

Transition in Chronic Illness

# Constant Change:

The Shifting Experience of Illness



BOOKLET 1

**Compiled by:** Dr Debbie Kralik RN, PhD  
Senior Research Fellow  
University of South Australia  
RDNS Research Unit

Ms Kerry Telford BASW, Grad Dip Grief Counselling  
Researcher  
RDNS Research Unit.

Email: [researchunit@rdns.org.au](mailto:researchunit@rdns.org.au)  
Website: [http://www.rdns.org.au/research\\_unit](http://www.rdns.org.au/research_unit)

### Titles in the 'Transition in chronic illness' booklet series

1. Constant change: the shifting experience of illness
2. Grief, loss and fear
3. Shifts in self and identity
4. Relationships
5. Sexuality
6. Fatigue
7. Pain
8. Interacting with others
9. Our inner world
10. Self-care
11. Understanding Transition



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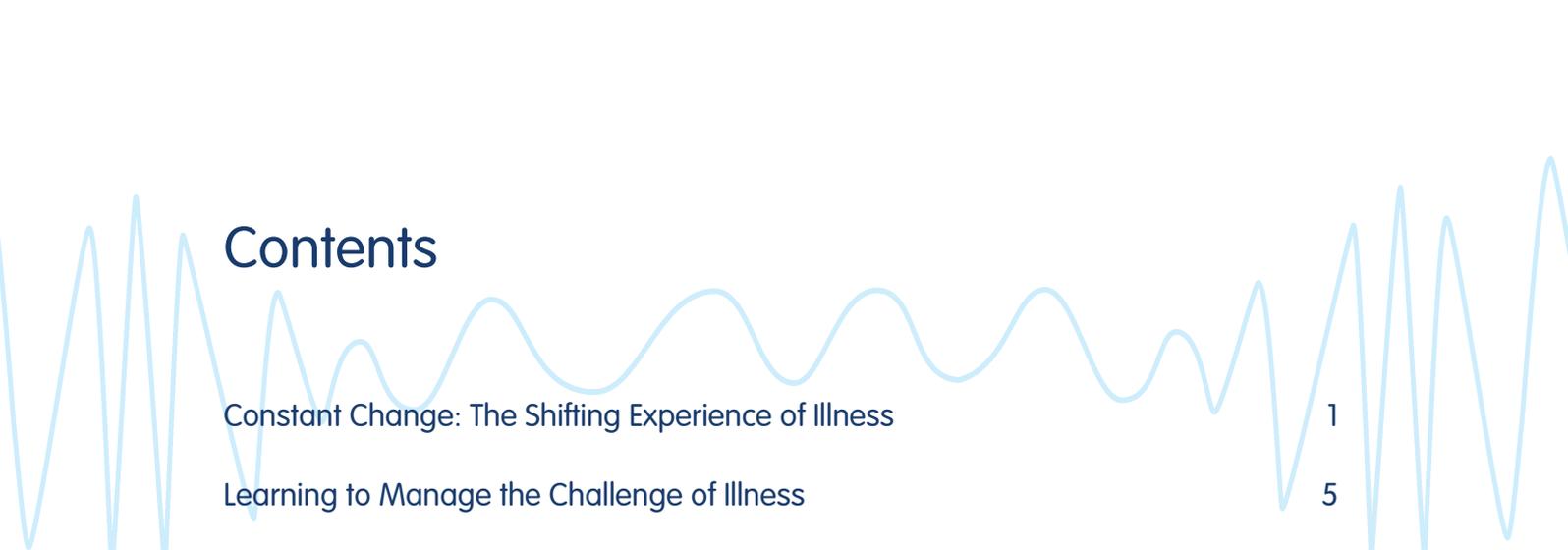
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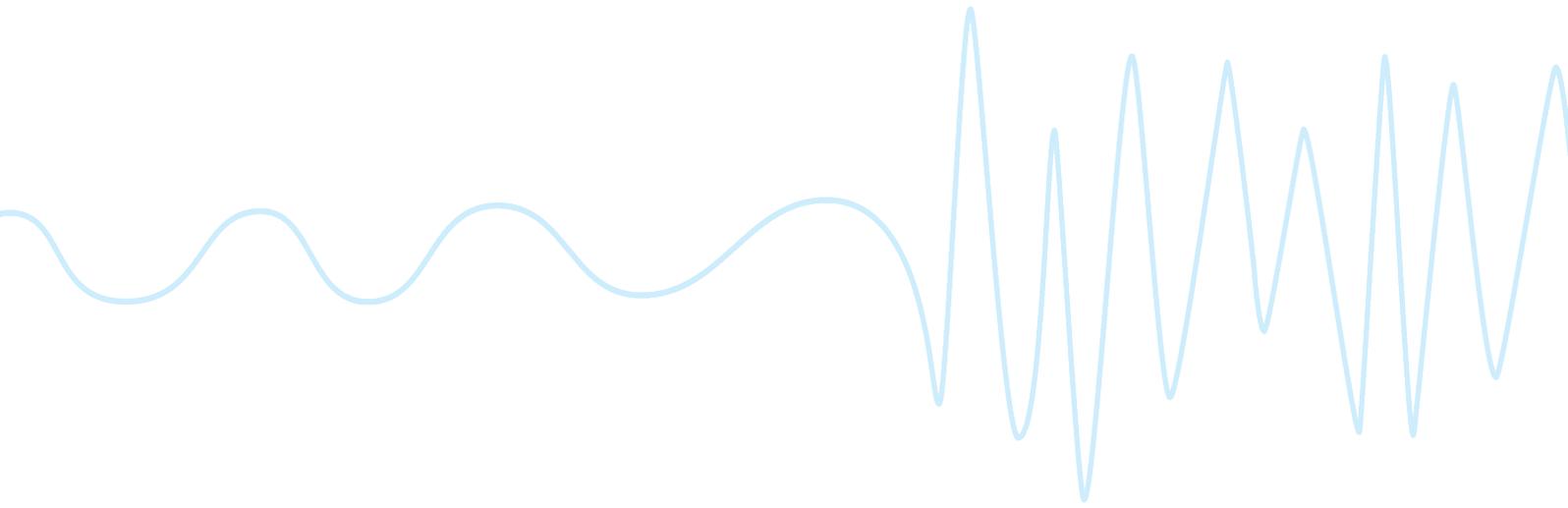
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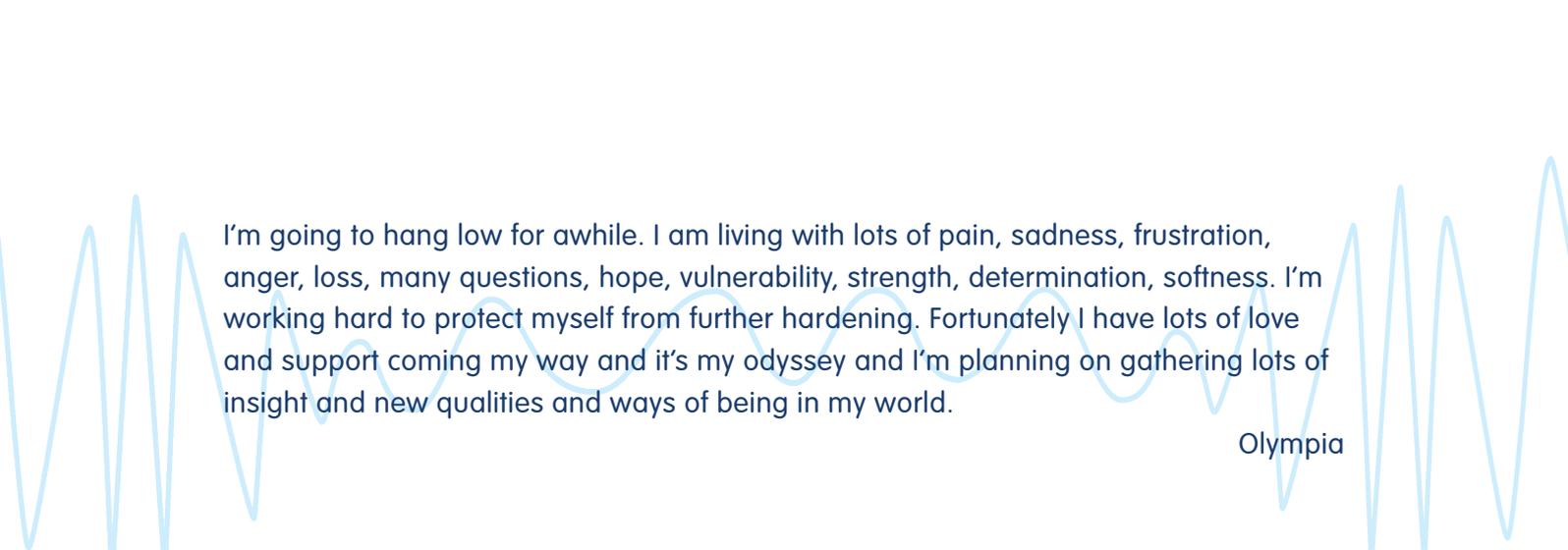
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I'm going to hang low for awhile. I am living with lots of pain, sadness, frustration, anger, loss, many questions, hope, vulnerability, strength, determination, softness. I'm working hard to protect myself from further hardening. Fortunately I have lots of love and support coming my way and it's my odyssey and I'm planning on gathering lots of insight and new qualities and ways of being in my world.

