospitals there. This professional advice meant that as a young child she was separated from her family for two years in a home which sounds just like an orphanage. She goes on to relate incident after incident when she was not noticed or cared for by health care professionals—doctors, nurses, social workers or counsellors.

*... but looking [back] the doctor never, ever, referred her [daughter Penny] to a child specialist or anything and her asthma got worse and worse and I was [up] twenty-four hours a day looking after her, and err, she was in and out of hospital all the time; then again we never got any help—and I was up in hospital, I was so sick that I couldn't even go to hospital ...*

(Na:392–398)

Peggy married and had two daughters. One of her little girls had severe asthma and often both of them would be ill together. Quite understandably she found keeping a home almost impossible. She had no professional help and the marriage was under strain. Peggy believes that if she had had some help at this stage perhaps her marriage might have worked or lasted longer. She believes being unwell and unable to cope is what brought the marriage to an end.

*... and Penny, the eldest, you [know], she [was a] severe asthmatic and then when I had the kids sick, I always used to get sick and I used to—I was so sick that I just, umm, that is when I should have had help at home, or should have had help through the hospital. But all the admissions in hospital I had, I never had any help. No one ever said 'How are you coping?' or 'Do you need any help at home?'—and they were the worst times, they really were, because I got so bad that I never used to change—I told you, I used to wear my clothes to bed because I was up all the time.*

Mary—*Did your husband help?*

*No he was a dead loss. He often told me I would be better off dead ... so it was about that time I thought if I don't do something I'll up and die—and that is when I decided to get out, but he started to drink a bit, but I mean—all due respects to him, I mean, I think in all fairness to him, I really believe if, that if we had support we could have made it ...*

*I do believe in all fairness to him ... I don't think I would like to be married to myself, you know, you know ... it didn't affect our sexual life at all but I mean it is not very nice for a man to come home and he has got a wife wheezing day in day out and, he comes home and he's got your kids wheezy, and washing up's not done and the ...*  
(Na:345–376)

Peggy feels that other people find her a nuisance. She knew that her illness disrupted the lives of her parents and her brothers and sisters. She is reluctant to become involved with people at any level because they might find her a burden. This attitude has made her life more difficult. She thinks she is as much to blame as her husband for the breakdown of the marriage. She will not ask neighbours or friends for help when she needs it, even though she helps others out by being on school committees and baby sitting for the neighbours. She does not like to cough in front of people and even hates to disturb her children's sleep by coughing or using a nebuliser.

*... I was so much of a burden to them [parents]. I was sixteen and I used to pray to God every day to let me die.*

Mary—*Did you?*

*Yes, because I was a burden on my parents. I used to pray and pray, 'God, let me die' because I was a burden to them, you know. 'Cause Dad used to—he was a real kind, very kind man—he used to go down and grow his sweetpeas and his vegetables—I think it was just to [get away]. And my brother was crippled, they had a double dose ... my brothers and sisters [said], 'Oh God, you are a nuisance—we can't go anywhere because of you.'*

Mary—*Oh.*

*You got this all the time, yes, yeah, and when I did go anywhere on holidays I'd hope I'd never get sick or wheezy or anything—you know?*

(Na:294–312)

*—because I wasn't, I had no one to look after my children and looking back you couldn't ask your neighbours—'Oh not again!' No I never ever asked my neighbours, never, ever.*

(Na: 397–400)

She told me of a recent trip she had with her daughter and son. Her daughter arranged for them all to go to the city and spend the night in a hotel. The next day her daughter

remarked on the noise she made in the night, wheezing and coughing; she had kept them awake and her daughter said Peggy should go to a doctor and get herself 'sorted out'. Peggy was very hurt by this and really the treat was spoilt for her (fldnte:3.11–12).

I was there when she telephoned the doctor and I am witness to the reluctance she had in bothering the doctor and to the feelings she had that she would be viewed as a nuisance. The doctor's receptionist did not reassure her but reinforced this feeling by intimating that the doctor was very busy and trying to ensure that she really needed to see him. At the time I was disturbed that Peggy was reduced to tears in order to get an appointment and heartily agreed with her when she said repeatedly, '*This isn't right*' (fldnte:3.12). The receptionist might have been correct to gather information to justify her decision to the doctor. However the receptionist's behaviour had made Peggy cry and reinforced her feelings that she was perceived as a nuisance to the doctor and therefore unlikely to be treated differently from any other patient. This seemed to be the case even though she was feeling very sick, and was known at the surgery as a severe asthmatic and certainly deserved to be noticed. Peggy is used to people knowing her history and still not appearing sympathetic or attentive to her needs.

*... but I still think looking back over all those years when the staff were aware in [the] children's ward ... the nursing sister in charge there has been there for donkey's years, and she knew how sick I was and she knew how sick Floyd [son] was and Penny [daughter who died of asthma in the hospital] she never ever said you know, 'Would you like a social worker?'*

(Nc:15–22)

*Except for one sister \*\*\*\*\* [name] she was nursing there one day and err, and she came up and she said, 'Oh you need all the help you can get' ... and I went up [to] the social worker—it was a Friday afternoon and she was painting her fingernails red and she said, ... 'If she can't help you,' (I think I had told her that I had been to the home services [or] something) she said, 'Ah, if they can't help you, I can't.' And that is as far as I went and I went back and told [name of the nurse] and she said, 'Ah, what can you expect?'*

(Nc:24–38)

*... but as I said, my biggest bug bear is the fact that my file is so high, it is just [full of] all the things that have happened, even losing a child, I mean ... I get frustrated at [the fact] that I can't get help. Do you know what I mean?*

(Nc:129–132)

Tragically Peggy's little girl Penny died on one of her admissions to hospital.

*... I took her to the doctor and umm, ...[pause]... he said, 'Take her up the hospital.' And so I took [Penny] up there and she was in an oxygen tent and she had a drip on her, that's right and she was, she was pretty bad and the drip on the arm ...[pause]... went through the vein—it went through the tissue instead of the vein and they took it off and put it in the leg, so in actual fact she wasn't getting any medication at all, and her arms were swollen twice [their size] because of it ... and err, by that time it was a couple of days, 'cause they realised it and then they put her in intensive care and err, that was the worst—that was in 197\* and she was [a] week in hospital, a week before Christmas 197\*. She was on a respirator for a whole week and err, on the second day she went into a coma, ... so anyway she was up there, and the doctor saw me and said, 'Well look she is clinically dead we will have to disconnect her from the life support machine' and at the time I just made enquiries if anybody else, ... I asked if anybody else had been disconnected and, ah, he did tell me that there was one man who was hurt in a timber accident and that happened. You see nowadays it is pretty common but then, I am going back to 197\*. So she was disconnected from the life support machine, midnight the Christmas Eve 197\* and my little boy Floyd was ... born two days later. But what makes me angry we had no follow through from the hospital—nothing. We just had to cope the best way we could, same as always, you know. Although the doctor who is my doctor now, he wasn't my doctor then, but he was looking after Penny—*

In all the years she struggled Peggy did not know how to ask for or demand help.

*... I just don't know how, they were the worst times when I really needed help and there wasn't any help there.*

Mary—*And you just didn't want to ask did you?*

*...[pause]... Well I didn't know if I was sick enough, or eligible enough to get help, you know I thought you had to be asked—did you want help.*

(Nc:4–12)

Even when it was offered something seemed to go wrong. After Penny's death Peggy recognised that she needed some kind of support:

*... a friend of mine was a nursing sister in the back road and I said, 'Look I really need someone to talk to' and at that [time] the only person they had was a fellow that worked in the community health centre, and he worked for the alcoholics, he was the alcoholics [counsellor] he was an ex alcoholic ... so he used to come out and he told me, 'I only come out here to get out of the office for a while.' So after the second time I said, 'Now—I'll be right now—don't worry about coming back.'*

(Na:459–469)

Eventually, many years later, Peggy did get some help from a good doctor, a woman she had never seen before but whom she went to for a routine Pap smear. They were chatting conversationally and Peggy was saying that she had been invited to sing in the church at midnight mass but would not do it. The doctor asked why not:

*... and all of a sudden I burst out crying, and I just told her what happened all those years ago and I was able to talk to her [about it all] and she said—she was wonderful—and she said 'Come back tomorrow' and she saw me every day for about a week.*

(Na:486–490)

*... you know because [by then] it was Nov[ember]—Christmas was coming up and umm, I just poured everything out to her, and err, she was—she listened.*

Mary—Yeah

*She was really genuine, she listened, you know, and umm, but I wasn't aware of that when I went in ... and after that I felt cleansed, I felt that it was all out of my system, and I can talk about Penny and not cry. And even Christmas Eve now ...*

(Na:554–564)

## **Peter**

Peter's mother was asked by a mutual acquaintance whether he might be interested in talking to me. Apparently he said 'yes' as he was bored at home all day and any outside company was welcome. Peter confirmed this when I telephoned to make the first visit.

Peter opened the door, as he was expecting me, and led me into the kitchen where we both sat at the table. He immediately launched into descriptions of his life, mainly concentrating on what he could no longer do. He is quite disabled; his movements are



clumsy, he clings to the walls as he walks. However he still washes and dresses independently and is able to drive his car. His speech is thick and he has to wipe the side of his mouth. He was easily audible on the subsequent tape recordings.

He was diagnosed with multiple sclerosis six years ago. Since then he has given up his home in a large city and come back to live with his widowed mother in a rural town five hours drive from his former home and friends. He did some tutoring work when he first came up to the town as a favour for one of the community nurses who visited him at the time. He no longer does that. He fills his day by reading the newspaper, watching TV and dozing on the lounge.

Peter's story appears to be one of loss—he *had everything* and now he has nothing he values. He begins by telling me how well things were going for him just before he was diagnosed with multiple sclerosis.

*Well right, I was a teacher for twenty years. I retired as an assistant principal. Err, I had just got to a school I wanted to get to and this happened ... I had bought a house err, ...[pause]... my wife and I had split up, I bought my own house and everything was going fine you know and ...[pause]... and then I found out I had MS.*

(Ka:1–9)

He enjoys telling of his success with women and he sees himself as a bit of a Rod Stewart.

*... I think I'm a bit like [a] Rod Stewart type you know.*

(Kb:391–392)

He finds that his single and celibate status now substantiates his view that MS has changed him. Sometimes he says that he does not want friends and does not want to be with people because he cannot talk properly and cannot walk, has bladder problems and gets too tired. Then he says that he wants to have his urethral catheter removed and to have a suprapubic one so that he can have sexual intercourse and be how he used to be.

*I can't talk as well as I used to. It is no good going out with somebody and asking them, 'Do you mind if you cut my meat up for me?' That's a bit embarrassing when you go out and ask somebody to cut your meat up.*

(Kb:340–344)

He gave up teaching because of his difficulty talking and walking; he felt that he would lose the students' respect.

His views of himself now seem to be vindicated by his previous views. He had an attitude that he was capable of anything and the best. He described himself as egocentric caring little for others' feelings—he now expects others to have similar attitudes, he does not want people's sympathy, only their admiration. He was proud of himself and his devil-may-care attitude:

*... I was a child of the sixties. Nobody in the sixties ever thought they were going to get old. Umm, ...[pause]... I mean I am forty-six and I'm feel [ing] better, except from the MS, err, better than I was when I was, when I was twenty-six. I can do things, like I've got money and I can ...[pause]... go out and do what I want to do—except I've got this bloody MS you know ...[pause]... so ... (sniff) [tears] Peter Pan you know?*

(Kb:359–366)

Mary—*Right, you are not prepared to change on sex?*

*No, well why should I—I've been married twice and umm, ...[pause]... do you think that is terrible?*

(Kb:392–394)

*... you might get the impression (chuckle) [that] I am an egoist—I used to be—and err, ...[pause]... I know a lot of people who would say I'm—good you know. I've [Peter's] got MS—'Oh good, couldn't have happened to a better person' ...[pause]... they would ...[pause]...*

(Kb:252–254)

Mary—*And yet you have given women up?*

*I can't do anything else. I have to, I had to. You know what I mean ...[pause]... it is like the girl that I lived with, it wouldn't have been fair on her if I had asked her to stay when I knew I had MS and err, ...[pause]... and I wouldn't have felt happy in myself if I couldn't be the best sort of thing ... (chuckle) you know what I mean?*

Mary—*Yes.*

*Yeah, because I used to think that once ... I still do except I have got MS.*

(Ka:325–334)

He says he sees nothing good about his present life and only hopes to be as he used to be, even though he knows that that is unlikely.

*Well no, I can't say I have good days and bad days—I have bad and worse days.*

(Ka:49–51)

*... so while I've got some life in them (referring to his legs) I hope there is a cure. Umm, even though there is not one at [this] time ... you know you get very despondent about it ...[pause]... and you think what your life used to be like and what it is now.*

(Ka:190–194)

He fills his days with reading the newspaper, watching television and the occasional trip into town in the car. He goes to bed early and avoids social contact with friends. However he will admit to a certain satisfaction in having enough money to live comfortably without financial worry. This security has come since his illness and he was able to retire, for medical reasons, with an adequate superannuation pension. He has a car and will be able to live at home still when his mother dies.

*So if anything happens to Mum I'm going to get in an au pair girl, to look after me ...*

(Ka:77–78)

*I've got no worries car wise or err, ...[pause]... money wise.*

(Ka:86–87)

He does not visit the doctor often nor does he generally rate the skills of the medical profession particularly. All he wants from them is a cure for MS.

*... and yet when I was over in the MS hospital I was reading a thing about MS and it was full of me, and my girlfriend at the time said, 'This is you.'*

Mary—*Yeah.*

*And the—with that [the paper he was reading] I could have diagnosed it myself. Err, the only reason that it was diagnosed as MS in the first place—the GP I had in [city], his sister, she got MS and he sort of knew from her symptoms what mine were [caused by].*

(Ka:172–180)

Mary —*Does your doctor—how does he or she help?*

*Here? Well the one here is a GP, he is not a specialist, so he sort of err, the only reason to [go] here is every now and again to have a ...[pause]... what do they call them ...[pause]... a check up type of*

*thing to see if I am getting any better or worse. And I get down to [name of city] now and again umm, but apart from that the GPs don't know anything. I mean even the specialist[s] don't. Nobody knows what causes it or what is going to fix it up.*

(Ka:160–169)

His attitude towards doctors extends to the nursing profession. They can offer physical care but at the moment all he requires is to have his urethral catheter changed every six weeks. He was assessed and offered help with washing and dressing but he declined the help. When I asked him if he thought they might perhaps come again and that nursing care could extend well beyond physical care, that perhaps he might like to talk to a nurse of his sexual frustrations and feelings, he was sure he would not. I asked how he would view someone who tried to get him out more and meet people. He said they would not be able to do it, it would be a gross infringement of his privacy. He has chosen to retreat from life.

