

Transition in Chronic Illness

Shifts in Self and Identity



BOOKLET 3

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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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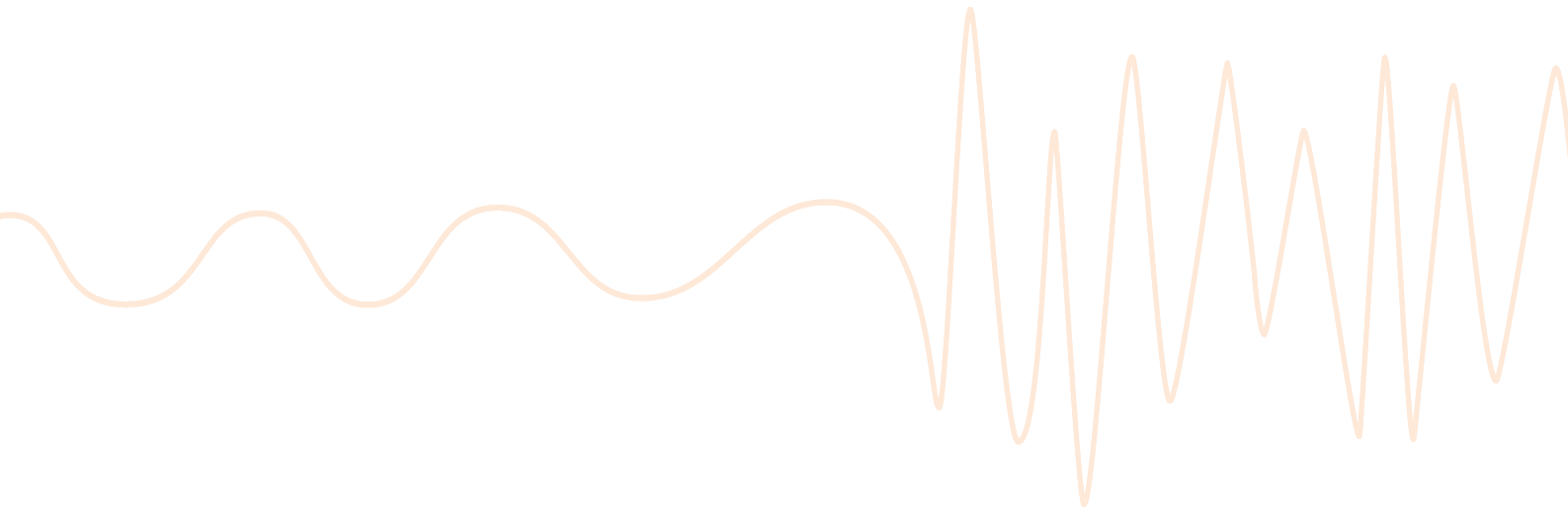
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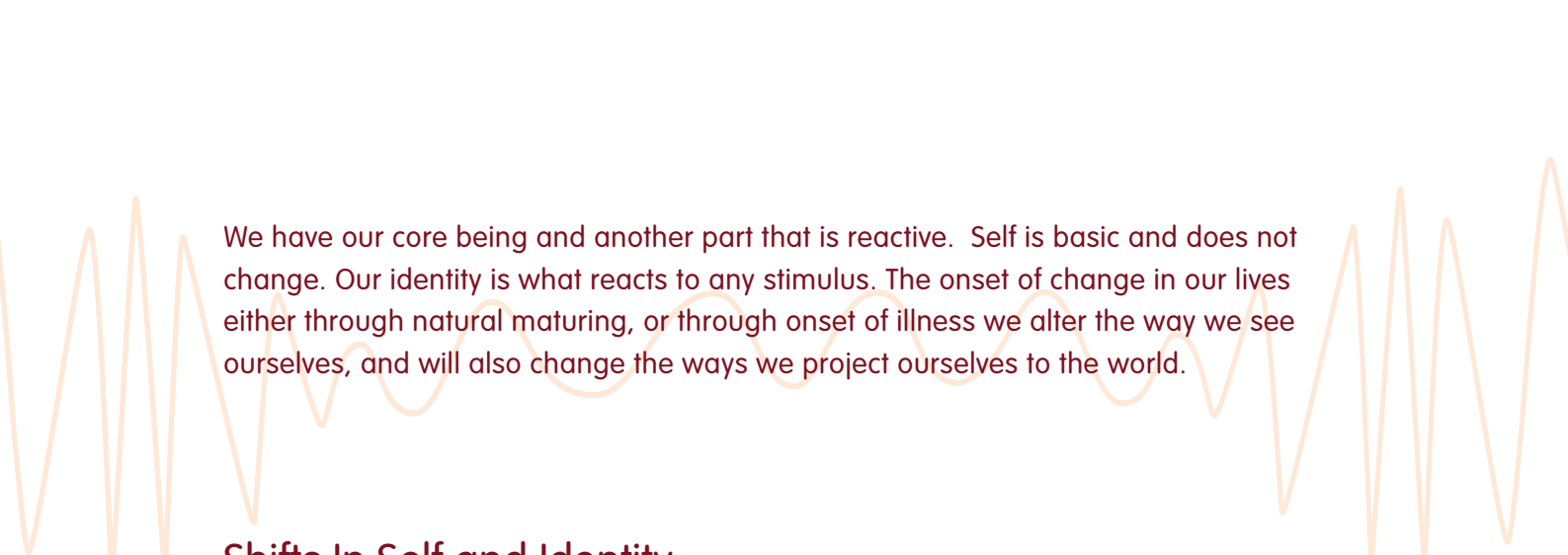
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We have our core being and another part that is reactive. Self is basic and does not change. Our identity is what reacts to any stimulus. The onset of change in our lives either through natural maturing, or through onset of illness we alter the way we see ourselves, and will also change the ways we project ourselves to the world.