Olympia

## Constant Change: The Shifting Experience Of Illness

This booklet reveals people's experiences of living with constant change as a part of the chronic illness experience. When we begin to experience symptoms of illness we often think that it will pass. For some people the experience of diagnosis comes as a profound shock. For others, there was an inkling or a suspicion that an illness was present. For some people a medical diagnosis never comes but symptoms persist. A chronic illness is one that continues over time and often without an easily definable beginning, middle and end. While the symptoms that accompany a chronic illness can usually be alleviated to some extent, the illness itself is not curable. When we are diagnosed with a long term illness for which there is no cure, life changes. The experience of coping with the changes brought about by illness is the focus of this booklet.

A chronic illness often presents as an end to our familiar lives. Life changes; and often there is no going back to what was familiar. Endings such as chronic illness can cause trouble and disruption to one's sense of self. Our sense of self is defined by the qualities, abilities, skills, and learned behaviours we have that help us to feel good about ourselves. It is how we define ourselves. Change means that people have to let go of the way that things, and the way that they themselves used to be. This marks the beginning of a transitional process towards a new way of living.

Entering into a life with chronic illness is a change event that causes interruption to our usual patterns of living and being in the world. Our usual ways of living no longer work and new ways of living need to be developed.

The illness experience is constantly changing as aspects of the illness and the body change on a daily basis. The uncertainty and fluctuations associated with the experience of living with illness means that nothing can be taken for granted. The consequences of illness pervade every aspect of our lives; yet we can only tell parts of our stories at one time. This means that the complexity of illness is not fully conveyed or understood. The unpredictability of each day makes it difficult to make plans or to commit to activities. The experience of not being able to do things that one could previously do or to attend planned events with others is frustrating and triggers feelings of loss.

When the changing nature of illness is experienced, we learn that strategies can be put in place in order to manage the uncertainty and to create some safety and choice. Learning also occurs around managing the fluctuations of illness. People learn to create the flexibility and space to tailor the day to fit with their physical abilities. Simple strategies such as not planning too much for the day, not expecting too much of oneself and learning to avoid the triggers that lead to feelings of fatigue, are examples of how the day can be made more manageable. Adopting a more flexible approach to expectations allows for not giving oneself a hard time if unable to do something that was planned. In support of this, setting ground rules for others which provides understanding about the decision to say no is also necessary, as is having a back-up plan should things change rapidly. There is no doubt that illness imposes a range of limitations on life, yet it seems possible to develop ways of managing them and to reclaim, to varying degrees, a sense of control in life. We now talk about how living with illness shapes the way we organise life, what we prioritise, and the way we interact with others.

### ***What does the constantly changing illness experience mean for your lifestyle?***

Living with uncertainty due to never knowing what tomorrow will bring. Due to the fluctuating levels of symptoms I am forever having to change what and how I do things. Ultimately this brings about a slowing of lifestyle to enable changes to be more easily accommodated and foregoing any long distance forward planning.

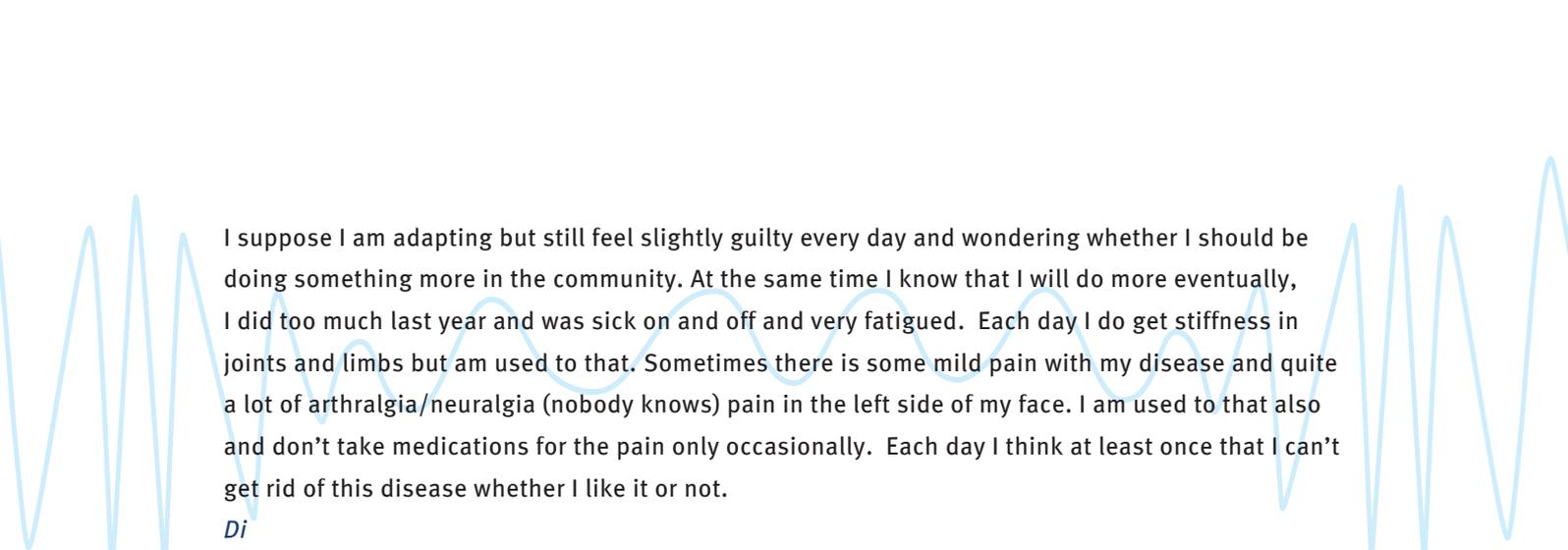
*Graham*

It means forever believing in yourself that you are just as good as anyone else even though you have a disability/ disabilities. (Self-worth) Finding out who you are and what you are as chronic illness changes the perspective of what you once were if you weren't born with the illness. Learning to love yourself because of your disabilities. It means learning to have patience with those who offend you when you are parked in a disabled car park and don't look on the outside that you have a disability. Learning to forgive a person who is ignorant and hurtful towards your illness. Learning to fight for your rights as a disabled person.

*Julie*

This year I am living a fairly quiet life, often at home, although go to movies and sometimes visit a few friends. I share the house with a friend and have two poodles so I am not lonely, although feel a little 'alone' because like many of our chronic illnesses it is not apparent like a neon sign to others so they can't relate to how I feel.

“It means forever believing in yourself that you are just as good as anyone else even though you have a disability/ disabilities.”



I suppose I am adapting but still feel slightly guilty every day and wondering whether I should be doing something more in the community. At the same time I know that I will do more eventually, I did too much last year and was sick on and off and very fatigued. Each day I do get stiffness in joints and limbs but am used to that. Sometimes there is some mild pain with my disease and quite a lot of arthralgia/neuralgia (nobody knows) pain in the left side of my face. I am used to that also and don't take medications for the pain only occasionally. Each day I think at least once that I can't get rid of this disease whether I like it or not.

*Di*

Not being able to tell what is going to happen next with respect to any normality in life, brings in the uncertainty or fear of what tomorrow might bring.

*Judyth*

Overall illness puts limits on what I am able to do. I tend to avoid things I know will make me feel ill. I avoid many outdoor activities as I can no longer tolerate being out in the heat and living in the tropics. This is a real concern. I avoid going out too often especially at night. I am far less active and am unable to participate in any sports, not only because of my pituitary condition but also because of spinal problems and arthritis. Increasingly I have to adapt to alternative activities that I am able to cope with.

*Chrispy*

It means that you have to be really careful about what you plan to do and where you plan to go and take so many outside things into consideration.

*Michelle*

It's difficult to predict how I'm going to be feeling both physically and psychologically so it's impossible to plan ahead - even on a given day. A lot of things that influence how I feel are out of my control, including the weather, how I've slept, and having to do something that I have no choice about doing. So by not being able to predict things it gives me a sense of lack of control even over basic things that healthy people take for granted. Or that if I end up going somewhere, I may end up leaving and being unhappy with having gone out, rather than happy that I had friends to go out with. It means I have to be happy with not being able to finish things that I start. It means that I am losing confidence in the most basic of things, and that I really have to make an effort and make myself do them.