## **Paul**

Paul used to come and meet me in an office in the hospital after his hydrotherapy on Thursdays. He was enthusiastic about telling me his story and said he was disappointed when the sessions were finished. It occurred to me that he had not been able to tell his story in such a relaxed way before; usually, as you will see later, he is trying to convince people that he is telling the truth. His story is one of chronic back pain—pain which has been compounded by stressors at work and then by the pressure imposed upon him by the insurance company with whom he is battling for compensation.

For a number of years he worked in a detention centre for serious young offenders. The set up sounds difficult. It was a place where the violence was contained only by the officers being stronger and more powerful than the young offenders. Eventually the centre was closed down following an inquiry into the suicide of one of the boys. When Paul talks of the detention centre it appears that the place still disturbs him greatly. He is angry that the staff were put in dangerous situations, were understaffed, over worked and unsupported. He is beginning to realise that there is public disapproval of the methods and techniques used in the 1970s and he feels that the reputation of those who worked in these places has been slurred—yet at the time they were behaving as was expected by the authorities and doing what was then considered a ‘good job’ under difficult and unrewarding conditions. His lack of compensation for his back injury sustained at work stands, for Paul, as a monumental confirmation of the institution’s shocking disregard for the officers.

*Being threatened with my life, being threatened in that job. People pushing me ...[pause]... that, you wouldn't call an assault. I know the police. If someone pushes them it [is] an assault on police, not for us though. It got to that stage that I would just come home and I would just lie down. It was all I could do.*

(Oa:295–299)

*And if you had to put one away, which meant physically remove the person you would go through three locked doors which meant you had to hold it, unlock the door, go through it, lock it, and there were padlocks so it wasn't like just a door like—so twisting and turning and stressing your back ... usually I would—the only place I could hold them would be around the neck and they would be punching into you ...[pause]... twisting your side. It would take you sometimes five minutes, to get them into the room, the cell ... then you would have a sore back, your back would be worse.*

(Oa:112–123)

He chatted to me comfortably both on and off the tape. He enjoyed talking to me about England in the early 1970s. Those were his halcyon days: he was young, fit and handsome. He worked when he needed to and at other times he travelled seeing the countryside. In Ireland he fell in love with a French girl, married her in France and brought her home to rural New South Wales. He loves rural Australia and therefore appreciates how much his wife has given to him by leaving her home in Europe to live his kind of life. He has worked extremely hard to earn enough to provide 'the dream'—a smallholding for his wife and children. The property they have nestles in the hills and has breathtaking views across the expansive pasture lands and eucalypt trees in the broad valley towards the mountains on the horizon. Unfortunately they have not been able to complete the house because of his back problem. He gives one the impression that being able to provide for his family is extremely important to him. He often talked about how much he appreciates his wife and how desperate he is when he cannot do things for her.

*... when my wife—she had been out all day and came home and was doing the gardening—I'd go out and stand in the garden with her, just to talk to her ... 'cause I felt pretty terrible with her doing all the work, it made me feel worse.*

Mary—Right.

*Err, ...[pause]... I don't know whether that ...[pause]... I think the pain ...[pause]... and that feeling of not being able to do things and*

*seeing my wife do everything, was the same. I would class them both as being the same, but different—different feelings—the pain you could feel and it was hurting, but this other feeling was, felt it was like a silent thing which was eating away and from being this healthy person that I was and wanting to be the person that would protect my wife and kids and do everything, now I couldn't ...[pause]... umm, it's a feeling, it is pretty hard to describe that feeling but if I go to the doctor's I would break down.*

(Ob:110–131)

Paul has a backpain problem that has been brewing for years. It has progressively worsened, culminating in major surgery last year. Throughout the illness Paul has been dogged by stress and strain. His work with young offenders was particularly unpleasant and he has only just begun to appreciate that it is a contributing factor to the pain that he has. The stressors which chisel away at his peace of mind are a perceived failure to provide for and be a father to his family, fear that he will never be able to move without pain again and the continuing scepticism from the insurance company whose behaviour is blatantly intrusive in his home life and threatening to him.

*The stress of the investigators—insurer's private eyes coming down through the hills, dog barking at them. The insurance company said, 'No, we didn't send anybody.' I went down the road in the car and saw this guy's car and I had it checked out, by a friend of mine who is a copper ... That's all he ever did was tell me lies ...[pause]... the last time he came to me he said, 'We're going to settle, we're going to get things fixed up for you on Tuesday. I just need this information ...[pause]... how much are you earning now?' I said, 'I'm on a pension now, which I don't like being on.'—'Where [sic] do you spend your money on?' So I itemised everything and gave it to him. Tuesday came and went, next Tuesday came and went, a month or so came and went. Nothing, he had just lied to me.*

(Oa:414–425)

Paul first had backache when he was doing his national service and was required to stand for hours on the parade ground. Even in this early example of the onset of the problem he embellishes the account with examples of his trustworthiness, the lack of concern displayed by authority figures, and medical facts.

*... I was getting the prize for being the best recruit and when the sergeant went to give it out I wasn't there and he wanted to know where I was and the other, the others there said, 'Oh well he's in bed*

*he's sick.' And then he came down and spoke to me and he was really annoyed at the medical post [as they] hadn't done anything about it, so I ended up in hospital for about two weeks.*

(Oa:30–35)

*I went to the chiropractor thirteen times, so I was still in pain.*

(Oa:62–63)

*... the X-rays showed that the ...[pause]... distance between the two vertebrae had greatly reduced in size. It was down to about half and there was bulging in the disc.*

(Oa:92–95)

It appears that the response that Paul has had to his back pain from authority figures (those people who provide social security payments and employers) has contributed to his concern that he has to convince people of his genuine disability. His story has many examples of others commenting on his fortitude and contains a detailed history of the onset of the disease. This concern regarding his responsibility to convince others is not a fabrication. The insurance company is trying to prove that he does not deserve compensation and his past employers have displayed disregard for his health or welfare in order to save themselves from blame and financial responsibility for his disability. Despite his protestations that his back pain is genuine Paul admits that just sometimes he doubts himself.

*So I thought, 'Oh no, is it just in my head?' With so many people saying these things, after a while you think, 'Is it just in my head that this pain is happening, or is it really there? Am I really suffering?'*

(Oa:612–617)

This relentless pressure has caused Paul to doubt his own perception of his health, to fear for his family's security, to worry that he has let them down and at other times to be incredibly angry. It appears from the early part of his story that he did naive things like instead of taking time off sick he turned up to work. This was in part to create the impression that he was tough. He describes the scorn that the young men at the detention centre would deal out if they thought they had hurt one of the officers.

*... you wouldn't take the time off because they were the type of kid[s] if you had time off work, they then would say when you came back, 'I beat you, didn't I?' You could not show that you were beaten in anyway otherwise you would never have worked in that place over there ... So you'd go to work feeling sore and not show any pain at all, and yet you had the pain.*

(Oa:149–151)

*You wouldn't go off work, if you did, sometimes I would have a day off, I'd put it down as sick leave when it should go down as err, work cover.<sup>1</sup>*

(Oa: 124–126)

Besides going to quite a few medical specialists Paul has seen a chiropractor, a physiotherapist and a naturopath. He gets sent to different doctors for assessment. Some are less than helpful and others confirm that he has a definite organic problem. For Paul the surgery is the ultimate symbol of his sincerity. It cost him a great deal in terms of money and he does hope that it will improve the pain problem—but also it demonstrates that there was a physical problem.

*The doctor told me he had to remove quite a bit of bone down there, from down the pelvic bone area where the vertebrae come down, and he had to enlarge the two holes where the nerves run down through the vertebrae—go down the leg, see, because there was no room at all, that's what was causing all m'pain.*

(Oa: 504–509)

He knows some doctors have not believed his pain:

*The specialist in \*\*\*\* [name of town] told me all I had was soft tissue damage. He's a specialist and in his report he said that err, 'Mr. James [Paul] sat calmly in his seat and didn't show any sign of pain at all.' (cough) Although he did say in his statement that I shouldn't lift anything more than ten kilos ...[pause]... which didn't seem right. In one area he [was] saying he didn't believe me and in another area that I shouldn't do certain things.*

Paul demonstrates the conflicting advice and diagnosis he has received from the medical profession.

*I had already seen two other specialists and they were saying that all I had was soft tissue damage.*

Mary—Right.

*And not saying that it was err, problems with the nerves that were running down there. Even though I had told them, I told one chap that the sciatic nerve used to really really really ache.*

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<sup>1</sup>Work cover is the worker's compensation scheme. Any injury incurred at work is covered by the state rather than the employer.



Mary—umm,

*And he told me, 'You can't say that.' And I said, 'Why?' and he said,  
'You're not a professional. You can't say that it is the sciatic nerve.'  
(Oa:141–151)*

He was confused by doctors who gave him a range of exercises to do for he knew that some of the exercises should not hurt and felt that he was being tricked into displaying dishonesty. He still tries to work out why some hurt him and others did not.

*Okay, they lift your leg and that really hurt down here [points] (cough)  
because now I see that it was because of the nerve ...another one was  
to bend down, squat down and stand up ...[pause]... I really don't  
understand that one, I don't know whether you do or not.  
(Oa:526–535)*

*'Oh,' they said, 'you're only 10% incapacitated.' I said, 'I am not at  
this stage, I am not at this stage, I'm not, [I] can't do anything. Half an  
hour sitting—I'm in agony' ... They wouldn't believe you. I said, 'I  
can't do those things.'  
(Oa:565–569)*

Paul feels as if he can never win and that he is a victim; that is, he is a victim of the workplace, made a victim by the young men in the detention centre and a victim of the compensation system which includes the medical profession. He cannot see that he has done anything wrong. He just worked hard to provide for his wife and family and he dealt with the young offenders in the best way that he knew how. It appears to Paul that he is an outcast of society. When he stands in queue for his social security payments with people who used to be his clients he feels he is being tarred with the same brush as them.

*And I would be in line with a lot of clients that I used to be involved  
with, ... these families who are sexually abusing their kids or  
assaulting their kids and there would be [me] standing near them and  
they'd [be] looking and saying, 'I wonder what he is doing here,' and  
people behind the counter—I think they just treated everybody as  
being [the same] on the dole, not having a sickness or something ...  
(Oa:442–449)*

Paul refers to his illness as a 'black spot':

*... the way I felt was ...[pause]... you're growing, how do I put it now  
...[pause]... it's like a black spot in my life to me.*

Mary—*Yeah.*

*Up to about the age of thirty-three, good health, right through till there, until these accidents ... it was because it was in that part of my life where I've got a family and they have suffered. I've done a lot of suffering but to me I think my family has suffered more. If, if I hadn't been married and didn't have any children then I would have to say that I suffered, but I think they suffered more because umm, ...[pause]... the kids want you to go and play with them and take them places and you can't do it, and you can't get those times back again. They're gone because the kids grow up don't they.*

(Ob:450–446)

## **Linda**

Linda telephoned me in response to a radio interview I did in the town. The house they were renting was on the outskirts of town (she and her husband had just sold one property and were waiting to move to a new one). As I walked up the lawn to the house two little boys raced out to greet me. Linda was not far behind and we shook hands in greeting. On the verandah were five pairs of bush boots in decreasing sizes, a sign that these people were not 'townies'. Inside the house things looked temporary. The furniture was rather large for the little house and there were packing boxes half full/empty in each room. The boys are extremely boisterous and once we started recording, the tapes are peppered with their interruptions.

Linda has been diabetic since she contracted mumps as a toddler. She considers herself an expert at dealing with her disease and hardly ever visits a doctor. Her parents were instrumental in ensuring that she perceived herself as normal. She always gave her own insulin and accepted responsibility for her own health. Her parents were most supportive and she refers to them as sensible and good.

*And all my parents said to me was, 'Well you have got this now err, you got it, you've got it for the rest of your life. You will have an injection every day for the rest of your life and that's it. You are not sick, you can't use it as an excuse for anything and that's it.'*

(Ha:54–58)

At the age of five in hospital the nurse told her she could not go home until she learnt to give her own injections. From that time to this she has always given her own insulin. Before it was acceptable she used to titrate her insulin doses because it made sense to her ... *well you can't have one dead set [dose], you know it is just hopeless, particularly, I think, particularly as a young person when you are very active ...* (Ha:165–167).

Her background, as she terms it, was ‘middle class Brisbane’ with English backgrounds. She twice gives illustrations of her father’s traditional attitudes towards women which show disapproval in what he perceives as inappropriate female behaviour (eg drinking alcohol) and roles (eg working when married). I formed the impression that Linda believes that you make the most of life and should not complain. There are two places in the transcriptions where she admits that having diabetes is a problem but the rest of the time she is matter of fact and totally in control.

*Why not, why not, why not? [talking about the possibility of a pancreas transplant] I mean, then for the first time in my life, or within my memorable life, I wouldn’t have to worry about what I ate. I wouldn’t have to worry about what I drink. I wouldn’t have to worry, for instance like now, when my husband is away, about being very careful that I don’t go hypo during the night. Okay, and travelling, I wouldn’t have to carry insulin, I wouldn’t have to carry syringes. Plus the more important thing apart from lifestyle umm, ... is that it may cut down on the problems of the future, like the blindness, the kidney failure and the rest of it. I would have a transplant tomorrow if it would work.*  
(Ha:710–725)

*Like a friend of mine in [town] she had three children, two boys and a girl, and the girl she couldn’t bring herself to get her immunised, and I said, ‘Well what do you want Sally, do you want her to have one needle and cry or do you want her to have two needles every day for the rest of your life? You know,’ I said, ‘the choice is yours.’—I got quite cranky with her, you know, it is not fair on the child.*  
(Ha:26–32)

She married in her early twenties and lived in one of the capital cities for many years. She set up and ran a successful business. They were a sociable couple who played sports and entertained a lot. In their late thirties the couple decided upon a complete change in lifestyle and bought a property in an isolated region of New South Wales. Linda’s husband loves the rural life of a grazier and she is determined that he should not have to give it up—indeed she does not see returning to city life as an option. Linda continued to work part-time in the nearest town. At forty Linda and her husband decided to start a family and she is proud of her two healthy children who are still both under five.

In her early twenties Linda started to have fits. She was diagnosed as having epilepsy and started on anti-convulsants. Linda decided that she did not want to be known as ‘an epileptic’ and stopped having treatment.

*... I went and saw a doctor at the \*\*\*\* [name of hospital]. I can't remember his name now, a professor, and he diagnosed what the problem was, and err, he put me on tablets which I took for three or four weeks and then I didn't take them any more ... Oh I just took them for a short while and err, at the age of twenty I didn't want to take anything. Err, and then really, well I didn't, I didn't tell anybody. I wasn't game enough to say anything to \*\*\*\* [university] of course ... and because of the problems I had had with diabetes [referring to being accepted into a professional training] so I never said anything about it and umm, ...[pause]... I suppose normally I'd have perhaps, I would have three or four grand mals a year and perhaps about ten smaller ones ...[pause]... where I don't lose consciousness.*

(Ha:96–115)

It is only in the last few years that the grand mal fits have increased in severity and frequency. Linda did seek medical advice but again decided to ignore it. She believes that accepting treatment will alter her life in unacceptable ways.