*Iolanda*

I find that sometimes I have the energy, clarity of mind and motivation to try to carry out some task or other that needs to be done, but often one or more of these factors is just not there and I know that it would be completely frustrating to push on regardless. So it means I have to live with an open, flexible timetable. I cannot fix a date and time on which I will definitely perform a task which has significant mental or physical demands. Therefore, I try to adopt an attitude to life which says do what you can when you feel up to it.

*Ted*

It places some restrictions of my lifestyle - I have to be aware of the possibility of change, and be prepared for it to happen. It means some extra effort in working out what is going on. It can also be stressful and frustrating - just as I have things working well and under control, it all changes again...I make sure that there are things in place in case things really do go wrong. For example, friend has copy of house and car keys. If things should go wrong at work, they can pick up car and feed the cat etc (I also have full Hospital and Ambulance cover). It gives some confidence that should the worst happen, its going to be dealt with.

*Andrew*

...I have to be aware of the possibility of change, and be prepared for it to happen.



The rollercoaster ride through Chronic Illness – Helen

It makes it very hard to plan anything as I never know if I will be well enough on the day for whatever it is. It means not over-structuring my time and making contingency plans if I am not well enough to do something. It is important to have understanding friends so that when you are unreliable they know you are not being difficult but are having a bad day. It also means that the way I feel varies all the time. Makes me not quite trust my body sometimes as I wonder what it is going to do to me next.

*Helen*

I find it incredibly frustrating because I like to think of myself as reliable. Last year my health and energy levels were going quite well and I agreed to take on a major editing project. Since then so many things have gone wrong health-wise that I can barely cope with the commitments I have, and had to dip out of the job. The publisher made sympathetic noises when I spoke to her, but really bitchy comments behind my back, so looks like I wont be getting any work from that source again.

*Brumby*

...the way I feel varies all the time.

## Learning to manage the challenge of illness

The process of learning to manage illness can be overwhelming, however there are some common ideas about what is helpful. The support and understanding of family and friends has a significant influence on the way one responds to the challenges of living with illness. The challenge is more manageable when the person knows they are supported and understood by significant others. Also useful are changes in attitudes to support the individual in their adjustment to illness. Attitudes that normalise change and adopt realistic expectations of oneself are seen to be important, along with developing a more relaxed approach to living. This is an approach that enables the person to manage life as it happens rather than worrying about things before they happen. Having a positive outlook and maintaining hope appears to assist the process of adjusting to illness. Spiritual belief often assists people to keep illness in the perspective of the whole person. The awareness that one is more than a body and the acknowledgment of the spiritual dimension provides comfort and encouragement for some people. There is support for the importance of finding a health care professional who is willing to listen and show respect for the needs and wishes of the person. The perception that the person is working together with the health care professional appears to facilitate the process of learning. The practical strategies for managing illness become important too. People find that strategies such as pacing oneself is necessary in terms of avoiding fatigue and being able to achieve goals. The value of sharing ideas and experiences with others in similar situations also seems to have many benefits. Finding a network or group of people with whom you can connect and share stories appears to reduce the sense of isolation, increase feelings of being supported and promote learning around managing illness. The Internet provides a way of connecting people to enable this sharing and support. Not only does the Internet connect people who would otherwise be unable to meet, but also opens up the opportunity for gathering information that assists the process of learning to adjust to and manage chronic illness.

While it is clear that each person's journey is unique, there are certainly some similar ideas about what assists people learn to live with illness. Each person will negotiate the challenges in their own way and select from the options available to them. That we all come to an approach that feels right for us as individuals is evident in our stories about what's been helpful in learning to manage illness.

### ***What has been helpful to you in learning to manage illness?***

My family support is the most important thing to me. This gives the strength to constantly manage the effects of illness.

*Graham*

Having faith that doctors are researching constantly to find a cure for all illnesses and that one day you might be cured. Never giving up because that depletes the energy of positive thinking and that is half the battle of winning the disease.

*Julie*

Learning to accept my limitations. I find this a constant battle. And learning to accept help when it is offered. I'm more used to helping others out and find it really hard to say yes, please do that for me.

*Brumby*

Being able to search internet to find out as much as possible. Finding a new GP who is at least willing to investigate and help. Not giving in to it and telling myself I am well. Finding readings and thoughts to become a more courageous person. Pacing myself and knowing not to do too much in any one day.

*Di*

One of the best things I have learnt especially with this group is pacing myself. I will set one thing I want to do a day outside the house, be it Dr's visit, necessary shopping, visiting the pharmacy or a church activity. I take regular days off doing nothing, and listen to my body more than I used to. It's working so I'm happy and my family are content. That's most important.

*Judyth*

I am very lucky in that I have a very supportive husband who shows incredible insight with my limitations. Actually he has suffered 2 breakdowns and is no longer able to work. The stress of these breakdowns and trying to support him through them further undermined my own health, but ironically I believe illness has better equipped me in understanding and supporting him and helped him to better understand my needs.

*Chrispy*

Having a good support network of friends and family who understand my limitations.

*Michelle*

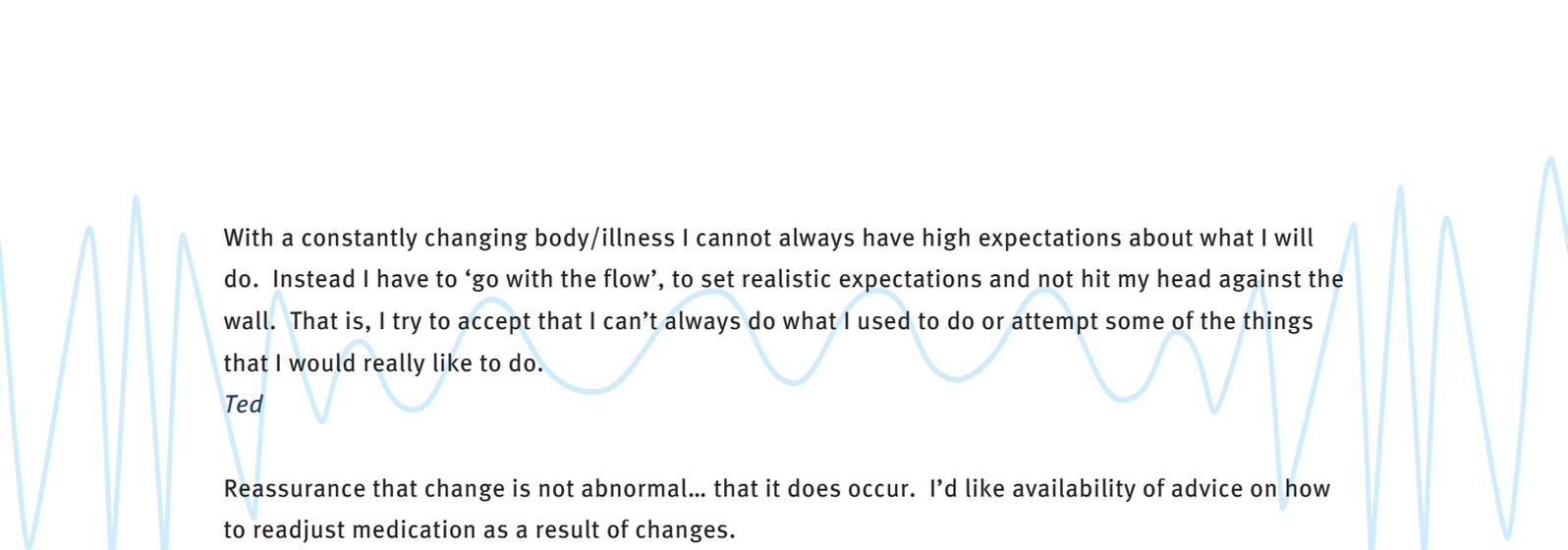


- Realism, adaptation, patience
- Having supportive family and friends.
- The Internet has been undoubtedly the best thing that I could have done for myself. It gives me a chance to feel proactive in researching my illnesses, helps my psychological need to connect to others and helps me feed my brain cells.
- I do not worry about my 'constantly changing body' and where it will end up because I am a supporter of voluntary euthanasia and this gives me unbelievable mental peace in psychologically managing the present and the future.

*lolanda*

Since I'm largely housebound, the internet is my connection to the world, providing me with camaraderie, support, friendship and information. I would hate not to have it.

– lolanda



With a constantly changing body/illness I cannot always have high expectations about what I will do. Instead I have to 'go with the flow', to set realistic expectations and not hit my head against the wall. That is, I try to accept that I can't always do what I used to do or attempt some of the things that I would really like to do.

*Ted*

Reassurance that change is not abnormal... that it does occur. I'd like availability of advice on how to readjust medication as a result of changes.