*Well, I won't go [to the specialist]. No, for the simple reason that the doctor in \*\*\*\* [city] told me that ...[pause]... he only, he saw me the once, and he said that I should have my driving licence taken away from [me] ... Well as far as I am concerned when you are living in the country that is a death sentence. So that is why I have never been back, because I don't want to lose my licence ... and how do you cope in the country if you haven't got one? You become virtually a prisoner on your own property, you know, 'cause my husband, once we go on the property he is terribly busy. Sometimes he'll go for two weeks and not leave the property [indicating the vast size], and if I want to work ...[pause]... well how do you get to work? How do you ferry young children around, all this sort of thing?*

(Ha:194–209)

Linda's views are multiple, complex and at times contradictory. Her first line is that 'I have this all under control'. Neither diabetes, nor indeed epilepsy, have stopped her doing anything. She is proud of her successes in life. A husband, a good social life, a successful business and two healthy children. She is aware that she may have had to struggle a little harder than others. On the whole she is impatient with people who bring misfortune on themselves because they are not as controlled as she is.

*It was their choice they went onto intravenous drugs. They still don't need them to live, so why can't [I]—I mean mine are vital to me.*

*Without them I die, so why can't I get syringes for nothing, if they can get them why can't I?*

(Ha:581–586)

*I mean I never drink or anything like that—how many times do people get behind the wheel when they are rotten drunk and all that sort of thing, which I think is far worse, because they knowingly do it.*

(Hb:466–469)

She has a certificate for deep sea diving and is qualified to supervise learners. She did not tell her instructor that she was a diabetic or had fits. Her reason for the deception is that she would not have been allowed to do it.

In order to lead this 'successful' life she does need to compromise. For example, in order not to become hypoglycaemic when her husband is away, and she has sole charge of the children, she runs a higher sugar than usual (she knows this is not good in the long term). In order that she is not sleepy in the day time and so that she can drive she will not seek medical treatment for her epilepsy. She has learnt in the past that by 'not mentioning' diabetes she could avoid prejudice and carry on with what she wants to do. At school she was known as a diabetic and because of it the school would not allow her to do certain things (she could not go camping and could only swim if her mother came to supervise). Her parents and she thought this attitude was unnecessary and showed an ignorance. When she took part-time jobs she just did not mention it. Later she ignored and failed to reveal epilepsy in the same manner. Her attitude is that as long as you look the same as others and do the same things you can hide the disease and it then has a low impact on your life.

Future problems do concern her, especially the complications of diabetes. She believes that she will have to pay for her present lifestyle in the future.

*I see my problems coming down the track to knock me down. Problems with the sight and ...[pause]... losing the legs and the kidneys failing and all this sort of thing that is down the track. That is when my problems will occur ... You just have to put it off as long as possible I suppose.*

(Hb:567–585)

I pressed her to talk about the dangers of her driving, to other people, herself and to her two young boys. She hedges as these are issues that are difficult for her to talk about:

*Mary—What about passengers and other people?*

*I know, and my husband keeps telling me that too.*

Mary—*I am sorry.* [Linda is distressed]

*No, it's all right, no I have thought about that too. Umm, because it has happened so, I mean I have only, in thirty years of driving I've only had two at the wheel so I think well ...[pause]... for the simple reason I have only had two.*

(Hb:456–465)

She has worked hard all her life and regards her achievements as rewards or products of her attitude. She feels that some things are not fair. It is not fair that she should have to deal with epilepsy as well as diabetes. To seek medical treatment for her epilepsy would mean she would have to give up driving her car and other pressures would be put on her family. Her husband would probably be advised to stay home at night and she will not conceive of inconveniencing herself and her family. She believes that she could not exist on a rural property without driving. She will not be the cause of her husband giving up what he wants to do so much. She says that the epilepsy is no great danger to her health. She believes that her lifespan is reduced by the diabetes and she concentrates on the diabetes and tries to believe that the epilepsy is benign in comparison. She knows this is a facade but one that she has chosen in order that she can live life the way she wants to.

Mary—*But the ball is left in your court?* [to make the decision whether to be treated for epilepsy]

*Umm, yep.* [very quiet]

Mary—*And do you feel solely responsible for the decisions you make?*

*Yes, well I am the one who is making [them] nobody else. I am the only one making them.*

Mary—*Yeah, is that lonely?*

*I don't think so because I have had to face it all my life.*

Mary—*Umm*

*I have been doing it all my life so it doesn't make any difference.*

## **Dr Craig**

In response to my first newspaper advertisement, Dr Craig telephoned and invited me to his house. The house is in town, invisible from the street, set behind hedges and a long garden. The house I noticed needed painting. In a later recording Dr Craig explained '... I

*should paint the house but I haven't got onto it because I haven't the energy ... I don't like getting up on ladders any more'* (Wa:213–217).

On the telephone Dr Craig introduced himself as a retired academic—I am fairly sure his leading motive to get in touch was to see what the contemporary PhD student got up to. On the telephone his voice was warm and full of humour. The first time I visited his wife joined us for afternoon tea: thin slices of fruit cake and biscuits in the drawing room—a room, like the hallway, lined with books and pictures. We talked of my study and how he might help me, but we also talked about his work and his wife's work and nursing; the time passed quickly.

Dr Craig had prepared himself when I arrived to start the first tape recording. He had his own tape recorder and had brought in an extension cord to plug mine in beside it. He started off:

*The chronic illnesses I want to talk about are gout and arthritis and diabetes because I have had all these for a considerable time—and I thought we might talk about the gout and arthritis at this hour and then perhaps say leave diabetes for [the] next one [hour].*

(Wa:1–5)

However he soon settled in a relaxed conversational style and told me many interesting things about his experiences of illness. As far as he is concerned the diabetes causes far more problems than the arthritis, despite the fact that the arthritis gives him almost unremitting pain. The arthritis, he explains is not his fault.

*I know exactly why it happened to me, I chose the wrong parents. Err, my mother's family, all of them, had arthritis ... So I think there is a strong genetic, err, element in the thing.*

(Wa:51–54)

The arthritis is also something which quite a few of his contemporaries have too:

*Err, I was down buying fish the other morning and there were four arthritics ...[pause]... buying fish with me, friends, and the one woman had had surgery to her leg and had had to have a series of operations. A man was having intensive umm, thing for arthritis of his back and they hadn't found anything that could act on [his pain]. There was me with my tablets and so on and, all together err, I think we were all fairly pessimistic about what really could be done for us. We were all in pain, we were all not knowing where it was going.*

(Wb:21–31)

Whilst it is unpleasant he does not feel there is much he can do to improve the arthritis and therefore all he has to do is endure it. On the other hand, the diabetes:

*Now, unlike the arthritis, none of my relations have diabetes ... but with mature onset diabetes, anyway, the responsibility is very much thrown on the patient, him or herself. It's your fault that you have got this—you're obese, you're overweight. If you can lose weight and get down to a proper weight the diabetes will clear up. I partly believe that [quieter voice] err, but it makes you feel very guilty, the fact that it is up to you now to cure [yourself]. It is not physician heal thyself, it's patient heal thyself.*

(Wb:97–109)

He really objects to the intrusion diabetes has made into his life:

*... what I find most ...[pause]... upsetting about the diabetes is that you can't forget you've got the illness for one minute of the day. Every bite that you eat you're saying to yourself, 'Err, am I doing the right things by eating this thing?' You test your urine two times a day, you test your blood sugar, perhaps two times a day and the result of this is you're focused, err, on your illness all the time and there is no way of getting away from it.*

(Wb:123–131)

He is quite cognisant of the effects of poorly controlled diabetes, which of course adds to his worries about getting older. He does not worry about death and is resigned to old age with arthritis:

*... you know some people say, 'You are never too old.' To my way of thinking you are too old for some things ... err, you are too arthritic for some things.*

(Wa:300–302)

*I think I'm a bit fatalistic ...[pause]... you know that story of umm ...[pause]... the man who saw death in the market place in Damascus and death looked at him, you know, and the man instantly got on his horse and he rode all day until he got to a little village a day's journey from Damascus and as he rode into the village there was death and death said, 'Now I was surprised to see you in Damascus this morning because I had an appointment with you here tonight.' And err, (chuckle) ...*

(Wa:310–321)



*I bought the little book 'Final Exit', which I haven't read yet but it is there on the shelf in case I need it.*

(Wb:258–260)

But his calm about these matters is disturbed by his concern about increasing physical dependence as he will probably become increasingly disabled. He dreads being a burden to either his wife or his children and of course if keeping to a diabetic control regime will lessen this likelihood he feels he should comply. However he is sceptical of the official word and pokes at the faulty logic of the medics.

*I find exercise is the biggest factor that can drop my blood sugar, if I've, if I'm, if I'm above ...[pause]... the level. Now the trouble is with the arthritis often I am so sore that I can't exercise.*

(Wb:139–142)

*... there are various difficulties that occurred from this. First of all as far as the diets are concerned, I was previously on a gout diet, an arthritis diet, on a weight loss diet and now on [a] diabetic diet—and that left me with about a lettuce leaf to eat.*

(Wb:66–70)

*... what people don't realise, I think, is that when two things occur together like diabetes and overweight, both of those may be due to a third factor—one may not be the cause of the other, but both may be caused by a third factor, and a lot of researchers just don't consider this possibility at all. They look for correlations and if they find a correlation they then say that one is the cause of the other and really I would be very doubtful about that kind of err, conclusion.*

(Wb:110–118)

Besides the irritations and worries caused by the diabetes Dr Craig is philosophical:

*... people will say to me, 'You know you have got this arthritis, Bernard, what are you doing, you know, how do you keep yourself amused?' ... and they get surprised when I say I'm doing nothing ...[pause]... umm, because to me it's become very beguiling just to do nothing, just to sit and not have anything that I force myself to do—and if I can still my mind so that the thoughts stop—also there is an emptiness which is amazing really that you get into, umm, ...[pause]... you know and time stops when you get into that ...[pause]... you can lose yourself and you can look up and an hour has gone where you can lose yourself and you think you have been there for an hour and you*

*can look up and the clock hasn't moved. Umm, so that—there's this umm, ...[pause]... new possibility.*

## **Analysis**

From Colin's story I felt an immense sense of sadness and regret at the **transformation** in his life, from a life of typical healthy male Aussie to '*weakling*' (Ta:101). When he describes something that is happening now he usually **contrasts** this to how he was. When he talks about his son he describes how they used to be equally matched in strength. When he talks of a loss of co-ordination he describes how he used to ride the motor bike rounding up the cattle. When he describes the day that goes so slowly he then relates how he used to be up at five in the morning and working by six. He talks admiringly of how he was. He really **valued** his strength, 'manliness' and skills that allowed him to run the property successfully. These are '*manly*' (Ta:101–106) attributes he fears he has **lost** and without them it is difficult for him to take a part in many of the aspects of his old life; he appears to **withdraw** rather than face people as different. When he talks of how he thinks others view him he uses the word '*spastic*', a word which is most commonly used in a derogatory way. Although he says '*... one of the worst things is other people's reactions ...*' (Ta:35–36), in fact, he describes how he thinks they view him rather than their specific behaviours.

The striking difference between Peggy's story and Colin's is the length. Peggy's is a **long story** of ill health. She describes herself as not feeling normal. I wonder if she is the **outsider** that Colin thinks he has become. Peggy does not make contrasts in the way that Colin does between his ill life and healthy life. She has never had a healthy life to experience and compare with. However she is acutely aware of things she has **missed** in life, such as a good education and a successful marriage, because of asthma. She does not talk of her symptoms like Colin and she does not describe her body as if it were an object as he does. For instance Colin says: '*There is no way you can show interest in something until your body is ready for it ...*' (Tn:320), whereas Peggy shows me her deformed chest which is her. She too feels **alone** with her illness and like Colin uses two instances of her children, making this more poignant, but she can also give examples of people generally not being supportive. She does not shun the world when she can join in and contribute, for instance the amateur dramatic society, the asthma support group for families of children with asthma and the parent/teacher association. But she will not relate to others if she needs **help** or be treated **differently** because she is asthmatic.

In an even more extreme way than Colin, Peter has **lost** the attributes he **valued** so highly when he was healthy. This is to such an extent that he **withdraws** from others in case they view him as he does himself. He expects people to behave as he would have done.

He does not want to be what he has become and avoids this reality as much as he possibly can—he does not want to be an outsider. His **body** has let him down and he perceives it as not his when he describes himself as young and as good as ever.

Paul introduces an interesting turn. He does not want to have back pain but he needs to **secure this diagnosis**. He therefore cannot shun his condition but must display it as often and consistently as he possibly can. He needs to convince other people, especially the insurance company and the medical profession that he is genuinely affected. His illness is **complicated** with all sorts of emotions such as guilt, anger and extreme frustration and, as he admits, sometimes he does not know which hurts the most. Not only has he lost his healthy life but he feels that his family have too.

Linda's is another **long story** and it contrasts with Paul's sharply as she wishes to **hide her diagnosis**. She avoids doctors and ignores symptoms as hard as he does the opposite. She ensures that her children and partner are not affected by **her illness**. She too is **alone** with her illnesses because she takes complete responsibility for them. She takes **control** of her diabetes and epilepsy and chooses thereby to take enormous **risks**. While she is the antithesis to Paul their stories throw up the same concerns for family and **relationships** and the **normal life** which chronic illness puts in jeopardy. There is a strange kind of reciprocity in Linda's attitude to life. On the one hand she does not make a burden of herself to anyone, either inside or outside her family, but in return she expects society to leave her alone without unwelcome control over her life.

Dr Craig is the most philosophical about his illnesses. He talks of a satisfactory life in which he achieved a great deal. He is quite reflective and had thought a lot about his experience of diabetes and arthritis before we spoke. He is ready to be old and wants to slow down. He does not want to **control** his disease—he would like the medical profession to do it for him. Like some others he would like to just be ill but instead he is disturbed because he thinks about the **future** and does find some things of concern and cause for feelings of **guilt**. For instance he does not want to be a **burden** upon his family nor does he want his wife to look after him, physically. His life is transforming: he is slower and does not want to socialise or do odd jobs around the house anymore. These are not perceived as losses as a result of illness but as part of the natural progression of his life.

Some of the people have responded to their illnesses by retreating to their homes which become the **space** in which they can be ill without notice from people outside their families. Others keep their spaces open but with a **struggle** and a certain amount of **risk**. In each case, the **time** that the person had had the illness affected their history and their ability to connect with the illness. Fears of the **future** are alluded to rarely and will need

to be retrieved from the texts. Linda talks about some fears for the future, for example, side effects of diabetes, but she does this to detract from the imminent risks caused by the non-treatment of her epilepsy. The **past** has become the focus for some because it is where they find their healthy selves. What matters a great deal are **relationships** which are changed and there appears to be a fear of being a burden upon people or being perceived as a **burden** or a nuisance. There is a certain amount of alienation from bodies which have let them down which ties in well with Leonard's theory (1994, p.53) that it is when the person becomes ill that they are suddenly aware of a body which they have in health intuitively accepted as integral to their self.

**Table 1: Impressive words**

transformation	contrasts	value
lost	withdraw	long story
outsider	missed	alone
help	different	body
secure diagnosis	complicated	hide diagnosis
her illness	relationships	normal life
control	future	burden
struggle	risk	guilt

I have extracted these words from the text as an *aide memoir*. They all represent things that may be important in later analysis and interpretation. Alone they mean little, for example, **lost**—lost what? Lost, when related to the texts above, is about the loss of health and old ways of life.

In the next chapter I will concentrate upon ideas and concepts but constantly relate these back to the stories and the whole background of the participants' lives. I will remind myself constantly that if I wish to understand the meaning of loss in chronic illness I will have to ask—*How is it possible for these people to be lost?* and *How does this relate to the participants' overall Being?* But in order to ask these questions I need to refer to their being *lost*. In this way the hermeneutical interpretation of the text which has begun in this chapter, with whole stories, will continue to unfurl meanings.

# Chapter 6

## Histories

*I remember, I remember  
The house where I was born  
The window where the sun came peeping in at morn  
It never came a wink too soon  
Nor brought too long a day  
But now I often wish the night had borne my breath away*

(Thomas Hood)

### Introduction

The people who helped with this study began to give me their histories when I initially made contact with them. The first interaction was usually on the telephone with some of them quite hesitant, wondering if they would have anything to offer. Before stating what disease or medical problem they had which made them chronically ill they always said who they were, where they lived, and what occupation they had. I reciprocated with information about myself including my background as an English student and a nurse. This was a helpful and quite ordinary first encounter—two strangers talking and both wishing to introduce themselves in a good light.

As the aim of the first visit was to give the person information about the study and for them to get to know me before they decided whether to help with the research or not, it would have been inappropriate to take a tape recorder. During these informal visits people would begin to tell me something about themselves. It would have been interesting to record these conversations because they contained some rich biographical information which they did not always repeat in the tape recorded sessions. Instead, however, I made fieldnotes and tried to catch most of the main themes talked about.

On subsequent visits I took the tape recorder and usually started the recording sessions off with the informal inquiry: *What has been going on? Tell me all about it.* This always initiated the start of a narrative which began with a personal history and then led on to incorporate descriptions of their illness. I seldom had to ask further

questions because the people's stories appeared to flow from them. The Spanish greeting, '*Que passe?*' would have been an appropriate beginning question here. The Spanish do not use it glibly as we use 'g'day—how are ya?', 'how ya goin' mate?' or 'how do you do?' spoken quickly and retorted to in echo—'good thanks, and you?' or 'how do you do?' The Spanish say '*Que passe?*' with a puzzled look on their faces and a shrug of the shoulders. They are curious—they want to know what is passing, literally. They want to know not only what is passing now, but what has been and the future—the whole story in other words. It is an invocation to have the situation explained. I remember a Spanish registrar who would arrive on the scene of a person's cardiac arrest and look around and say, '*Que passe?*'. He needed to know the story in order to help the person.

Once again, as on the initial visit, most people began with a description of life before the illness. It appeared that their illnesses, which were the focus of the narrative, could only be discussed and made sense of in terms of the context of their whole lives. The illness was a part of the participant's experience and identity; it did not take over their entire persona. Corbin and Strauss (1987, p.251) make a similar point when discussing the information they gained from interviews with people with chronic illness and their partners. The same format is noticed in reports about people with chronic conditions. Writing in the *Sydney Morning Herald* about Genni Batterham, a person with multiple sclerosis, Lim (1995, p.12) introduces her not as someone with multiple sclerosis but this way:

It was Genni Batterham's bouncy personality and skill with a soccer ball that persuaded Wendy and Gordon McCarthy that she would be the perfect babysitter for their three boisterous children ... she could run, jump, kick balls around and do all sorts of things ... this was a non-hypochondriac kind of young woman ...

The participants make the point that these attributes from the past still contribute to their total make up. Without this information, it is not possible to appreciate who they are now or indeed what possibilities may lie in the future. Pauline<sup>1</sup> said to me on my first visit that she had to establish that she could still be loved and that she was worthwhile (fdnt:3.1). Part of establishing that worth for Pauline is for others to know how ceaselessly she used to work when she had energy. The participants drew heavily on their past to establish their credibility and worth. Olson (1993, p.69) makes a similar deduction from her experiences as someone with renal failure and writes, 'We search for the future through dialogue with what is past. We do not recall events that are over. Rather, our experience lives in us making us what we are.' Register (1987, p.28), a sufferer of chronic liver disease, also contributes to this idea

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<sup>1</sup>Pauline is a wife and mother of four children. She, her husband and family moved from the city to the New England region five years ago. She has had chronic fatigue syndrome for the past four years.

when she describes a persistent worry that ‘... your identity will be subsumed by your disease’. I formed a distinct impression that the participants relished the opportunity to tell their stories to an attentive and impressed listener.

As the participants’ narratives unfurled and histories were given they turned to the initial symptoms of the illness. These symptoms came in different guises and rates of progression. The symptoms led the people to seek medical attention and thereby to obtain a diagnosis.

This chapter is arranged in the same order that the participants’ experiences are revealed in the transcripts. I asked the question, *What has been going on?* The response was: ‘First I was well and this is what my life was like, then I got problems, and then I went to the doctor and he told me I had ...’ In this chapter I will write about life before the illness occurred, the onset of symptoms, the trail to the doctor and the resulting diagnosis. These areas in the person’s history all impact on their now and future. Past experiences constitute their moods, actions and views of the possibilities arranged in their futures. From their experience of life and illness they draw expectations of what will occur in the future and construe the meaning of their illness.

In this chapter there are four ‘excerpts from people’s past’—that is, I have chosen to present vignettes from selected participants’ lives in order to highlight concepts which are emerging from the texts. This is an exercise in looking at the whole situation in order to reveal parts. The interpretation in the rest of the chapter is concerned with developing concepts which are exemplified by isolated examples from all of the participants.

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## **Pam**

Pam has been ill since she was fourteen years old.<sup>2</sup> She can recall the exhilaration of being well vividly and enjoys recounting those days in her past. Her story is scattered with ‘I remember’:

*I was always a very healthy child and I took pride in my strength—  
my physical, umm, I can remember being fanatical about  
basketball and, especially basketball, I was the captain and I used*

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<sup>2</sup>Pam did not tell me her age. She said that she was still young because she had missed out on her youth and was slowly working up the chronological ladder. At a guess she has had arthritis for twenty-five to thirty years. When I met her she was living independently, a magnificent achievement after years of hospitalisation from the age of fifteen to thirty. She has completed a degree and works part-time. She takes an active interest in her rights and is one of the first locals in the region to be allowed to select her own care assistants.

*to take the ball home and polish it with shoe polish at night. I honestly took intense pleasure and got some sort of—I don't know what—sort of excitement. It was from the noise of grasping the ball cleanly and crisply and I remember the feel of polish on my hands.*  
(Sa:5–13)

*I really, I love winning and I can remember the adrenalin. I can remember getting out on the umm, on the basketball courts and the feel of the sort umm, uhh ...[pause]... the[y] pad down the soil, so that underneath your feet was this feeling. I can remember the feeling of everything ... and the excitement would brew [up] in me for weeks you know; about a game coming up and if I lost anything I was devastated.*  
(Sa:21–29)

*... so that early part of my childhood was a very physical thing. We used to climb. You know how people get out with all the bit[s] and pieces and the ropes joined on to each other and I used to get out, umm, without all that and climb up the face of—we used to call it Mount Gibraltar, but it is nothing like it, it's where I grew up, in the bush ... and we used to climb up, just hanging on by our fingers and toes to the crevices and haul up sausages and potatoes and we'd get up the top and build a fire, umm, against the rock so that the fire was so intense that you had rock pinging off at us ...*  
(Sa:49–60)

Now Pam spends a large proportion of her day sitting on a long raised sofa with her surgically booted feet stretched out in front of her. When she looks up over her boots she has short views of her sunny patio planted with petunias and distant views towards the hills. She dresses in pretty floral skirts and lacey tops. Her vivid and sensual memories bring her a great deal of pleasure but they are bitter sweet memories—tinged with regret at the changes arthritis has made to her life.

Viktor Frankl's (1985) account of his time in the Nazi death camps during World War II includes reminiscences similar to Pam's in a passage where he explains the personal significance of vivid memories.

When given free rein, his imagination played with past events, often not important ones, but minor happenings with trifling things. His nostalgic memory glorified them and they assumed a strange character. Their world and their existence seemed very distant and the spirit reached out for them longingly: In my mind I took bus rides, unlocked the front door of my apartment, answered my telephone, switched on the electric lights. Our thoughts often



centered on such details, and these memories could move one to tears (p.59).

Pam loves her memories and spent over two hours telling me about her past. Her memories conjure up the picture of a robust girl who enjoyed life. While she may not have consciously appreciated her health she demonstrates her love of life of which her health was an essential part. The other participants did this too; they did not talk of appreciating their health when they had it but they did demonstrate the advantages they took of it when they had it.

The memories of childhood still work for Pam and help to create her self concept. What she was and could achieve is still a part of the self concept which she feels and wishes to portray. It is therefore an integral part of her. Note she does not refer to her love of winning in the past tense—she still loves to win; she is still that ambitious and remarkable person she describes so vividly.

To an extent she uses these stories in the same way as other people (in this case country Australians) who reminisce about their childhood in the bush. These were days of freedom, fresh air, exercise, exhilaration, resourcefulness and shared hardship. Many people who reminisce in this way are able to marvel at how much they have achieved and how far they have come from their days as children in the bush. Pam's stories show how much she lost when she lost her health and how restricted and difficult the way has been for her from those beginnings in the bush.

In effect, the past histories or biographies given in this study serve three purposes: *first* they impress the listener in terms of who the narrators are, through the images of who they were, and what they managed to achieve; *second* they show what the narrators value; and *third* they figure the changes in the narrators' lives. These changes or contrasts show particularly what has been lost because of ill health and to some extent the effect it has had upon their lives. The texts have to be searched carefully to reveal any benefits the changes in health status have wrought in their lives.

### **Dr Craig**

Dr Craig<sup>3</sup> painted a satisfied portrait of his life, both on the tape and during our conversations when I was visiting. He has achieved a great deal and he fulfilled the promise of his natural abilities. Those achievements contribute to the construction of his self concept, show his values and demonstrate contrasts, albeit ones which are not so stark as Pam's. He describes his life thus:

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<sup>3</sup>Dr Craig was introduced in chapter five.

*I'm a retired university lecturer, for most of my university career I've taught \*\*\*\* [names subject] and [names another subject] as well. Umm, I have taught various other things—things like \*\*\*\* and \*\*\*\* [an impressive range of theoretical and practical subjects] but those are my main interests. Umm, I have been a \*\*\*\* [names profession] for about ...[pause]... oh ...[pause]... fifty years umm, people started coming to me in my final undergraduate degree and that was in 1942.*

[He describes some of his eminent work which cannot be transcribed for reasons of confidentiality.]

*I'm not very keen on sport or music—I am tone deaf, err, on the other hand I like doing things with my hands. Err, I have made all the book cases in the house, umm, I've made ...[pause]... I do all the electrical repairs and so on ... I am essentially a solitary person, I don't like much social life, umm, and I [am] not a joiner in any sense.*

(Wa:14–33)

Dr Craig values his intellectual acumen and his achievements in his work. His illnesses did not cause him to retire early or disturb his career or his sociability. Although there are changes in his life brought about by his illnesses these do not correspond to the things he values most. He was expecting the changes that arthritis has brought upon his life to come with older age. However there is one notable exception to this composure: the fear he has of losing control and independence in his life. He recounts the dreams he has had recurrently during his life which centre upon the value of his ability to control and organise himself and his family. One dream is of train travel overseas with his family and a mess of children, wife and baggage. The other is:

*I'm in a little terrace house in London and a whole lot of street louts come in and play cricket in my front yard ... and I go out to remonstrate with them and they don't listen to me and this, that and the other. So ...[pause]... the thing that's threatening me, to me in the [dream] ...[pause]... disabilities increasing, is umm, that I am going increasingly 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:196–203)

The discomfort that bothers him most is worry about the complications of diabetes—specifically the fear of losing his sight. He fears losing his sight because his wife may then have to ‘look after him’. This worry is related to his value of independence and control fostered during his life. These worries are in the future; it is thoughts of the past that he finds comforting and restful.

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## **Self concept, values, and contrasts revealed in histories (the way we were)**

### **Self concept**

Corbin and Strauss (1987, pp.254–255) define conceptions of self as ‘... not merely self-esteem but the views held of oneself, in relationship to the whole of identity—who I am.’ It was apparent in this study that the people were anxious for me to know that ‘who they were’ was still relevant to the portrait of ‘who they were now’.

Pauline drew a rich picture for me of her early days as a mother:

*My first son Clifford was born \*\*\*\* [date] I breastfed him for ten months. The first three months were difficult as he cried a lot, but after he settled we enjoyed each other so much.*

(Pa:43–45)

*I was busy and extremely energetic, I needed eight hours sleep at night but was on the go all day, with various activities, bible class, craft making and so on ... I really enjoyed being a housewife and mother.*

(Pa:52–55)

Now Pauline has to measure her energy carefully. She reserves most of her strength for her children who are all teenagers. Even though it takes her a long time and careful planning she still maintains the role of housewife and mother. Dried flower arrangements decorate the sitting room. Everything is neat and tidy and as the children and her husband drift through she prompts them with this or that to do or remember. She is the good mother and wife she was, even though she does not do as much. I am reminded that she is unselfish and a contributor even though she is limited nowadays by what she is able to do. These points are validated by stories of what she could and did do when she had the energy.

I noted the first time I ever spoke to another participant, Elizabeth, on the telephone. She talked about how she looked in high heeled shoes. She cannot wear them now, but she did feel good, she assured me (fldnte:3.19). When I met her she was a pretty,

middle aged woman who of necessity dressed comfortably; however, we both knew there was more to her—the ability to be chic. She reiterated the point on the occasion of the first tape recording:

*yeah, yeah and then of course the high heel bit (chuckle), we all like to wear high heels. And then your fingernails ...*  
(Ib:587–588)

In participants' histories there was a notion of 'this is still me'. There was no concept of linear time in terms of the past is over. The past became, if anything, more important because it contributed to how they want to view themselves and how they want to be viewed by others. It is almost as if they want to lessen the space that illness takes up in their narrative. The concept of 'who I am now that I am sick' depends on 'how sick am I?' and 'how much does it matter?' (Register 1987, p.44). I suggest that 'how much it matters' also rests upon 'how was my life before?' and 'how different is it now?'