*Andrew*

My Christian faith is very important to me and the knowledge of a perfectly functioning body in the world to come is a big help. Knowing that I am more than a fragile body - that I am a brain, a soul, a person with feelings etc. quite apart from my health problems. My health problems are only a part of the whole that is me.

*Helen*

## Goals ARE important

Imagine going on a trip and never deciding upon a destination. You could end up anywhere and probably nowhere close to where you'd really want to be. Life with illness is like that. If you don't have goals, you could end up anywhere. It is risky to leave life up to pure chance. Living without goals is like sitting in a sailboat and letting the wind take you where it may. You risk drifting aimlessly through life, finding little satisfaction or sense of purpose.

Anger, depression, hopelessness and withdrawal can result from the perceived loss of power to effect change. Our responses demonstrate the importance of having small achievable goals that provide a sense of accomplishment in terms of coping with the unpredictable and overwhelming challenges of illness. There is a strong desire to live life as fully as possible despite the impact of long term illness. Having goals is a way of creating a vision for the future... goals to strive toward is essential in maintaining a life that is fulfilling and meaningful. Achieving personal victory over the adversity of illness, no matter how small the victory is, fosters personal strength and confidence. Learning ways to cope from moment to moment and from day to day are significant achievements when living with chronic illness, and are worthwhile goals. It is worth valuing the power we have, in the moment we are in, with the people we are with, and the opportunities that are presented to us. Striving toward goals is a part of the learning process. If we set goals that are aimed too high, it can be disappointing. Trying to change or shape our lives by only focusing on the 'big picture' can be like pruning a forest of trees with manicure scissors.

The task can be overwhelming. We learn to adjust so that goals are within reach and build confidence when achieved. We learn to be flexible about what we strive for.

It is important to remember to strive toward bringing joy or pleasure into life as well. The experience of illness can be all consuming. There is a need to maintain some balance to the trials of illness and to avoid allowing illness to overwhelm life. Illness becomes less of a burden when the focus is on the things that each person can still do rather than those that they can no longer do. This focus enables the person to find meaning and value to oneself and to life. The challenge is to rebuild a life that reflects the person's interests and priorities, and the image that is to be presented to the world. By setting small goals it is possible to learn about personal strengths, to learn about what is possible in terms of achievement and to learn about oneself. As we learn about these things and put the pieces of our life together, a new picture of our self, identity and life situation evolves. As people living with illness our goals have changed, but we still work toward achieving things that are important to us.

If you find yourself drifting, forgive yourself, and get back on course. When you are confronted with a difficult situation try to lower your sails and ride it out. Try not to be unrealistic about what you can accomplish during such times. We all need time to recoup and regain our physical and emotional energy after a crisis. Sometimes, we need to just be still. When you feel ready, raise the sail and continue on your journey.

### ***What do you strive toward in your experience of illness?***

I strive from hour to hour just to be.

*Graham*

Finding a balance between having self-worth and accepting limitations and accepting others' help.

*Brumby*

Striving to be equal to others, being accepted for who I am, others not judging me just because I have an illness.

*Julie*

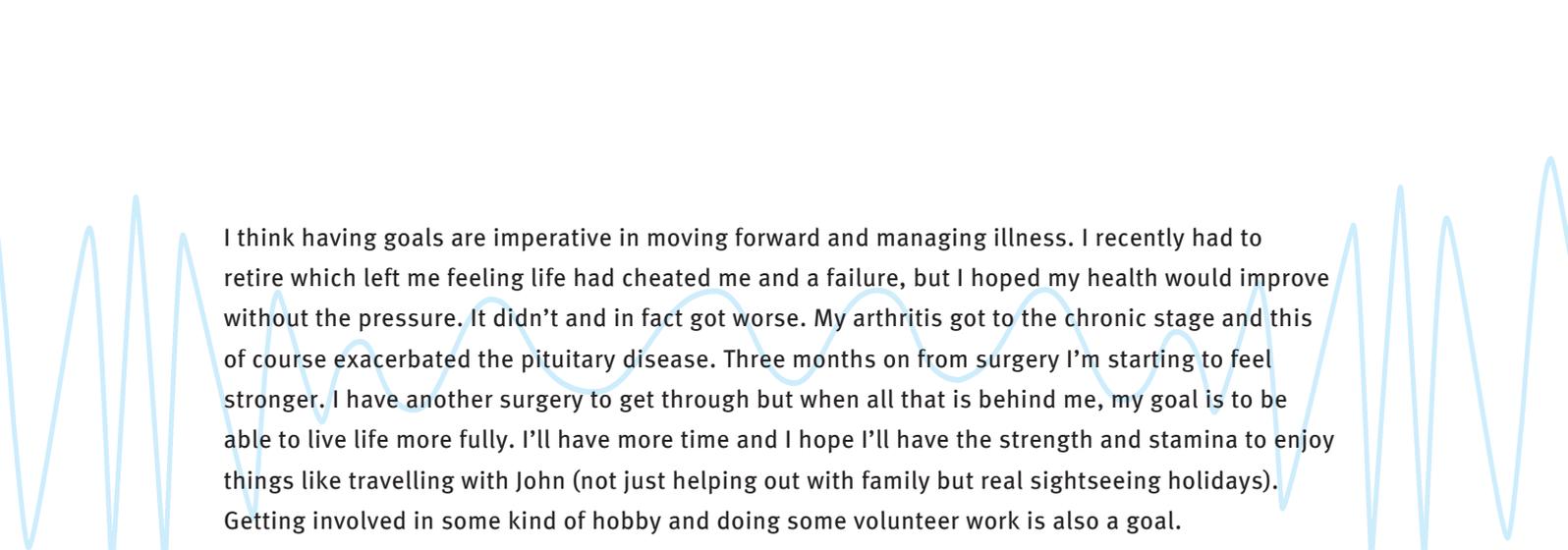
Rather than have specific goals I wish to gradually build inner strength...

Rather than have specific goals I wish to gradually build inner strength and I am very interested in talking with God and developing the spiritual dimension to my life. I don't wish to become too self-absorbed but to pursue being as self reliant and resourceful as possible but not being afraid to ask for help, from those who can help, when needed. I do have one definite goal, which is to learn to relax, believe in myself and go with the flow. As I flow along my life's journey being well enough to work part time is a possible goal. My desire is to enjoy every day as much as possible, the glint of sunshine on a tree leaf is a beautiful sight.

*Di*

Coping from day to day.

*Judyth*



I think having goals are imperative in moving forward and managing illness. I recently had to retire which left me feeling life had cheated me and a failure, but I hoped my health would improve without the pressure. It didn't and in fact got worse. My arthritis got to the chronic stage and this of course exacerbated the pituitary disease. Three months on from surgery I'm starting to feel stronger. I have another surgery to get through but when all that is behind me, my goal is to be able to live life more fully. I'll have more time and I hope I'll have the strength and stamina to enjoy things like travelling with John (not just helping out with family but real sightseeing holidays). Getting involved in some kind of hobby and doing some volunteer work is also a goal.

*Chrispy*

I strive towards having a pain free or fatigue free day. My goals for managing my illness are to not always have the 'up yours attitude', which I seem to have a lot of lately, (lots of laughs)... and also to avoid focussing on my limitations which I find frustrating.

*Michelle*

I try to work around my limitations if I can. Obviously I don't want to go climbing Mt Kilimanjaro, but I'm realistic enough to know that I still can't go out for an afternoon without suffering for two days afterwards. To not let it get to me psychologically I'll use whatever means there is. My smiley collection is a prime example. My family thought it wasn't something a 33 year old woman should do, and I had to get the opinion of a psychologist at the pain clinic to confirm that there is absolutely nothing wrong or unusual about having my collection. I want to try to surround myself with positive people and avoid people that put me down. This is important for the psychological management of illness as is doing things that feed my sense of achievement.