## Values

When the participants describe their old lives before they were ill they reveal what it is they valued. Valuing things that they no longer have can make the burden of chronic illness greater because they construct and believe their own diminishment. Peter, the teacher who has multiple sclerosis, said:

*... I don't want to go out and that, to have people feeling sorry for [me] or ...[pause]... being embarrassed with my bladder problem or with things like that. So I, I prefer to stay [in], you know. So ...[pause]...*

Mary—*So if you were given a choice you wouldn't go out?*

*No.*

Mary—*Even if people were understanding?*

*Oh even then I probably wouldn't go. No, because err, ...[pause]... no I just—as I said, I think [of] what I used to be like and what I am like now—there is no comparison. Now I don't want to be like this, you know.*

(Ka:215–225)

While they do not necessarily say derogatory things about themselves, they believe and say that they are viewed as 'less' by other people. The word 'less' has been chosen carefully. It feels nearest to what was described by participants about their

perception of other people's views of them; that is, they might be seen as less strong, less able, less intelligent, less beautiful, less quick, less entertaining, less worthy, less useful, or less admirable than people who retained their health. It is seldom that they back this belief up with evidence of people behaving as if they had little regard for them as human beings (there are some examples—mostly from health care professionals). For instance on each occasion I met him, Colin (who was introduced in chapter five) talked about his writing. He believes that you can judge a person's basic education by their handwriting. He says the teller in the bank must think that he is stupid because of his shaky handwriting on cheques (Ta:114–116). Scambler and Hopkins (1986, p.38) find a behaviour similar to Colin's amongst people with epilepsy. They proposed the following cycle occurs—people view their diagnosis as undesirable, they fear social rejection in various forms and therefore conceal their disease whenever possible. Their lives then become restricted by the stigma they feel rather than that which they experience from people. This idea is termed 'felt stigma' and is self perpetuated. Colin uses the word 'spastic' to refer to how people may view him. 'Spastic' is now considered a politically incorrect word which was originally used to label people born with cerebral palsy. Colloquially it is retained in the language to denote someone who is incapable—it is a derogatory term. Colin hesitated slightly before using it (fldnte:1.74), as if it occurred to him it might not be appropriate, but then definitely chose it. Colin's use of this term to describe himself is interesting and may be a clue to his assurance that people see him as less able—it is a view he holds himself. That is why he can be so sure it is how others behold him. Peter (who was introduced in chapter five), too, presumes people will view him as pitiful:

*... I don't want to be out there and have people feel sorry for me or take advantage of you [me] because I'm in a wheelchair.*

Mary—*Right.*

*So ...[pause]...*

Mary—*And do people give you that impression?*

*No, but maybe they would if I was really bad, you know.*

(Kb:206–211)

However, through the things they describe about their lives before illness it becomes apparent that along with society they appreciate, to differing degrees, fitness, physical strength, looks, an ability to work and to fulfill family roles. These attributes are often compromised in chronic illness but they are still viewed with admiration.

Jim<sup>4</sup> talks about the work he could have done:

*All this paddock over the front here.*

Mary—*Yeah.*

*That's all going to be turned into a park and garden. Err, the middle of 1990, the way things were working for us, we planned that we were going to get the plans drawn up for the extension on the house. This is only half of the house that we are going to have.*

Mary—*Oh right.*

*You know it is [going to have] ten foot verandas all around it.*  
(Ja:396–404)

Jim also talks about the cars he has renovated and the variety of work he used to be able to handle. Now the yard is an overgrown mess strewn with wrecked cars and the house less than half built with internal walls which are bare hardboard. When he was first diagnosed with chronic fatigue syndrome he was very depressed and wanted to sell the property:

*... well, what's the point of having a property you can't do nothing on it?—I might as well sell the bloody thing and move into town ...*  
(Ja:226–228)

The property is in an idyllic spot. It has a hillside of bush behind which is rich with native flora and fauna and has views across the plains in the front. What he means by 'you can't do nothing on it' is: 'I can't do my work, I can't make this a property to be proud of.'

Another person who helped me with the study was Tom. Tom had had several strokes which left him with a severe dysphasia and marked weakness on one side. The first time I visited him I could not understand his speech but I was left in no doubt about his history and the achievements he valued. This excerpt from the fieldnotes shows how I learnt a bit about him and his loves through his past:

Mrs Palmer left us 'to it' and went into the garden. I asked Thomas to tell me what having the strokes had meant to him. He launched straight into talk I could not understand and started to point to a

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<sup>4</sup>Jim lives with his wife Nancy on a smallholding out of town. They moved here from one of the big cities. The move was the realisation of Jim's long time dream of 'the good life'. They have three grown up sons, two of whom live locally. Jim has had chronic fatigue syndrome for three years.

photograph on the wall. The photograph was of a horse with a young man on its back. Remembering what his wife had said, I asked, 'You used to work with horses?' He started to cry and got up. He clumsily walked into the hall. I followed him. He was standing and crying in front of more photographs of horses. I waited a while, he looked at me and I put an arm around his waist and said, 'Just tell me about them—I don't understand everything you say but it is nice to hear you talk of the horses.' He talked away, occasionally crying. We walked around all the photographs; I gathered that he had trained \*\*\*\* [type of sport] ponies and coached a junior team which had been very successful. (fldnte:2.2)

Once when I asked Tom what he did now he answered emphatically, '*I don't do anything.*' At this response his wife, who was with us, protested and said he did a lot of things (fldnte:2.4). She proved it the next week by making him write a list of the things he had done and the places he had been. As Jim dutifully handed me the piece of paper, he made a face indicating to me that he did not value these activities and he stood by his original answer (fldnte:2.5). He wanted to be driving a car and riding horses. He told me that he still did drive a car and ride, which I found incredible. Apparently he visits his old horse on a property and when they are off the road he drives.

People may change their values as they shed their health and reflect carefully upon what is happening to them. However, whatever their development, they can remember the shared values constructed and maintained in society and the culture which they probably held themselves. These memories mean that they know what other people's attitudes towards them are likely to be.

## **Contrasts**

There are three negative aspects of life with chronic illness which are revealed when considering contrasts. All of them are uncomfortable positions—losing what you used to have, missing what you never had and ignoring differences wrought by illness and thereby risking one's health.

The contrasts between 'life then' and 'life now' were often stark and demonstrated substantial loss. In the previous chapter it was noted how vividly Colin and Peter contrasted their old lives before illness with their present predicament. Whenever Colin talked of anything that was constraining him now he would refer back to how he was before.

*I could do one hundred sit ups, lifting [was easy]. [I] used to outdo the men on the farm ... do all the hardest jobs.*  
(Ta:64–65)

*Now it is like there is a physical barrier to movement. Sitting up from lying down, [is] impossible.*  
(Ta:73–75)

Ruth, who is a mother of four, told me about her energy before the symptoms of multiple sclerosis began to slow her up:

*... and umm, I was so active I was, umm, \*\*\*\* [husband] and I were building a house and uhh, ...[pause]... and [we had] decided to have two kids—extra kids. I already had two (chuckle) ...[pause]... and uhh, ...[pause]... and then we shifted to \*\*\*\* [town] and I studied [B.Ed.].*  
(Ra:61–69)

*... [it's] very hard, very hard. Of course this house is unfinished, it never looks nice, it never looks finished ...[pause]... I start the day off cleaning this house, so therefore I get depressed ... All I can do is wash up and put the washing on and things like that ...*  
(Ra:128–135)

Holly is an amazingly energetic woman despite twenty years with crippling arthritis. However she remembers well that she was even more energetic when she was well:

*... then I was really—the main thing that irked me about the whole business; I was quite sporty and I loved my, umm, ...[pause]... I was golf mad and I liked tennis. I played a lot of golf over the years and err ...[pause]... and I just couldn't manage it any more and then as time went on and, umm, my knees got, became worse and worse and worse and I was almost in a wheelchair.*  
(Qa:52–59)

*I mean, at other times, it's so frustrating when you cannot do the things that you used to do and the things that you can do—it takes you three times as long to do them ...*  
(Qa:100–102)

Paul, too, drew the contrast that his troubles had wrought on his life:



*And from being this healthy person that I was and wanting to be the person that would protect my wife and kids and do everything, now I couldn't ...[pause]... umm, it was a feeling, it is pretty hard to describe that feeling but if I go to the doctor's I would break down.*  
(Ob:124–129)

These changes in the people's lives reveal how it is *possible to be* or *what it means to be* chronically ill. Being chronically ill means that life's course takes an unwanted turn. By and large the change in course is expressed in negative terms. The people in this study talk of what they can no longer do and of plans they will not be able to fulfill. Bury (1982; 1991, p.455) and Corbin and Strauss (1987) refer to this meaning of chronic illness as 'disrupted biographies'. Paul seems to sum it up quite well:

*... the way I felt was ...[pause]... you're growing—how do I put it now? ...[pause]... it's like cutting a part out of my life, it's like a black spot in my life to me.*  
(Ob:47–449)

In the cases of Peggy, Elizabeth, Linda<sup>5</sup> and, to a certain extent, Pam,<sup>6</sup> there is not this same sense of change and contrast. This was because they had asthma, coeliac disease, diabetes and rheumatism, respectively, from an early age. They did not have lifetimes of health with which to compare their current state. However, there is an immense sense of loss throughout the texts of their narratives. 'Loss' is not the correct term, though, because in order to lose something it has to be possessed in the first place. This loss is probably most accurately expressed by the word 'miss'. Peggy and Elizabeth missed out in their lives because they have always had chronic illness. Peggy described how much schooling she missed when she was a child. The tragedy of this lack of educational opportunity is put into sharp relief when she describes how talented she is when she has a chance. When she at last got to business school she quickly made up for lost time. (During that year Peggy learnt to read, write and type well enough to take on a clerical job.):

*... [it] was the turning point in my life ... But if I hadn't had that I'd hate to think because it taught me to read and write and everything really.*  
(Na:199–201)

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<sup>5</sup>Peggy and Linda were introduced in chapter five.

<sup>6</sup>Pam became ill at the age of fourteen and therefore missed many opportunities in life. However she does remember being well and therefore feels the loss of good health too.

*I know if I had the opportunity, yeah, yeah. But umm, ...[pause]... I mean, I was ...[pause]...*

(Na:211–213)

Elizabeth struggled on with the stomach pains until she was diagnosed as having coeliac disease in her early forties. It was difficult for her to manage two small children:

*So with the stress of the little babies and Sally [daughter who was diagnosed with coeliac disease as a baby] being like this [referring to coeliacs] and me having this big operation, my stomach was just worse. And I can always remember being so sick every Christmas. I used to hate Christmas time because I would be so sick. I don't know how many times I ended up in hospital in casualty over Christmas Day, eating plum pudding ...*

(Ia:73–79)

Elizabeth is a good business woman. She has started two enterprises, both of which she had to give up and sell because of her health. Just as Elizabeth began treatment for coeliac she developed rheumatoid arthritis. She is now very disabled with restricted movements and constant pain:

*And just to get up the stairs is such a battle. You're exhausted, just getting up the stairs. It was such a battle. You'd be exhausted, just getting up the stairs—and with all your sewing under your arm, and then your hands won't work properly and ...[pause]... things that you know in [a] normal life situation you would have done much better.*

Mary—*Yeah.*

*And you are still trying to do [the sewing] but you can't quite do it the same way. And so in the real life the teachers aren't there to make [an] exception for your disability. If you're going to Tech, you must be well enough to do the work ... yes and I think that that is where some of this heavy tiredness inside of me comes from—to know that no matter how hard I try I can't quite achieve it.*

(Hb:955–971)

Although Elizabeth has always been ill she makes a contrast with times when she was 'better' than she is now:

*I said to Dr \*\*\*\* [name of specialist in the city], '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.*

(Ib:260–263)

Pam is acutely aware of what she has missed out on in life and this makes her annoyed. She believes that it was not only her illness that constrained her but the old fashioned system she was treated in. She started life so fit and full of promise—eventually she looked back on her life and could see no trace of the aspirations she had. These two exemplars from her transcripts demonstrate her naivety and lack of opportunity to learn:

*They were nice women [the physiotherapists] umm, and interesting and I, they used to talk about having travelled overseas and I used to, well, I didn't know you, I didn't realise that people could actually go overseas. Or they would come in with some exciting clothes on that I would think, 'Jeez,' you know, I recognised that sort of self expression which was denied to me.*

(Sa:474–480)

*... and in the meantime that was my youth. This is why I can't tell people how old I am now. I still have young friends, I still do impossibly stupid young things because I never had a youth as such. I spent it in pain and in institutions.*

(Sa:549–554)

Linda has missed out on nothing because she has set herself against it. Right from the age of five she was diagnosed as being diabetic and she and her family worked hard to minimise the effects it had on her life. Now with epilepsy she takes the same stand and for over twenty years has refused to miss out on anything because of it. She has run a successful business, learnt to scuba dive, drives a car, and so on. These things she has achieved and still achieves throw into sharp relief what she could have missed. However, she pays a high price for not missing out and she lives in dread of hurting herself and her sons. As Curtin would contend, she is 'spending her health' when she does not have large reserves to draw upon (1990, p.7).

Linda and Peggy both fear the same thing even though their adaptive behaviour manifests itself in apparently opposite ways. Peggy will not join in things if she thinks she will stand out or be seen as a nuisance. She presumes that being a nuisance or a burden upon a group means she runs the risk of being excluded. Linda joins in things and does not tell people she has epilepsy, thereby preventing possible

exclusion. Although my initial reaction to Peggy was—‘this is over sensitive’, when I look at Linda’s case I understand that they are both right in practical terms. If Linda tells people she has epilepsy she will be excluded from a range of activities that healthy, independent mothers do as part of their role. Immediately boundaries will be imposed upon her behaviour because of her illness. She will not be able to take the children to the school of her choice, visit friends or set up a business for herself in the new area. Peggy’s sensitivity is born of experience, for she has had plenty of rejections and is now prepared to avoid being hurt. When both women join a group they make sure they contribute and do not ask for any favours. There are plenty of examples in this study of ill people trying to join in and just not being able to keep up.

### **Early symptoms (what went wrong)**

The onset of symptoms marks the beginning of the illness history. It is when ‘things first begin to go wrong’. There are a variety of ways the symptoms first appear. For the people in this study some were sudden in onset, others were insidious. Some symptoms were tolerated for a long time before they were associated with a disease, let alone a disease which would become a chronic problem. It is only in hindsight that some of the participants can recall things that happened or feelings which were the very earliest signs of the illness.