*Iolanda*

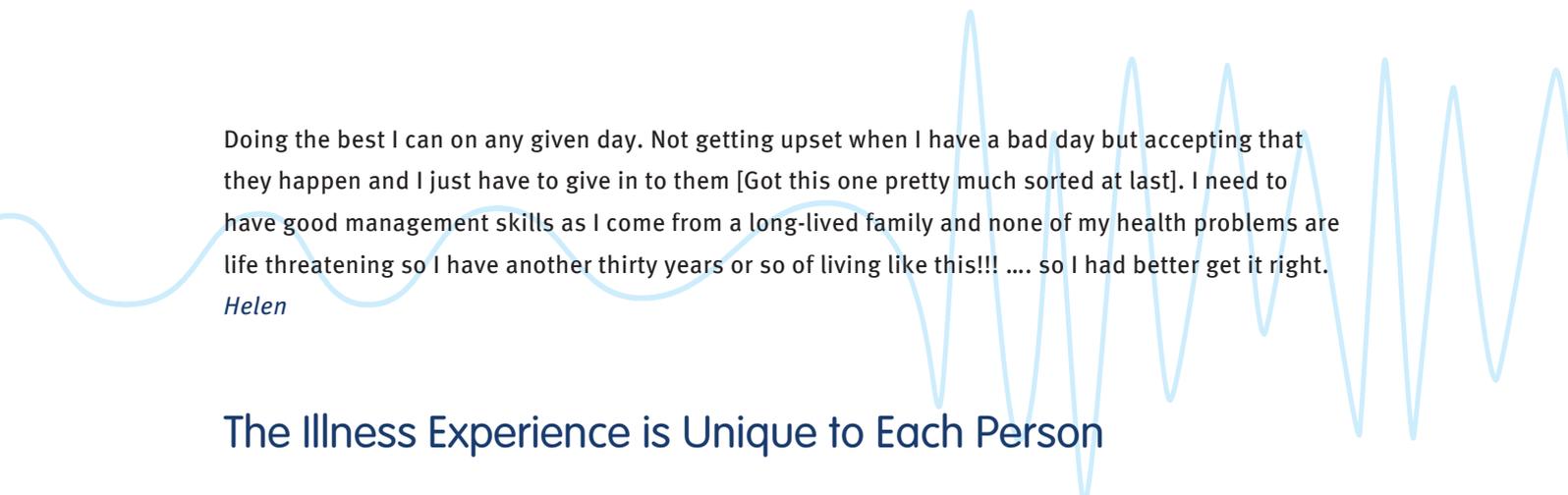
My goals in managing my illness are to cope as best I can using whatever facilities that are available. To tap into the best help, resources, treatments, etc. that I can muster; to try to ensure that all that can be done for my body is being done and then to let go and not worry.

*Ted*

...it is important that the goals are ACHIEVABLE. While it is good to aim for the stars, we can easily get disappointed when we don't reach them - and this can set us back further. Instead of reaching for the stars, reach for the sky. Once you reach the sky, the stars are a step closer. Divide large goals into little ones. A bit like eating an elephant - one bite at a time.

Really I strive to live as much as possible despite the illness. I feel that this illness has placed boundaries on my life that I do not want to have. So my goal is to live life as far as those boundaries will allow me to, and to improve my overall health to push those boundaries back. A few weeks ago I had a period of tiredness and I said to my housemate that I did not want to be tired, that I wanted to go out and do things. My goal is to exercise a lot more, improve my energy levels and my confidence. The other thing is to get by until they find a cure for this. I don't think a cure is too far away, which is my big hope.

*Andrew*



Doing the best I can on any given day. Not getting upset when I have a bad day but accepting that they happen and I just have to give in to them [Got this one pretty much sorted at last]. I need to have good management skills as I come from a long-lived family and none of my health problems are life threatening so I have another thirty years or so of living like this!!! .... so I had better get it right.

*Helen*

## The Illness Experience is Unique to Each Person

People will deal with chronic illness in their own way. The experience, personality and spirit of the person translates to a unique approach to living with illness. People have diverse backgrounds, personal resources and personalities. These unique characteristics influence the individual's attitude toward illness. We might have been raised in families where sickness is seen as weakness and it is hard to depend on others for help when we need it. Past experience may mean we have a rebellious attitude toward our illness, which fosters determination and perseverance. In managing illness we tend to do what is familiar to us. For example, if one is used to reading and researching, then gathering information in order to understand illness better may be what feels important. Maybe a pragmatic, practical approach to illness management is what feels best for some people, especially if this has been their way of approaching life. Other people find that their spiritual faith assists them to negotiate the hurdles and learning opportunities presented by illness.

The illness experience is rich soil for learning about ourselves and our life. We each find within ourselves our own way of putting life back together again following a diagnosis of illness. This will be the way that makes sense to us and is meaningful in the wider context of our life. It is likely to change as we move through different experiences of the illness, of our bodies, and with regard to relationships with others. All of these changes are reasonable. There is no right or wrong way to respond to illness. Lets look at how our backgrounds, experience and personalities have influenced the way we manage illness.

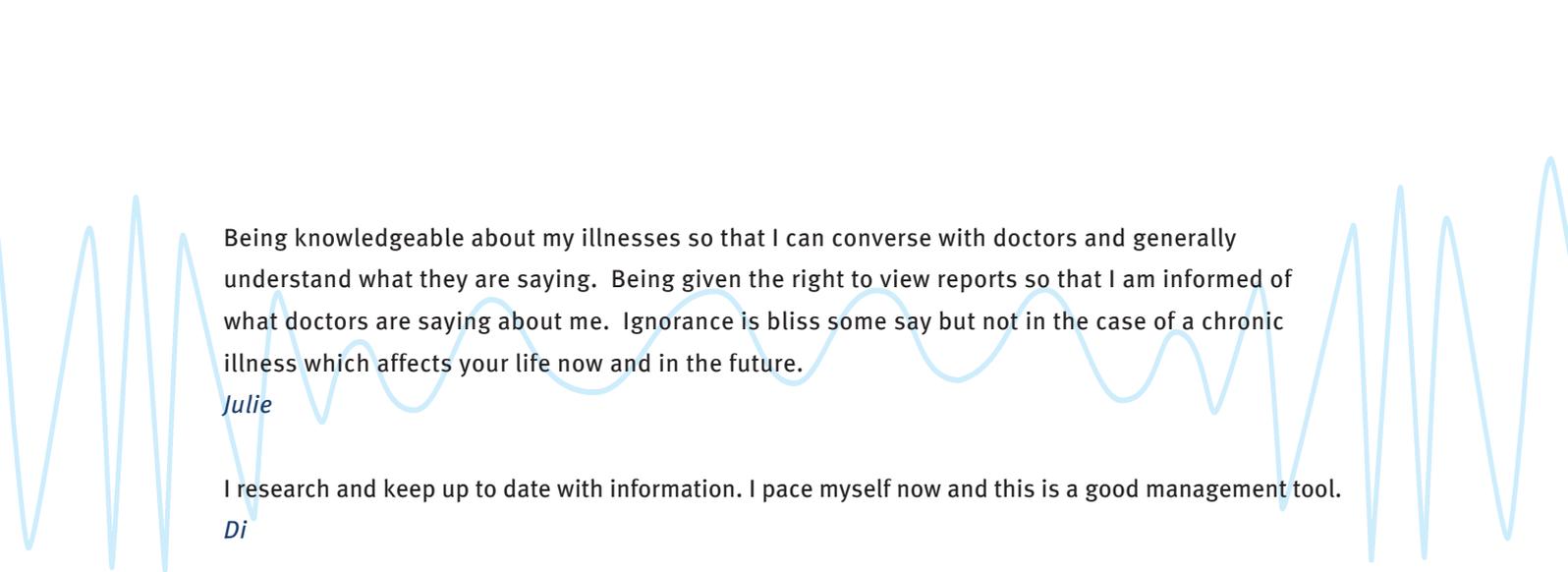
### ***What is it about you that has determined how you have managed illness?***

Intelligence to be able to research my problems and methods of managing it. Character strength (or is that plain stubbornness) to get out of bed every morning and achieve something for the day.

*Graham*

I suppose I'm very stubborn, and my family background is such that it is weak to give in to illness. When I first needed glasses for distance vision, for instance, my mother kept discouraging me from wearing them, saying my eyes would be stronger if I tried to do without them. That sort of upbringing is hard to reconcile with chronic illness, particularly things as vague as fatigue.

*Brumby*



Being knowledgeable about my illnesses so that I can converse with doctors and generally understand what they are saying. Being given the right to view reports so that I am informed of what doctors are saying about me. Ignorance is bliss some say but not in the case of a chronic illness which affects your life now and in the future.

*Julie*

I research and keep up to date with information. I pace myself now and this is a good management tool.

*Di*

That I have accepted the seriousness of my conditions, I am realistic of my care plan and I always am truthful with my family, who care for me

*Judyth*

In some ways I'm dependant (e.g.. I happily let my husband manage all the money side of things) but in other ways I'm fiercely independent and insist on doing things for myself. I found the physical limitations that the hip replacement put on me very difficult and hated being dependant. Fighting to be independent does help me cope with my illnesses. Although illness brings me down at times, I think determination that it isn't going to beat me has played a part in managing it too.

*Chrispy*

I'm stubborn!!! Therefore I don't/won't/like to give in.

*Michelle*

It's important to know that 'how you manage illness' and 'something about yourself' can be very much dependent on such things as the type of illness that you have (the most obvious example being whether it is life-threatening) and the years since diagnosis. In some ways I am a COMPLETELY DIFFERENT person than I was when I was facing cancer. I've faced the school of hard knocks and have some 'scars' to prove it. I'm a hard-worker and switched-on and this is probably how I've approached my illnesses. What I mean by this is I'm aware of things in my environment and me and try to steer them in the right direction. For example, I'm part of a few online medical communities that help me feel like I am 'looking after myself'. I am well aware of my psychological state at any given time and refuse to give in to anything but temporary flare-ups.