The nature and significance of the early symptoms establish the pattern of events leading up to the time of a diagnosis. Obvious symptoms are more likely to lead to a quick diagnosis. Such episodes mean a rapid transition from well to ill for the person and can be quite shocking. Colin’s general practitioner noticed the signs of Parkinson’s disease as Colin sat in his surgery complaining of an unrelated problem. He told Colin and his wife straightaway. In contrast, the two people with chronic fatigue syndrome had uncomfortable years while their symptoms gradually grew to a stage when they asked for medical help. They then went through over a year’s worth of hunting for a diagnosis. These were fearful times when diseases such as multiple sclerosis or cancer were suggested and in turn rejected and times, as well, when the people were so worn down they began to doubt themselves.

This part of the history is told in detail. Ill people are used to recounting symptoms to the doctors and have cogitated at length over how it all started and why. The symptoms become the clues in a search for the right diagnosis. Rehearsal of events and feelings helps the person to make some kind of meaning out of the illness. Symptoms of illness mark something unusual and make people aware of their bodies in ways that have hitherto been unnoticed (Leonard 1989). Being able to express

what is the matter is important. It helps the ill person to organise his/her ideas in a meaningful way and is necessary in order to impress others, particularly general practitioners and specialist doctors.

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## Elizabeth

Elizabeth is the person mentioned above who had coeliac disease for half her life before it was diagnosed. Her story exemplifies an extreme example of a person living with symptoms and waiting for the sanction of a diagnosis before she could hope to be treated as a genuine person.

Her earliest memories include a stomach ache. She was taken from doctor to doctor but nothing could be found to be causing the pain and distension.

*... and then they would test me for an ulcer.*

Mary—*umm.*

*And the X-rays weren't quite right and they would say, 'Come back'—still they couldn't quite find out what was wrong. So I was put on ulcer medicine.*

(1a:24–29)

*I had a lot of operations—hysterectomy ... first they took cysts, and then a hysterectomy, and then a gall bladder, and then a laparotomy.*

Mary—*All this was for the [stomach] pain?*

*All this was for the tummy pain which in the end was—and I was forty before they found it—was coeliac disease.*

She learnt to live with the discomfort. Times of remission served to impress upon her how genuine her illness without a name was:

*... then I had my children, Sally and Michael, and I was wonderful when I was pregnant, I loved being pregnant because I was well.*

Mary—*Oh, now that is interesting.*

*One of the best times of my life because I didn't have this tummy pain.*

(1a:30–35)

Added to the worry of not knowing what was wrong and having to live in pain, Elizabeth had the pressure of suspecting that the doctors did not believe her:

*Always feeling sceptical [referring to the doctors' attitudes towards her] always feeling as if the doctor thought I was a hypochondriac.*

Mary—*Yeah.*

*Always worrying ...[pause]... and still to, today [worrying] that they don't believe you.*

(1a:87–91)

This scepticism on the doctors' part was genuine. They could not find the diagnosis and were perplexed and impotent. Register (1987, p.8) admits that '... if nothing is demonstrably wrong, the doctor must consider the possibility that the patient is malingering, or at least having delusions of illness.' Suspecting that the patient's input of information is faulty may restore the doctors' confidence in their own powers and methods of deduction. In Elizabeth's case they resorted to suggesting that her cure was in her own hands and her illness may be due to depression. This attitude greatly increased her feelings of discomfort and unease:

*I had one doctor actually say to me, my husband took me in one day. I was doubled up with pain and he said to me, 'Oh I have never seen anybody so depressed.' He said, 'What you need is an affair.' I came out and I told my husband and he brought me home and I can remember just sitting there crying and crying and crying ... yes I was depressed because I had the pain and nobody could find what was wrong.*

(1a:97–104)

*... after I had had the laparotomy and they couldn't actually pinpoint anything, but they did do a bypass for an ulcer, and I said, 'But look, the pain is still there.' And the specialist pushed my tummy and he said, 'Oh you are just a grumble guts.'*

(1a:128–132)

The doctors were making her feel worse. This doctor's behaviour was demeaning; his use of touch served no professional purpose other than to belittle Elizabeth and her view. It functionally reduced her to the state of a thing which could be poked or prodded, at his whim. A medical doctor does have a social sanction to touch people for the purpose of diagnosis and to comfort. This gesture was neither of those things. His perfunctory humour and familiarity demonstrate a lack of esteem for the person.

He might be surprised at this interpretation of his actions but it does represent the significance of them to Elizabeth. How difficult it must be for her to confront or talk to doctors about her problems when the relationship is so unequal and one party has the power to dismiss and demean the other in such a cruel way. Elizabeth retaliates to this type of behaviour by dismissing or ‘dropping’ the doctor.

Even though she looks back on some of the doctors and criticises their treatment, she can be candid. She admits that she did not have classical symptoms. She feels that instead of admitting that they had failed to find a diagnosis, doctors transferred their failure onto her by casting doubt on her credibility and focusing upon her depression. They thereby increased her worry and stress rather than alleviated it. Perhaps the introduction of a ‘no fault policy’ might improve tensions in this type of difficult situation and realign ‘doctor and difficult-to-diagnose patient’. It was by chance that she was finally referred to the specialist in the city who diagnosed coeliac disease:

*But the ironic thing is, this dear man [GP] ...[pause]... umm, he was so gentle, had coeliac disease himself and he could never pick it in me. But he was so close because he would say to me, ‘Elizabeth cut down on your dairy products.’ ... And umm, anyway, he wasn’t there one day and I went up to \*\*\*\* [town] to Dr \*\*\*\* [junior partner in the GP practice] because I felt so bad that day. And he said, ‘Oh Elizabeth, there is something really terribly wrong here.’ He said, ‘I don’t know what is wrong. I want you to go to \*\*\*\* [city] and see Dr \*\*\*\* [name] he’s a rheumatologist.’*

(Ia:156–169)

After years of dealing with gastrointestinal specialists who failed to diagnose coeliac disease, Elizabeth describes with illuminating simplicity the doctor (a rheumatologist) who was successful:

*And umm, we went down to \*\*\*\* [city] to Dr [rheumatologist] who was also a very gentle sort of a person and he listened to our story and he took all my history, my parents’ histories, my children’s histories and the minute I mentioned coeliac in my daughter he, he thought for a while and he turned around and he said, ‘Well I know who has coeliac disease here.’*

(Ia:186–191)

He was gentle—he listened to her history, he heard her, and he found her diagnosis. There was no technology in the form of machines to process her signs and

symptoms. He noticed her and gave her his direct attention. When I asked her what her reaction was to being told what was wrong with her, she said:

*The relief when he spoke those words was just unspeakable. It had a name—I wasn't crazy after all ... forty years of not knowing what was the matter with you. Yeah ...[pause]... and operations and embarrassment and umm, I think that probably during that time I was very nervous, I would become nervy because I didn't know what was wrong with me.*

(Ia:209–216)

It is interesting how symptoms come first but they are only given credibility and understood by others when a diagnosis has been conferred. Until then it is only the person who has the symptoms, who feels and knows what the illness is. This doctor's diagnosis made Elizabeth feel better.

## **Sky**

Sky had always wanted to be a midwife. She studied nursing at university and then went away to learn midwifery. While she was at university she first started to get symptoms of ulcerative colitis:

*I suppose the first six months that I was nursing [after university] I started to get umm, a lot of pain. Umm, I got [a lot] of gut pain. Umm, I used to periodically get diarrhoea and then I started to bleed from the rectum ...[pause]... and I guess I had had it on and off for a couple of years before that, umm, ...[pause]... I don't know, it used to flare up occasionally before exams or particularly before a prac.*

(Ua:8–12)

She looks back and remembers that she probably had the disease well before she went to the doctor. In the first instance the GP diagnosed irritable bowel syndrome caused by candida:

*I went on this really radical diet, I went on the candida diet at one stage, and got really thin, didn't I. Just radically, radically thin and umm, was incredibly cold, the whole time but umm, and I was still sick even though I was living on bloody alfalfa sprouts and buck wheat.*

(Ua:34–40)



*... but what was really annoying I would go back to the doctor and say, 'I ['ve] still got these symptoms,' and he would say, 'Oh well you mustn't be following the diet.' You know, 'You mustn't be doing the right things,' and [he] just got [me] really pissed off with him in the end.*

(Ua:60–65)

Even before a definite diagnosis is made it seems that the doctor is sometimes prepared to blame the patient for the persistence of symptoms. However in this case Sky was not intimidated by the doctor. She knew her own body and was sceptical of his opinion.

*You could go to him with a toothache and he'd tell you that your gastrointestinal system is clogged with candida albicans and that if you simply follow this radical diet you will be alright. He prescribes it for everything from toothache to breast cancer ...[pause]...*

(Ua:72–78)

When he angered her by accusing her of not sticking to the diet she adopted the same tactic as Elizabeth—she dropped him and went to another doctor. However before consulting another doctor she tried a number of diets and remedies which did not help long term. Eventually she was diagnosed with ulcerative colitis when she chose to consult a physician in town. He prescribed her tablets which didn't agree with her.

*... salazopyrin and [I] came back and I said to him, 'Look these tablets are really shithouse they make me feel really bad,' and he got really cranky and he said, 'Look you sort of got to take them,' you know, 'And that's all there is to it' and 'I don't believe you,' sort of thing. And umm, so I just stopped taking them for six months and then got very sick again and had to [go] back to him on my bended knees and he sort of said, 'Well I told you so.'*

(Ua:96–104)

Sky tried to avoid a formal diagnosis and helped herself to start with. She never really believed that she had candida but she was prepared to try a healthy diet and other therapies before she went to the physician for help. She hates the conventional treatments because of the way they make her look and feel. Unlike Elizabeth a diagnosis was not welcome but in a similar way to her and all the other people with chronic illness the diagnosis was just the beginning of her illness journey.

## Both women

The texts of these two people are exemplary of all the texts in as much as they present different experiences. These differences beg questions which when explored reveal underlying explanations. To an extent the two women are examples of their era.<sup>7</sup> Sky is more assertive and cynical about the powers of doctors and medicine. She saw her diagnosis as being as much in her own hands as the doctor's and indeed to a certain degree she controlled when she would have a diagnosis. Elizabeth, on the other hand, trusted and waited for the medical profession to offer her a diagnosis. Her trust and respect for the medical profession was in turn disappointing (when she was demeaned and blamed for her own illness) and vindicated (when she was respected and diagnosed correctly).

The two women demonstrate how different the onset of symptoms can be and yet they both show how symptoms can be endured for some time without medical intervention. Elizabeth shows how demeaning a pronouncement of 'a psychological disorder' can be, yet Sky chooses to accept and tries to understand the role stress plays in her disease. This may be partly a result of her experiences as a nurse. The diagnosis heralded for both women a change in treatment and a change in their life plans.

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I have chosen to examine the early part of the experience of illness in the following ways: the onset of symptoms, referring/deferring to a doctor, and psychological doubts.

### The onset of symptoms

The time from the first symptoms to the time of contacting a doctor was often a long period. When symptoms first appeared they were commonly vague—tiredness, breathlessness, change in bowel habit. These were things that were explained away by the participants in terms of: 'I must have been doing too much'; 'I was stressed at the time'; 'they are not abnormal' or 'they don't bother me'. Sometimes the earliest symptoms were recognised in retrospect. Pam recalls:

*... and I can remember this day being very conscious of being breathless, very tired, in the middle of this climb and thinking, 'what on earth is wrong with me?'...*

(Sa:66–69)

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<sup>7</sup>Sky is in her late twenties and Elizabeth her early fifties.

*And I, and I realised that I was arthritic at that stage, had someone taken a blood test. But I didn't complain because it never affected me, I just felt tired you know?*

(Sa:75–78)

*... I'd just been feeling ill for quite some time. Ahh, just nauseous and umm ...[pause]... tired, really. Emm, nothing, nothing dramatic it was just sort of there 'nd it was a bit uncomfortable. Not enough for me to actually go to a doctor umm, and complain about those symptoms. But if I was taking my daughter to the doctor for any reason I would just mention to him that I was very tired and not feeling particularly well and uhh, ...[pause]... umm, on most occasions I was prescribed mogadon and told to go home and have a good sleep ...[pause]... which didn't solve the problem.*

(Va:12–20)

These early symptoms did not seem to worry them unduly as they did not act as portends and they did not seriously interrupt their lifestyle. Most people will complain of vague symptoms at some stages in their lives. Doctors are commonly confronted with people who have a number of vague symptoms which do not add up to some disease instantly. In these cases doctors are often faced with a double bind. On the one hand they can aggressively seek a pathological cause, or they can try to ride out the episode hoping for a natural resolution. Either way, their behaviour can be regarded negatively by clients as either medically aggressive or dismissive. The literature abounds with accounts of people, especially women, who have been dismissed by doctors (Register 1987, p.8). However some understanding of the doctor's dilemma appears when one considers Hoffman's (1993, p.11) estimation that five million Americans visit their doctor each year to complain of general fatigue. I would suggest that this problem presents a tremendous challenge to doctors. Perhaps it is an area worthy of research, for no matter how difficult their task, their inappropriate behaviour can add substantially to the misery and stress endured by ill people (by inappropriate I mean behaviour which makes the patient feel worse). How clients are treated in the early days of their illness has a marked effect on their continuing relationship with their doctor which in the case of chronic illness is a long one.

Some symptoms did cause concern, especially when they caused inconvenience, but still participants recounted that they found plausible explanations for them:

*Yes, I went out to it on the back lawn, and umm, then I kept having, that was the first grand mal, the petit mal I kept having them all the time. I didn't know what was going on ...*

(Hb:92–95)

*Because I mean it's not—fair enough the fits themselves are bad, when I get the really bad fits, but normally it's, I mean, I haven't got bad—what you would call bad epilepsy.*

(Hb:240–244)

*... err, I used to drive a long way to work, sixty-one kilometres a day, to work and sixty-one home. And in the morning I was sort of getting out of the car and running behind trees ... and err, so I knew something was wrong, but I thought it was just that I was working hard, you know.*

(Ka:29–33)

Some symptoms were more dramatic but they disappeared and were dismissed:

*... it [the pain] was terrible and it was so bad that I had to get umm, my husband to lift me umm, out of bed of the morning because I just couldn't take a deep breath and half the time I would just cry. (chuckle) [I needed him] just to help me sit up and also he'd help me lay down again because I was just in so much pain ... uhh, that was quite a shock but it went away after—oh I don't know—four or five days ... I just sort of let it go ...*

(Za:27–40)

*I just thought I'll ...[pause]... oh probably it will go eventually. I just had this funny feeling it wasn't pleurisy ... I thought it might be radiating from my spine into my chest you know and sort of making me feel ... I went to the chiropractor a couple of times (chuckle) but that's what I really thought it was that I had just ...*

(Za:66–76)

It is much easier to piece the puzzle together with the benefit of hindsight, and there is some sympathy for doctors who are presented with general symptoms and who fail to spot the diagnosis.