*Iolanda*

Within myself I try to be optimistic, live like a 'survivor', be willing to accept help, try not to inflict the negatives of my illness on others, try to dampen my 'task oriented' nature.

*Ted*



#### MY BITS

A selection of the things I have to keep at home for looking after my diabetes. As well as all of the things I carry with me, I have my insulin supply (which takes up a whole compartment of the fridge), new needles (which I get 600 at a time), safe storage for the old needles, supplies of test strips, lancets, tissues and jelly beans (which I always carry around in my pocket).

– Andrew

I know that I am able to think things through. By learning about my illness, how it affects my body and the medications I am on I am able to understand more what is happening. From this I am usually able to work out what has gone wrong, and what I need to readjust to bring things back to some form of normalcy. Understanding helps management - and confidence.

*Andrew*

My faith. I am also stubborn and tend to think ‘I’ll show them’ which means that I will fight to get as well as possible. I also like to learn as much as possible and tend to question my doctors etc. when I feel it is necessary.

*Helen*

## Let’s be Proud!

Illness changes our sense of self and identity. Who are we with illness? So much in life has changed that we need to reclaim our lives. Living in a society that places value on achievement and self-reliance can make us feel as if we don’t measure up. We can easily feel bad about ourselves in this context. This is despite the fact that we are confronting and conquering challenges that would seem overwhelming to any human being. There is much to be proud of in people’s stories about coping with long term illness. As people living with illness, we may place high expectations on ourselves in terms of successfully managing symptoms that are sometimes unmanageable, of maintaining independence in the face of a failing body, and of ensuring that we make a worthwhile contribution to families and friends. We try our hardest to fit with the norms of the wider society even at a cost to ourselves. We may not have access to some of the means of attracting accolades in this society, such as sporting achievements, etc... but we are champions of a different kind in that we face adversity and make the best we can of it. Let’s be proud of our achievements in managing illness and our strength in living the best life we can. We can see from the following responses that some of us find it hard to say they are proud, despite overcoming huge challenges.

## ***What are you proud of about the way you have managed illness?***

I put this one in the too hard basket as I cannot say what I have to be proud of in managing illness.

*Graham*

Learning to stand up for myself, not being scared of being ridiculed. Achieving goals because I have learned to pace myself which is the only way you can live a good life and still do the things you want.

*Julie*

I'm not sure that I am proud of myself yet. I am always very hard on myself and expect a lot from myself.

*Di*

I'm proud that I have survived two usually fatal illnesses, that I am still able to work, have a child despite the odds and am able to contribute a bit to the running of the household/family life. I'm also proud of my writing, which is a large part of my identity.

*Brumby*

That I am still alive this far down the track, considering all the things that have happened to me and how many times another problem arises, like when the insulin stopped working. I have worked around ceasing to use it, with the support of my health professionals.

*Judyth*

I don't know about proud but perhaps a feeling of satisfaction is the word I'd choose. As illness progressively limited me, I made sure I was always there for the kids in other ways. I helped and encouraged my dyslexic son to cope with his disabilities by working with him every day after school. I encouraged the kids to always communicate and talk through their problems. They are all adults now and I still enjoy a close relationship with them and the grandchildren. I took a special interest in many of the deaf and special education children I worked with. A couple of them still keep in touch and one deaf boy drops in to see me from time to time even now he's a grown man with a child of his own. The limitations posed by illness don't have to limit many of the things in life that really matter.

*Chrispy*

I am proud of the fact that even though I have this horrid illness I can still homeschool my children and do my painting and gardening. I still lead a relatively active life.

*Michelle*

I don't know if you could say proud ... it sounds pretty foreign to me to say to myself I'm proud of... but you could say that others have congratulated me on the way that I've handled it all ... that others would have taken it a lot worse and would have been on anti-depressants at a minimum, but have done less for themselves over the years.

*Iolanda*

If anything, my persistence in seeking help and following through on likely leads. I feel that most of the helpful things in my life have been God's goodness and grace towards me (Or, if you prefer, good luck, kind fate, good fortune, people's kindness and care.)

*Ted*

I think I do OK. I am never completely happy with the results of my blood tests. I always feel that I could be doing better but it is difficult as side effects from diabetes can take 5,10 or15 years to occur. This is frequently on my mind Am I doing well enough to avoid these problems? Hopefully a cure is not that far away.

*Andrew*

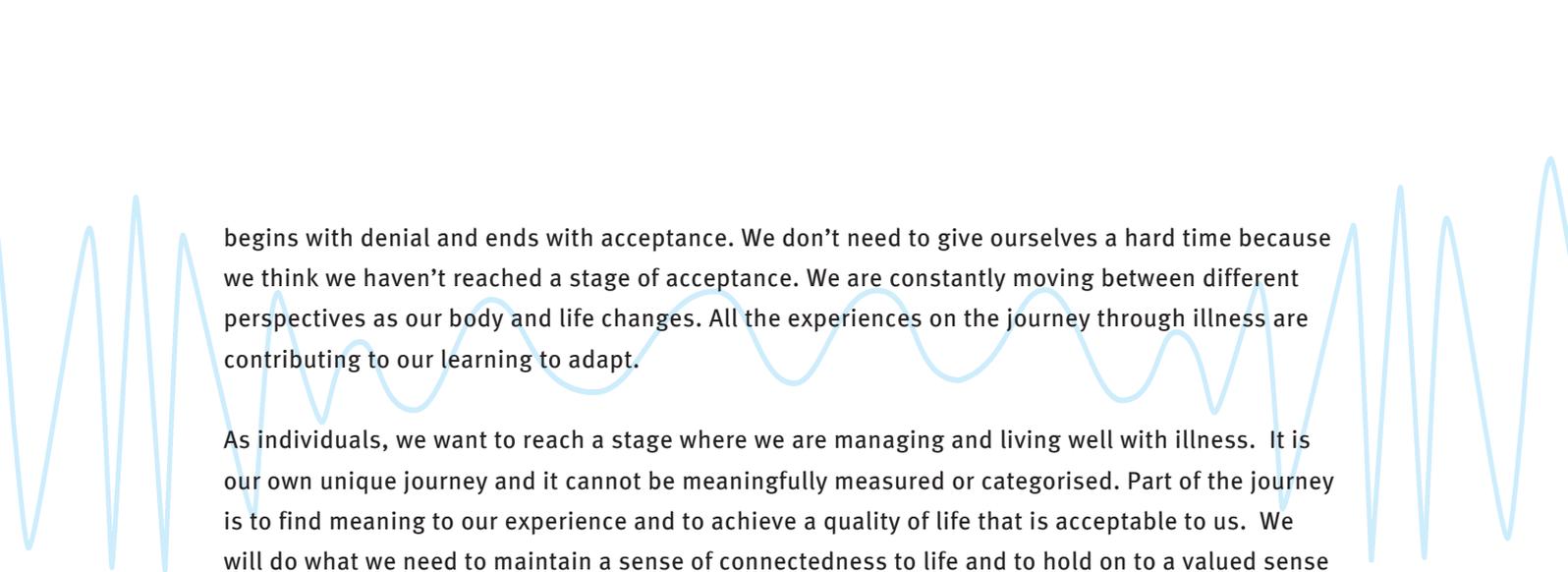
Not sure if proud is the word but I am pleased that I don't panic or get upset when I have a bad day or week. I know it is part of my pattern and it will pass in time. I know also that it is easier to give in to it, if circumstances allow. Pleased that I am able to quilt and that the recipients of my quilts are pleased to receive them. This is very important to me as it is something that no one else in my family can do. I am also pleased that I have been able to help my husband and kids from time to time. It amazes me that I have been able to do these things and I find it is important to remember these things on bad days.

*Helen*

## Acceptance and Denial

Health care professionals often refer to the words 'acceptance' and 'denial' to describe the way people are adjusting to living with illness. These words have different meanings for different people and little relevance for others. The experience of illness indicates that acceptance and denial are not stages we reach and are finished with. We move toward and away from these states as we live with illness. The experience of illness is complex and cannot be fitted into neat categories such as 'acceptance' and 'denial'.

The way a person responds to illness varies and changes, goes back and forth between different emotions and is ongoing, rather than having a definite end stage such as acceptance. Some people have described the changing nature of the illness experience as a 'cycle' where one is often revisiting emotions and learning. It is also explained as moving back and forth on a continuum of emotions and perspectives. Adjustment to illness does not appear to be a linear process that



begins with denial and ends with acceptance. We don't need to give ourselves a hard time because we think we haven't reached a stage of acceptance. We are constantly moving between different perspectives as our body and life changes. All the experiences on the journey through illness are contributing to our learning to adapt.