*It [chronic hepatitis] was pretty rare at the time it wasn't the sort of thing that doctors come across. Umm, I think the only other case in \*\*\*\* [city] had been five years before. So ...[pause]... I mean it is something a GP can go through his whole practice, I mean his*

*whole practising life, and not (chuckle), and not come across ...  
and with those symptoms, jus' vague tiredness and nausea.*  
(Va:60–68)

There is a curious tension between understatement and the need to be impressive enough to get attention. Most of the people displayed a reluctance or at least a hesitancy to go to the doctor with their problems. This reticence appears to demonstrate that they are stoic, an attribute which is lauded generally and learnt in life. Alan is an extreme example of this understatement. He was admitted to hospital in near endstage cardiogenic shock and still would not complain of symptoms. In fact he laughs when he recalls that he did not want the nurse to carry his suitcase when he was admitted to hospital. The first exemplar, which came near the end of his narratives, may be a clue to his extreme resistance:

*Dad's answer [to complaints] always was, 'You're just a bloody big  
sook.'*  
(Lb:735–736)

*... and I went to a doctor there and he referred me straight to a  
physician who was in the same building there [that] afternoon ... I  
came back from that, err, just down the corridor and he said,  
'You've got problems fellow—with your heart,' err, and he said, 'In  
rather a big way'. So at that stage I started to realise, 'I'm in  
strife'.*  
(La:63–72)

Alan was admitted to hospital and recalls how later the cardiologist told him how sick he was:

*I was there flat out on the heart ward at the \*\*\*\* [name of  
hospital]. Jimmy [cardiologist] said he put me in with a fifty/fifty per  
cent chance of either dying or waiting for a heart transplant.*  
(La:146–149)

*... and all the time I was in the \*\*\*\* [city hospital] they would  
come down in the middle of the night, two and three times and they  
would say, 'Mr James we are just checking your, your monitor.'  
And when I said that to Jimmy he said, 'They were checking to see  
if you were still alive.' He said, 'I got calls at all times of the day  
and night saying, 'What are we going to do with this bloke's  
heart?' and Jimmy said, 'All I said to them was just wait and see.'*  
(La:284–291)

By way of a compliment, the cardiologist said to Alan's partner, *'The man is too stubborn to lie down' (laugh) (La:302)*. Stoical behaviour does appear to be admired generally and rewarded. Alan is on first name terms with his specialist and they chat in the office, marvelling over Alan's remarkable survival, stamina and spunk. I believe they both derive considerable satisfaction from these interactions which confirm what they perhaps unconsciously perceive to be positive traits in each other. The story is deeply satisfying and illustrates almost classically idealistic stereotypes of the successful patient and successful doctor. Consideration of this type of satisfaction and harmony illustrate the frustrations felt on the reverse side of the coin, when the patients are hard to diagnose and clamour for attention.

Linda's early training is even more revealing and explanatory:

*... and I had this Sister come in and she said to me, 'Right,' she said, 'you know you have to have an injection now every day for the rest of your life?' She said, 'I have brought this orange in and I will show you how to do it.' And she said, 'And you practise for the rest of the day.' And she said, 'Tomorrow you have to do it yourself.'*

Mary—*Was this when you were five?*

*Yes! And she said, 'And you don't go home until you can do it!'*  
(Ha:69–77)

*And all my parents said to me was, 'Well, you have got this now err, you got it, you've got it for the rest of your life. You will have an injection every day for the rest of your life and that's it, you are not sick, you can't use it as an excuse for anything, and that's it.'*  
(Ha:54–58)

Quite often the participants reported how others said they appeared. This extra evidence is seen to lend credibility to their state of illness:

*... and I picked her up [partner who he had not seen for a few months] err, this was a week after I came out of hospital. I drove up to \*\*\*\* [town] I picked her and Kelly [partner's daughter] up off the bus. And she got off the bus and she thought I was dead I just looked so grey (laugh).*  
(La:205–209)

Other people's observations and views lend credibility to the case and make the person's story more worthy of attention. Another source of credibility is to refer to one's character. Jim's wife attested to his uncomplaining nature (Ja:357–359).

The patient appears to want to ensure that they are viewed by the doctor as worthy of attention, believable, and interesting. In turn the doctor wants to have patients who are believable, interesting and worthy of their attention. The patient's case is rendered stronger by a variety of means such as overstatement, understatement, other people's evidence and character reference, some or all of which may be used at different times. The whole situation is made easier if the person has classical symptoms which are obvious but this often means that the person is much sicker. When Jane became jaundiced and was diagnosed with hepatic failure she traded the stress of not being believed for the stress of knowing that she was in mortal danger. There is a perverse status conferred upon people who are 'really very sick'. Having an obvious diagnosis is the one of the hallmarks of the 'very sick'.

### **What's up doc?**

Finding out what is causing the symptoms is a medical challenge, one that reaches to the heart of professional pride. Unless medics can find a cause of symptoms their treatment lacks control or purpose and this is a state with which most doctors feel uncomfortable. Patients who are difficult to diagnose can threaten their reputations. The power relationship is not all one sided, even though the strategies chosen by people tended towards subversion rather than confrontation. The participants who were dissatisfied with their doctors had no hesitation in telling me, and anyone else, what they thought of them. In the small towns and cities of this study this type of slurring does have an effect and there really is not much that the doctors can do. I have already given the example of Sky's denunciation of one general practitioner—here are two more examples:

*... I couldn't bear this fellow ... he had all the counselling skills of a dead slug.*

(Sb:274–275)

*... and he was a bumbling butcher if ever there was one.*

(La:228)

All the participants named their doctors without hesitation and usually supplied the address of the practice too. The participants' stories sometimes reveal the stress the doctor is under, either with reference to the doctor's rare admissions of failure, irritation or evading tactics.

*Anyway, this day, some years ago, I went in and ahh, I was in agony with some parts. Anyway, I said, 'Uhh, oh, do you think if I tried some physiotherapy it might...?' and \*\*\*\* [name of GP] said, 'Oh well if it doesn't do any good it won't do any harm.' And I said, 'You are not a doctor's bootlace. If I said "Pete, if I go home and stick my head in the oven," you'd say—Oh well if it doesn't do any good it won't do you any (chuckle) harm.' He said, 'Holly you know I am not a specialist, I am doing the best I can.' Oh he got quite upset then.*

(Qb:281–291)

*And he said, 'Mrs Timms you are never happy.' He said, 'Every time you come in here there is a problem.'*

(Ia:321–324)

*He said, 'Look I just can't cope with all your problems.' And he said, 'I will see you in four months.' I was so taken aback I didn't know what to say.*

(Ia:327–330)

*... you go back [again] and they say, 'Oh you know you are beyond help go back to your home, you have got to live with it.'*

(Xa:122–123)

People who find a diagnosis eludes them can either lose faith in doctors or doubt themselves. Register (1987, p.7) speculates that it is probably easier to doubt oneself because to doubt the doctor is to risk losing hope of a medical cure:

Declaring yourself sick enough to consult a doctor, you are also expressing your faith in the likelihood of diagnosis and treatment. As a diagnosis eludes even the most competent specialist's efforts, that faith begins to wane. Either you lose your confidence in the medical profession or you begin to doubt the validity of your symptoms. Surrendering confidence in the medical profession is risky business. If doctors have no capacity to heal, what hope remains? Self-doubt may be easier to live with, and so you wonder if perhaps you are only imagining things.

In Australia it is easy to simply exchange one doctor for another. If the participants were unhappy with medical treatment they stopped seeing that doctor, whether it was a general practitioner or a specialist. This type of doctor dropping does not speed up the diagnosis and may add to the inconvenience of travelling to consult a specialist.

*I had another inflammation in my eye and I thought, 'Look I am going to go to another doctor and we just [might] see' ...*

(Za:161–163)



*He said, 'I suppose you never want to speak to me again.' Well, I haven't ... but I hurt myself because I waited eight months with that bad back.*

(Ia:367–368)

*... every visit [to GP] he would say, 'Are you going to see [name of specialist above] I am not really qualified to treat you—you really need to go and see [him]' ...[pause]... and I ...[pause]... No, no I just feel I can't.*

(Ia:376–378)

So Elizabeth had to start the horrendous treks down to the city again to see a specialist. After leaving it so long she was immediately admitted for a prolonged stay in hospital.

*... and he wouldn't even let me go home and get a toothbrush. He admitted me there and then, my back was so bad. And I was there for six weeks.*

(Ia:387–389)

Knowing who to choose as a specialist is a hit or miss affair. Either the person relies upon the recommendation of their local general practitioner, who may not know a wide range of specialists in the city and may have a loyalty to the limited number of visiting or resident specialists in the locality or goes upon the recommendations of family or friends. Alan considers that the recommendation of a friend, who worked in a pathology laboratory in Sydney and asked around, saved his life. Colin talked to his next door neighbour who had medical connections to find his 'expert'. Jim who was reliant upon Medicare was referred to a specialist by his general practitioner. He had this complicated course:

*... the specialist he sent me to was an orthopaedic—to do with bones ... and he said, 'Ah it's not life threatening, don't worry about it—at this stage—it is out of my field.' ... He said, 'I will refer you to another specialist'.*

(Ja:113–130)

*And after about two weeks I never heard any more from him and so I thought, 'Well I had better go and check.' And err, when I went back to this other bloke they looked up their books and they said, 'No haven't got any indication of anything here.' ... And err, they said, 'Well, we will write to this other doctor and get him to send a referral through.' ... [and then they realised] 'He wouldn't be able*

*to see you until the end of May, the doctor is going away on holiday.'*

(Ja:135–144)

*So I went back to my own doctor and said, 'Look this is not good enough, I want to see somebody now.'*

Mary—Umm.

*So he said, 'Well, leave it with me.' Anyhow, he rang me within a week I think it was and said, 'You've got an appointment to go and see a doctor \*\*\*\* [name] at the ...[pause]... \*\*\*\* [name] local hospital.*

(Ja:162–168)

By this time Jim was seeing a specialist who was functionally a third choice.

While some people are extremely difficult to diagnose, some of the participants described severe or classical symptoms which were not picked up by doctors. In the first exemplar Pam's rheumatoid arthritis became very severe before she was noticed:

*And when I got out of bed in the morning I felt that my feet—I was treading on eggshells, that is just what it felt like. it was just in my feet ... By the end of that year my hands umm, started to swell and go black, the joints the main joints and ... there is something wrong with a fifteen year old who complains about sore feet and umm, hobbles ... I can remember going ...[pause]... up to my friend who lived up the hill, and I can remember having to walk backwards because my toes were too sore to take the rolling action that was required to walk frontwards up a hill.*

(Sa:84–151)

Pam explains that it took so long to get real attention, from either her parents or the general practitioner, because of the era and the place in which they lived. Out there in the bush children were tough—no one took too much notice of them. There was only one local doctor and there were no requirements for him to keep up to date. Pam was the first child he had treated with rheumatoid arthritis. There was no thought at this time (about thirty years ago) of questioning a doctor's acumen. After thirty years of dealing with doctors and hours spent looking at her own deformities, which might have been minimised by good treatment, she is more critical of him now.

Alan appears to have classical symptoms of heart failure. He describes the symptoms which he had during the three years before he was diagnosed with cardiomyopathy:

*Uhh, back in eighty-seven, eighty-eight, I had shortness of breath, err, walking and things like that and one or two other things ... and it got so bad, the blood pressure was starting to drop, I couldn't lie down and going to sleep at night you would sort of lie on your face 'cause that would stop you coughing ...*

(La:8–12)

*... some nights I would get up short of breath and I would be standing leaning out the window trying to get your breath back and you would wake up, 'What's all this about?'*

(La:52–59)

Being credible is given great importance in terms of the person's worthiness. Being seen as worthy or trustworthy has rewards:

*... but these [headaches] didn't go away and I needed to go to the doctor. The doctor knew me and my energetic way of life and he took the headaches seriously and I had all sorts of tests.*

(Pa:103–106)

This type of behaviour serves to confirm the belief that one must be stoical and not complain too loudly about symptoms in order to be granted attention. Credibility is more difficult to establish when the symptoms are complicated and/or vague and one is not known by the doctor, or s/he does not listen to the person's history.

### **It is psychological—am I going crazy?**

For people who have problems finding the cause of their symptoms a psychological solution is almost insulting. Even when they admit they are depressed it is necessary for the doctor to acknowledge that the depression is caused by a physical problem. The majority of the people in this study were or had been treated for depression. Several of them describe a low point in their lives when they begin to doubt themselves and it is usually expressed in terms of—'Am I crazy?' which appears to be analogous with 'Have I made this all up in my head?' This self doubt commonly marks an all time low in the period before a diagnosis is made.

Two myths which appear to be flourishing are revealed in the textual exemplars. The first myth is that psychological illness or frailty is a sign of weakness and of self induced problems and the second one is that there is a clear line to be drawn between the mind and body when attempting to understand personal symptoms. On reviewing my own prejudices in these matters, I was surprised how resistant and repulsed the participants were at the mention of psychological illness. I thought that attitudes had changed towards mental illness and that the integral nature of the person was

understood. Interestingly, Sky, the other nurse, holds similar views to me but we are alone.

Pauline demonstrates a tolerance of psychological ‘weakness’ in others but still dreads it in herself:

*However there came a time when I began to wonder myself. Now I understand that you’re ill, no matter, and doctors are supportive even if it is psychosomatic ...*

(Pa:156–158)

*I remember I went for another battery of tests in \*\*\*\* [city] and this woman said, ‘Well this is it, if we don’t find something conclusive this time we will have to refer you to a psychiatrist.’ This was my worst fear—that I had brought, somehow brought this all upon myself. They put some skin patches, for sensitivity, on my forearm and I had to wait forty-eight hours for them to be read. All that time I thought, and by the end I was accepting of the worst—if I had to see a psychiatrist I would accept it and work hard. The doctor came in to read my arm, I had no idea how significant this would be. She uncovered my arm and looked and I asked her if it was conclusive, thinking she would say, ‘no’. She said, ‘Yes! These reactions show your immune system is compromised and you must have chronic fatigue syndrome.’ Well, she will never know the relief, she left the room and I just wept.*

(Pa:164–179)

Even more revealing is the next part:

*My doctors here were also relieved to have confirmation of an organic disease. One almost cried with relief. They then decided that I should go to \*\*\*\* [city] regularly to see a leading specialist who is the expert in Australia regarding chronic fatigue syndrome.*

(Pa:180–185)

These exemplars led me to revise my view to some extent. Symptoms having an ‘organic’ cause which can be discovered are rewarded with medical time, attention and resources. Organic is the participants’ term; I am not used to it in my practice or in life generally. The worthiness of physical problems is fostered quite generally by the participants and the medical profession. They valorise organic problems and thereby demean psychological problems. Doctors see ‘organic’ problems as their province but psychological problems require the patient to ‘pull themselves together’

or to be treated by a psychologist. The participants felt, quite literally, that they were being dismissed when the doctor suggested that they had psychological problems. In this example no one except Sky consciously appreciated the unification of mind and body and the reasonableness of co-existing problems, physical and psychological.