As individuals, we want to reach a stage where we are managing and living well with illness. It is our own unique journey and it cannot be meaningfully measured or categorised. Part of the journey is to find meaning to our experience and to achieve a quality of life that is acceptable to us. We will do what we need to maintain a sense of connectedness to life and to hold on to a valued sense of who we are. Behaviours that others might equate as 'acceptance' or 'denial' might be what we need to do in order to achieve this. We are constantly moving in and out of behaviours which may look like 'acceptance' and 'denial' but are actually other understandable reactions such as frustration, resistance, rebelliousness, contentment, hope, optimism etc. Rather than indications of whether we are coping well or not, these behaviours are responses that any human being might demonstrate when confronted with the complex process of adjusting to living with a chronic illness. Our varying levels of comfort with these labels are evident in our responses.

### ***What do the words 'acceptance' and 'denial' mean to you?***

One of the things about acceptance and adaptation to be careful of is resignation...unless you get frustrated and stressed as new hurdles are put in your way you can fall into the trap of not caring or resigning to your situation.

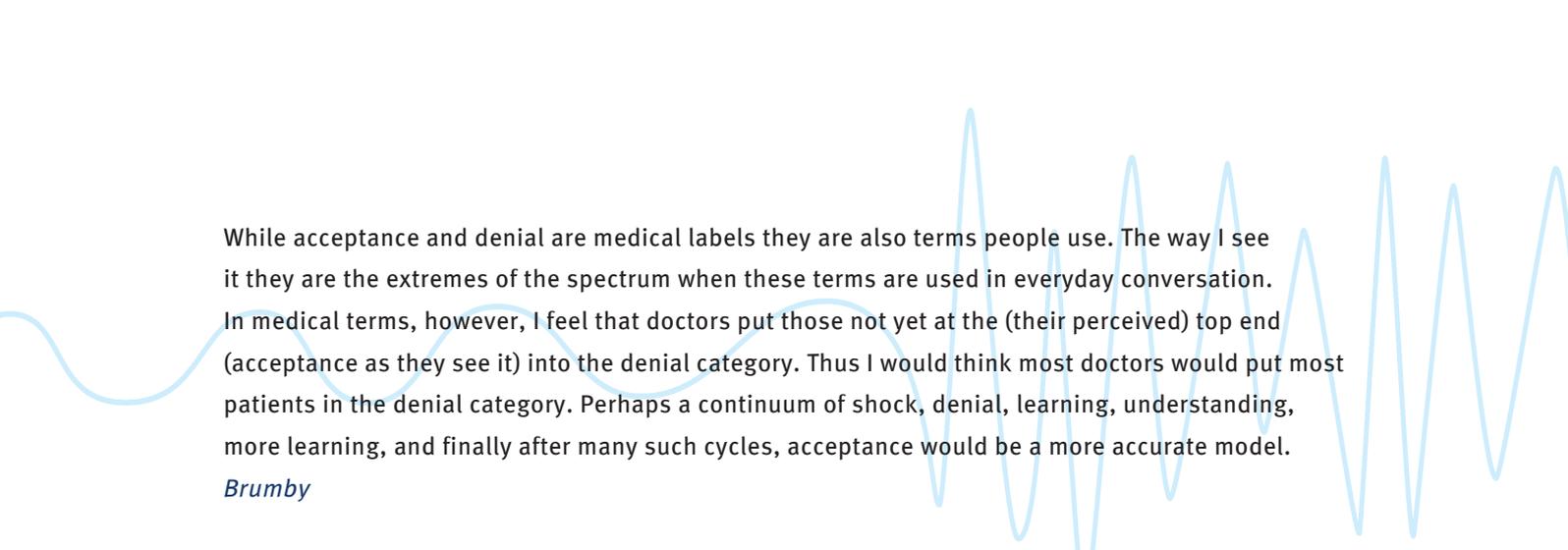
*Graham*

Acceptance and Denial are medical jargon that is bandied about quite a lot. I think we should just use the words that are real and the truth, like shock, or disbelief and don't use any jargon words about it. The real issue is that there are many stages and one who is chronically ill slips back and forth through the stages. Does anyone ever wholly adapt? I may have accepted my own illness to a degree, in that I know I am probably stuck with it for a long time, if not for the rest of my life, but I don't think that I could say that I accept all of the details all of the time. There are times when I kid myself that I can get away with an activity that is beyond me and times when I'm pretty realistic. On the whole, I do try to stay closer to acceptance, but as a fallible human being, I don't always manage it.

*Di*

Some people will deny that they have a problem, and either refuse to go to get a medical diagnosis or ignore it/deny it after the diagnosis. They have not psychologically accepted the possibility or the reality. Acceptance however is multifaceted. Some people will accept a diagnosis yet look actively for ways to help themselves. The remaining accept a diagnosis and just try to 'put up with things' as they are without trying to help themselves with research or without being proactive in their treatment. To a large degree the way you deal with illness is governed by things like what generation you come from, your sex, your multicultural background.

*Iolanda*



While acceptance and denial are medical labels they are also terms people use. The way I see it they are the extremes of the spectrum when these terms are used in everyday conversation. In medical terms, however, I feel that doctors put those not yet at the (their perceived) top end (acceptance as they see it) into the denial category. Thus I would think most doctors would put most patients in the denial category. Perhaps a continuum of shock, denial, learning, understanding, more learning, and finally after many such cycles, acceptance would be a more accurate model.

*Brumby*

Acceptance has an entity/life, that is closely connected to my experience at the time, over time my entity of acceptance accumulates 'a knowing' from every experience it survives and that knowing is connected to hope, courage and a resilience.

*Olympia*

This is such a hard question. I don't truly believe in using the word acceptance as sometimes you can "accept" your illness and the limitations that it imposes and other times you can't. It's really hard to explain. It could almost be the same with denial. Some days when I'm in a bit of a mood I act like I'm not sick and just go gungho at whatever tasks I feel like. I then pay for it later when I then have to face facts and admit (not accept) that I do have limitations.

*Michelle*

I didn't go into a real state of denial with my illnesses. This is probably because they came on very gradually over a long period of time. When the symptoms got really bad and debilitating I think I was in a state of shock rather than denial, wondering whether I was ever going to feel any better. At one stage I really thought I was going to die. Finally getting a diagnosis did help. Though Hypopituitarism can only be managed at best, at least I was able to start treatment to improve the way I was feeling. The arthritis in my hip did progress much faster though. If I did have a stage of denial it didn't last long, as the severe pain would make denying it rather futile. I think I have accepted the conditions I have reasonably well. Without acceptance at least to some degree, I don't think I would be able to keep progressing and managing my symptoms as well as I might. Of course acceptance isn't something which suddenly happens one day and all is well. Just when I think I've accepted something reasonably well, I'll have an adrenal crash or some other problem, only to find I'm not accepting my lot so well after all. Then gradually I push forward again. I think acceptance is more a one step forward, two steps backwards kind of thing. It happens gradually but we still have to deal with all the little setbacks that life dumps on us.

*Chrispy*

To me a 'acceptance' means receiving what is given to me. With illness it means taking into my thinking (and hopefully into my understanding) the reality (i.e. what the inconvertible facts are) of my illness including the everyday effects and the long and short term prognoses. Denial' seems to me to be the opposite attitude i.e. refusing to accept the reality of part or all of my illness situation. It might involve accepting what is the present reality but refusing to accept some or all of the prognoses.

*Ted*



Each day brings new challenges both physically and emotionally to which I have to adapt.

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In some ways, we deny ourselves some of the things we used to do because we lack the confidence in our ability to adapt to our new circumstances. Somebody said to me once that you can do everything you used to be able to do before diabetes. I think it is pretty close to the truth, but it can take a lot more effort to do so. Acceptance to me is to realise that our lives have changed. While it may be possible to do everything we used to be able to do, it may be much harder and no longer 'worth the effort'. Acceptance is about letting go of these old activities and plans and GOING OUT AND FINDING NEW ONES – new activities, new interests, new groups of people and a new way of living. Our lives are not over, just changing direction.

*Andrew*

Acceptance has to be a dynamic, not a static process. Each day brings new challenges both physically and emotionally to which I have to adapt. The process of aging adds new burdens to my body; quite trivial events remind me of things I used to be able to do and would love to repeat. I have carefully built a structure in which I can function reasonably well, but outside circumstances and outside pressures can upset it. The tension between acceptance and denial is always there.