Over half of the people in this study were ‘depressed’ and the only treatment for depression any participant was given by the medical profession was anti-depressant pills. Once the label of psychological problems was upon one then it gave the medical profession a loophole. To fail to find a cause of symptoms is to fail as a doctor. This myth is perpetuated as much by the clients, it appears, as the doctors themselves. All the diagnosticians were praised as being ‘good doctors’. We have just heard Elizabeth’s views on her specialist and Pam’s disregard for the doctor who misdiagnosed her. It is likely that the doctors feel pressurised into finding some cause for their clients’ symptoms.

The reality is that the body can manifest diseases in a range of symptoms all of which are interconnected. Paul, who was introduced in chapter five, had an injured back causing him pain. He also had a great deal of stress and guilt laid over from his work with young offenders. He could not afford to express this stress or deal with it because it might undermine his case of physical back pain. Sarah’s problems with arthritis began after a car accident in which her husband was killed. She has had to deny the psychological trauma that must have been caused by this in order to get attention for her physical symptoms.

*I was fobbed off by everybody—even sent to a psychiatrist who said, ‘There is nothing wrong with you.’ The doctor said, ‘Oh it is your grief, it’s the menopause.’ (I was only forty-two) umm, ...[pause]... ‘You’re just imagining things, go and divert yourself.’ And even my family didn’t believe me. So I was mad with pain.*  
(Xa:14–23)

‘I was mad with pain’ is a fitting, if unintentional, confirmation of my unification point.

Jim was wary of the doctors trying to give him a psychological label and was quick to see which way questions might lead him:

*And the first thing he did, he started asking me questions like, ‘Do you feel like life is passing me [you] by?’ umm, ‘You’re getting stressed out?’ ‘You’re getting depressed?’—I said, ‘Yes,’ and err, err, his sort of reaction came back and [he] said, ‘Do you think the*

*depression is causing you to feel this way?’ and I said ‘No.’ I got a bit cranky with him.*

Mary—*Yeah.*

*And I said, ‘No.’ I said ‘I think it is the other way around.’ I said, ‘I can’t function the way I normally function, and so that is getting me depressed’.*

(Ja:169–179)

Whichever way around it was in any of the participants, there was a significant number of them with distressing depression and stress which was not being dealt with in a helpful way. The prevailing attitude towards mental illness was a barrier to progress and any hope of relief from the lethargy of depression.

### **A diagnosis (I’ve got ...)**

The advent of the diagnosis is a stressful and worrying time for most people; it is a time of fear for the future and often involves personal doubt. It also seems to have most influence upon the initial reaction to the naming of the illness, far more so than the nature of the disease or the threat it poses to lifestyle or indeed to life itself (although of course these reactions set in later). Pauline said she would be almost relieved to hear that she had multiple sclerosis rather than carry on life without knowing what was the matter (Pa:148–151). Paul was relieved when he at last got confirmation of something physically wrong with his back:

*... then I went and saw this Dr \*\*\*\* [name] and that is when I had the magnetic resin images done and it showed the problem.*

Mary—*Yeah.*

*And I felt ...[pause]... I still had the pain, but I felt better in a way ...[pause]... that was sort of one of the needles pulled out you might say.*

(Ob:184–191)

People do not on the whole have just one reaction to a diagnosis. The initial reaction is swift, relief, shock, disbelief, tremendous fear and trepidation. There have already been exemplars from Elizabeth and Pauline demonstrating their extreme relief upon diagnosis—Elizabeth because she was at last believed and Pauline because she was frightened that she might have brought the illness upon herself. Alan was shattered

for he had not been expecting it and he felt he had not done anything to compromise his health:

*Well, for a person my size and [I had] never had [a] heart problem and [I had] been on a relatively healthy diet all my life, I felt shattered.*

(La:118–120)

Holly had a sudden onset of excruciating pain and was diagnosed quickly. Her reaction was:

*Right at the beginning I was, I was, I guess, devastated and umm ... actually I was a complete wreck for about ...[pause]... at least two or three months.*

(Qa:2–8)

Sky, the nurse, had an idea of what was the matter and put off going to the doctor she knew would give her a diagnosis of ulcerative colitis. Her initial reaction was anger and dismay:

*I just did not want to know, I did not want to have this bloody illness and it had stuffed up my life and I was thirty-three years old ... who wants this fucking illness? No way! And I just didn't cope, I just didn't cope for three months, you know, I probably spent three months in a bag of dope, in a big bag of dope ...*

(Ub:487–501)

The last example I will give of an initial reaction is one of fear. Pam was only fifteen when she heard she had arthritis. This demonstrates the fear that can be generated when someone is not included or allowed to know what is happening. The story Pam recalls happened over thirty years ago:

*And he took a blood test and I can remember waiting for the results because I was afraid, I knew there was something wrong with me. And something that the doctors with all their power and mystique of medicine probably didn't know about ... and I can remember the phone call, I was wiping up, err, with my sister, I was fifteen years old. And I can remember that my mother took this phone call and I knew it must have been the doctor—she was in the hall and I heard her say, 'Oh no,' like that, and the next minute she says, 'Yes doctor, no doctor,' that sort of approach. [She] put the phone down and there—nothing—she didn't appear. And I went after her*

*because I thought, 'What's wrong?' you know [really loud voice] 'tell me!' And this was the story of my life—tell me. And I went down and there was my mother howling quite hysterically in, in with my father, father's arms around her. And I panicked, you know because that was, you know, I was afraid ... and you know my father said that, 'It's just that it is an old person's disease,' you know.*

(Sa:161–183)

Mingled with the first reactions to the diagnosis can be some satisfaction at other people's reactions:

*I was overwhelmed by other people's care for me. I had been a vital sort of person who had been involved in a lot of things ... People's responses were quite amazing and umm, and I was really—I must say sometimes I actually needed breathing space because I was really quite overwhelmed. Umm, and in fact I'd have to say that it was quite euphoric if I was to be quite honest.*

(Pa:207–211)

Pam remembers this amongst the fear, worry and pain:

*And I can remember my friends brought me the most beautiful posy and I remember that flower [arrangement]—there were carnations and the smell was gorgeous, cecil brunner roses, two types of shades, pinks, and carnations and forget-me-nots, all in rings around a lace doily. And I remember that was so beautiful because there was a lot of dagginess and what—dreariness in our lives at that time.*

(Sa:193–199)

### **The meaning and significance of the named disease**

After the initial response reactions tended to dampen and develop according to the significance of the disease. The diagnosis gave the disease a name and allowed the person to distance themselves from it slightly—in terms of 'I didn't do this', 'I didn't bring this on', 'This isn't me', and 'I am deserving'.

Elizabeth's acclaimed diagnosis of coeliac disease has changed her life in as much as it has validated her lifelong complaints of illness. She is still grateful for the diagnosis. However the diagnosis did not herald a cure. While she sticks to a rigid gluten free diet she still has stomach pains and the medical profession is now proposing that she *may* have Crohn's disease. Overriding the stomach pain nowadays



is a vicious arthritis which limits her activities and is painful. She does not talk about the new diagnosis in the same way she does the diagnosis of coeliac disease. It appears that what she required was a legitimisation of her sickness state. With her named disease and doctors she trusts there is no question of her authenticity. She is able to walk the path of illness in a calmer way than when she was constantly wrestling to prove herself.

There was a measure of pride in some diseases and shame in others. The stigmatising illnesses are still with us. Alan is quite assured when talking about his heart problems and in his understated way he is the hero of his story. Lupus, too, is an acceptable disease—certainly one that may be talked about and shared with friends. Linda can accept diabetes because she ignores it: when she is with other people it does not exist. The people with these three illnesses did not at this stage have any outward appearances of their particular diseases, for example, no swollen ankles, wheezy breath, swollen and knotted joints, or red and swollen eyes. They were not obviously sick to the general public. They could share their concerns about the illness with whom they chose without having to deal with other people's imagined or real prejudice.

However an illness can be too indistinct. Zoe, with lupus, was also irritated by people who willed her to be well and who could diminish her experience of illness (fldnte:1.3). In her case this was quite easy for people to do. She has a reputation for giving lovingly to family and friends. She is a wife and mother of five and a public servant. She smiles a lot and people want to be with her. They do not want her to be different and so they pay her compliments which she finds quite irritating. 'You look great' is interpreted by Zoe as a statement which is both leading and manipulative. What they mean is 'You are better, aren't you?' (fldnte:3.6).

The two participants who were diagnosed as having chronic fatigue syndrome had similar problems. Despite a clear diagnosis, the discourse surrounding chronic fatigue syndrome is mixed with fact and suspicion. The cause is hampered by labels such as 'yuppie 'flu'. This means that it is more difficult for sufferers to reach and display their full potential because it might be regarded generally that they are better or at least not very ill. Jane with her hepatic failure was free from this kind of restraint. There was no doubt about the severity of her condition and she was able to celebrate good days:

*... every now and then I would have a day when I felt well and that was pretty terrific. The problem being that I would go absolutely berserk on that day and move mountains and err, and zonk out for*

*a week (chuckle). But emm, ...[pause]... I, I was, I was very involved with school activities and err, [impressive list of activities and committees].*

(Va:126–132)

To gain this kind of credibility Jane was indeed very sick. She faced death and describes her response in this way:

*I sort of lived my life in stages really. I err, ...[pause]... I umm, I umm, looked forward to Danny going to infants' school and sort of getting settled there and then I thought, 'I, oh well, I'll hang on till primary school' and 'I'll get him through primary school' and then 'Oh well, we've got this far I'll hang on now, get him through into high school' and umm, and get him through that and umm, he has done all that and he did his HSC [Higher School Certificate] last year and err, he is at college at the moment. So umm, eighteen years older umm, I feel as if he can look after himself at this stage (chuckle) ... but then I am not sort of contemplating carking it at this stage, so... (chuckle).*

(Va:173–189)

My response to Jane at the interview was an expression of admiration—‘*What a tremendous achievement!*’ (Va:190). Her tenacity and selflessness are impressive qualities which have endured for unrelenting years. Although it should not, this type of example serves to diminish the experiences which are not so dramatic. The number of times that I speak admiringly on any of the tapes is confined to three. Each occasion was a case of extreme fortitude like this one. It would appear that just ‘plain old struggling along’ is just not dramatic or impressive enough to elicit my vocal admiration. In order to gain attention one needs to be extraordinary. An ordinary experience, even if it is an illness experience, is not enough. Sarah said once:

*... and with, with cancer, people pour all love and all the sympathy or empathy onto you because they know it is terminal and poor thing you have got cancer. Not that I'm jealous it is just ...[pause]... I'm, I'm stating a fact.*

(Xb:187–191)

This is not how I feel and I hope that I did convey to all the participants my admiration and respect. Perhaps Milton's poem is an adequate expression of the worth of people who endure ‘mild yokes’.

### *On his blindness*

*Ere half my days in this dark world and wide,  
And that one talent which is death to hide  
Lodged with me useless, though my soul more bent  
To serve therewith my Maker, and present  
My true account, lest he returning chide,  
"Doth god exact day-labour, light denied?"  
I fondly ask. But Patience, to prevent  
That murmur, soon replies, "God doth not need  
Either man's work or his won gifts. Who best  
Bear his mild yoke, they serve him best. His state  
Is kingly: thousands at his bidding speed,  
And post o'er land and ocean without rest;  
They also serve who only stand and wait."*

(Milton)

The three people with multiple sclerosis were frightened by the diagnosis but only began to hate it as they became increasingly disabled. Peter kept up his job as a school teacher until he thought he was losing the children's respect because he was slurring his words:

*I started talking like this and when I started writing like that  
[indicates all over the place with his arms] err, I knew then that I  
should give up, because you can't expect kids to write when you  
can't write very neatly, you know. And you can't talk properly.*  
(Ka:64–68)

When they involve a degree of loss of physical or mental control, neurological disorders are demeaning and the diagnosis is unwelcome. Colin feels this keenly. The diagnosis marks a clear landmark in the illness history. It is the time when the disease is named and some type of order can be re-established and plans can be made. Living goes on and new patterns need to be established.

## **Conclusion**

This chapter is a testament to Heidegger's (1962) notion of existential time. The past has not *been*, never to return. Rather, it is with each person and shapes their Being and in this particular context their Being chronically ill. Even though the individual personalities shine through in the texts it is possible to speculate where their attitudes have been shaped and influenced. Understanding and meaning-making of the process of chronic illness are generated from the person's communion with the shared world of popular values and cultural practices.

It is possible to trace changes in these shared meanings over the years by contrasting the treatment meted out to Linda, Elizabeth, Pam, and Peggy with that meted out to

the others who have been diagnosed and treated more recently. One might review Sky's case: she is the youngest in the group, and despite being assertive and free from many older prejudices, is just as surely influenced by the situations she has been immersed in.

A person's history is the key to his or her self knowing. In order to have any comprehension of what the experience of chronic illness is for the individual then some understanding and appreciation of a person's history and context is advisable. To draw upon people's memories is to learn about and to know them carefully.

What makes time so valuable is that it is convertible into nourishing memory. Memory is where the proof of life is stored. It offers material for stock-taking and provides clues about where our lives are going (Cousins 1983, p.232).

Learning from these people allowed me to contemplate about how near and how far I was from each one's perspective. Dwelling with the texts and investigating them minutely has engendered a deep respect for the depth and influence of past experience. I now have a better notion from whence ideas and views come and the source of their strength. I have also been faced by my own rhetoric. Just like some of the participants, I value some of the things which serve to demean the chronically ill. I have said, and thought I meant, that some losses do not affect a person's worth when in fact the reality is that they do.

The past is constitutive of the self identity of the person and reveals their values and the impact of chronic illness on their lives in terms of loss and missed opportunities. The specific illness history starts with the onset of problems or symptoms which mark the beginning of the illness trajectory. It is a path that entwines the people in this study with the medical profession and means that they have had to face considerable change in their lives and on the whole this change is predominantly viewed in a negative light by the person, their relatives and the medical profession. It is certainly a path they did not choose or deserve.

These histories are the springboard of the present (things I am doing now) and the future (possibles). They portend the moods of the person, whether they be hopeful, hopeless, confident, timid, angry, accepting, or depressed. This is because these moods are adopted according to past experience. Peter's gloom is derived from his experience and the knowledge that these experiences are likely to continue and constrain his future 'possibles' too.

In chapter seven the next of Heidegger's (1962) *ecstasis*, the present, will be explored. In order to consider the present, Gelven's (1989) question is used to

extrapolate what it means to be in the present. The questions he used are, *What is the person doing?* or *How is it possible to be chronically ill now?* The ideas are not confined to the present and demonstrate how naturally dependent the present is upon the past and the future.

In this part of the dialogue with the text there is a pervasive notion of diminution. The person with chronic illness feels squashed by their own values, their own inabilities, shared prejudices in the culture and by the medical profession. The participants feel they are smaller in many ways and this feeling extends into the the next chapter where actions and situations are explored to reveal the present.