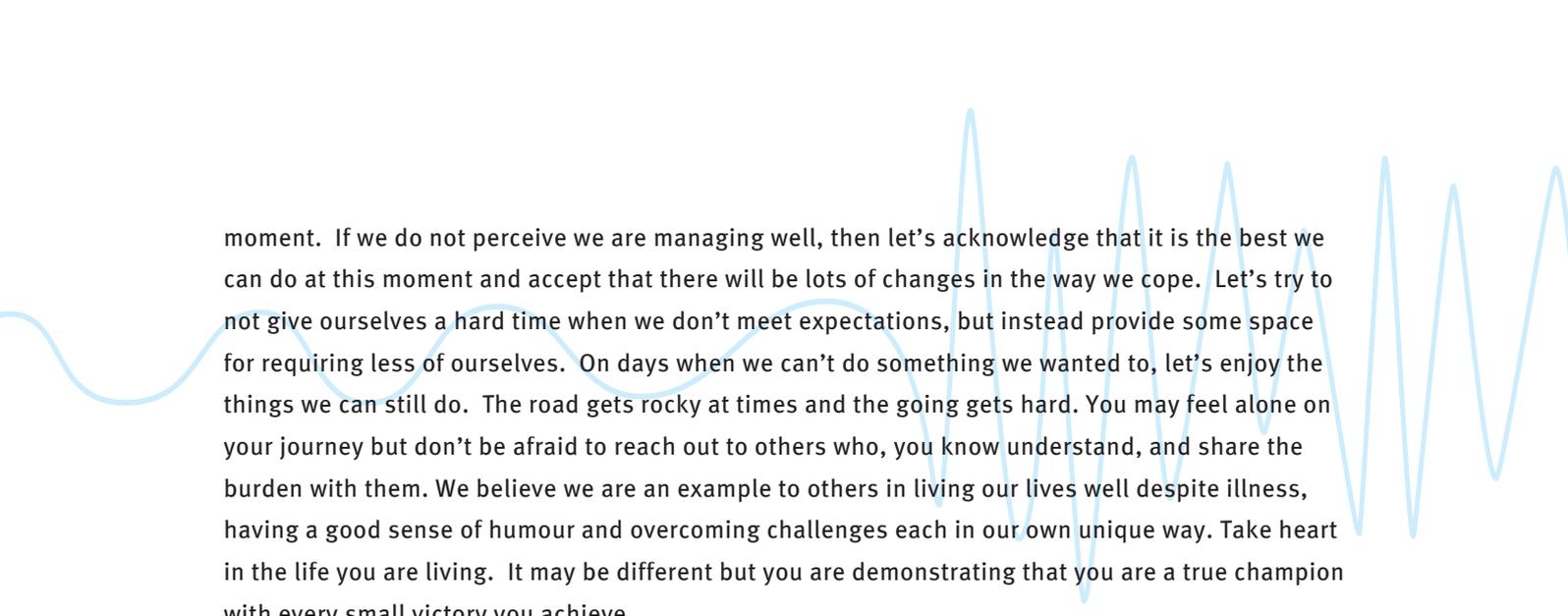
*Helen*

Adapt was the word I think I suggested instead of acceptance or we could use the word adjustment. These words are better than acceptance. I feel as if acceptance means that we are forever trying to accept the illnesses we have and their effect on our daily lives. It creeps into our daily lives all the time...well it does for me even though I accepted what I have from the beginning. I know that I am always trying to accept that I will never be 'normal' again.

*Julie*

## Our message to others with illness...

As people adjusting to life with long term illness, we are faced with overwhelming challenges. We need to be gentle with ourselves as we experience the journey. The attitude toward oneself is important in the meaning we make of what is happening, and how we negotiate the hurdles that illness presents. Let's choose to value ourselves and be proud that we are managing illness each



moment. If we do not perceive we are managing well, then let's acknowledge that it is the best we can do at this moment and accept that there will be lots of changes in the way we cope. Let's try to not give ourselves a hard time when we don't meet expectations, but instead provide some space for requiring less of ourselves. On days when we can't do something we wanted to, let's enjoy the things we can still do. The road gets rocky at times and the going gets hard. You may feel alone on your journey but don't be afraid to reach out to others who, you know understand, and share the burden with them. We believe we are an example to others in living our lives well despite illness, having a good sense of humour and overcoming challenges each in our own unique way. Take heart in the life you are living. It may be different but you are demonstrating that you are a true champion with every small victory you achieve.

## Our message to health workers...

The process of learning to manage illness can be overwhelming and learning to adjust to change takes time. Learning is about trial and error. Transition occurs in the course of every attempt at change. Transition is the state that change puts people into. The *change* is external (the impact of chronic illness might mean changed diet, changed relationships, change to employment), while *transition* is internal (a reorientation that people go through before the change can work). Some health workers imagine that transition is an automatic process for people... that it occurs simply because the change is happening. But it doesn't, it is a process that people have to work through. Transition happens much more slowly than change.

When learning ways to adapt to illness, we will make mistakes. We aim to learn from that experience. Give us the space to do that. When people are living with illness, it is not a process of automatic adjustment... we need time and we need you to walk with us with understanding and compassion, rather than instruct us. You only have a small glimpse of our lives, so don't assume that you know all the answers. By truly listening to our story of the way we experience illness you will convey to us that you are interested and wanting to work on issues in a way which includes our perspective. Suggestions, compassion and gentle questioning can sometimes help us to find our own answers.

Make sure that steps are taken to help people respectfully let go of the past. These may include offering information, and understanding and acceptance of the symptoms of grieving. As health workers, you can help people move through endings by emphasising connection and concern. Conversations with focus can help us to find a path that leads towards transition. These conversations need to explore the reasons for letting go of old ways of being and doing, provide a vision of a different but positive future, set out a plan of how the journey to that future might be travelled and offer what support you can provide along the way.

## About us

We are men and women who live with chronic illness. Our ages, sexuality, backgrounds and economic situations are diverse and these all impact on the way we experience illness. We are participants in an Australian research project that connects people living with long term illness through the Internet. Talking with each other on the Internet facilitates an opportunity to discuss issues related to our experience. We came together through being involved in a research project. Over time we have got to know each other through our email conversations. We feel strongly connected to a network of caring and support that carries us through the hard times and enables us to celebrate each other's good times. Knowing that we can always tap into understanding and support of others who live with chronic conditions is important in our approach to making sense of, and managing, illness.

There has been a lot of discussion about chronic illness self-management promoted by health care professionals. Yet it has been estimated that between 95 percent and 99 percent of chronic illness care is given by the person who has the illness. In other words, we look after ourselves. On a day-to-day basis, we are in charge of our own health, and the daily decisions we make impact upon our quality of life.

We all have something in common: we live with a chronic illness. A chronic illness is one that persists over time without an easily definable beginning, middle and end. While the symptoms that accompany a chronic illness can usually be alleviated to some extent, the illness itself is not curable. What we share is that illness was an unexpected intrusion into our lives.

Living with chronic illness brings many life issues to the fore. One of the primary experiences for us has been the realisation that our lives have changed, often permanently. Illness has disrupted our future plans. It has troubled our partners, family and friends when they realise the way in which illness has intruded on our collective lives. However, we are learning to deal with the many changes that the illness has brought to our lives.

Over time we have come to realise that although there are differences among us, there are experiences in common too. Some of these experiences such as pain or isolation have made us feel alone in the past. We have learnt the value of hearing the ideas and perspectives of other people in similar situations so we have worked together to develop this series of ten booklets. Not all of the people in this project have been able to contribute to the booklets. Rather, a group of eleven people have been consistently involved.

## About the booklets

We decided to share our experiences in a series of ten booklets. The purpose of these booklets is to share some of our conversations about many interesting and difficult aspects of living with illness. Our conversations have been a safe place where we can seek understanding and support as we tackle the issues that confront us physically, emotionally, socially and spiritually. We are supporting each other by sharing information, emotional comfort and friendship. In these booklets we share our discussions.

The booklets are set out in question and answer format and are intended to connect you with our voices about our experience of living with long term illness. There are no right or wrong answers to these questions. Our answers reflect our current thinking and understanding about what it means to live with long term illness. Maybe you will find some experiences and ideas that are familiar to you or have meaning in the context of your life. We acknowledge that challenges are part of life and fall within the experience of all human beings. Given this, our experiences may also be helpful to other people living without illness.

## About the research inquiry

A three year research grant (2003-2006) from the Australian Research Council (ARC) was awarded to our research team. This was a collaborative project between The University of South Australia and The Research Unit, Royal District Nursing Service. The investigators are Professor Tina Koch, Dr Debbie Kralik and Dr Kay Price. Project Management Members are Kerry Telford, Professor Jim Warren, Gino Pignone and Natalie Howard.

## What are we researching?

The main thrust of the research program has been to understand the ways that people make transitions or learn to live well with chronic illness. We are interested in ways that people can learn to incorporate the consequences of chronic illness into their lives and move on. How people learn to move on or make transitions is important to understand, and so this project aims to describe this transition.