Shifts In Self and Identity

The concepts of self and identity are quite difficult to put into words but they seem to be central to the experience of living with illness. As an introduction, we have tried to express our ideas about what self and identity mean to us. According to our perceptions, self and identity are linked but are not the same. Self is considered to be who we are in terms of personality, character, mind and soul. Self is experienced as a core inner presence. To some extent it is constant, but some aspects may also be changeable, according to our situation. Others may or may not have an awareness of the self. We can present our self to others in ways that disguise it, according to what we want others to know or think about us. Sometimes there is a difference between what we present to the world and how we perceive ourselves. This can be experienced as pressure between inner feelings and the image we portray. The image that we present to others partly informs their judgements and attitudes toward us.

Our identity is developed and maintained through the social relationships we have with others. The way others perceive us is our identity. It is our public image. We are sensitive to the stereotypes others have about people with illness or disability and we may act to present a different image. Not disclosing information about illness or disability may be one way of doing this. The reactions of others can impact on our sense of self and identity so it is understandable that we would act to present an image of ourselves which fits with community values as far as possible. We all want and deserve to be seen and treated as valued human beings.

What do you understand by the terms self and identity?

Self: I see this as our basic inner being or personal character traits. This can never be changed as you are who you are. This could be your personality (happy, sad, carefree, inhibited, extroverted etc). It is possible to mask this, which brings up the concept of identity. I would guess that the majority of people have no idea of what the true self is, as they have never had to face major obstacles as we do when faced with serious illness.

Identity: This is the public face we show to the world and is an important part of that interaction. It is possible to repress, expand or override your 'self' by portraying what you want the world to see. We can even convince ourselves that this identity is who we truly are which could be a reason for the difference between how you see yourself and how others see you.

Graham

I suppose self is more about personality, mind and soul - the essence of oneself. The 'you' that only some people get to know, recognise and relate to with rapport, dislike or attraction etc. Identity seems to be more about the surface attributes, like name, body language, size and shape and what you as an identity have done or are known for.

Di

For me, the self is me, the person you are hearing is me. This person has always been me from when I was a five year old girl to the Julie of current age. The Julie that was five hadn't been through all the experiences that this Julie has been through yet it is that same person. My identity though as a five year old girl is quite different to the identity of this current person because of all the life experiences. These life experiences are facts, because they happened. However the person is still the same even though this person may have experienced more pain and happiness than the Julie of five years old.

The things that make up your identity such as being knocked back for a job or being fired, being told you have a certain illness, the loss of your child etc., are only events. These events tend to mould who we are however they don't necessarily change our emotions and inner feelings. The self during the period of loss of a child feels great grief. The identity then becomes a mother who has lost a child. So therefore if I can recognise that I am a mother who has lost a child, I understand my identity. But I also understand myself and the intense pain I went through at that moment and to a lessening degree later on is a part of myself. I do feel that there is a big difference in identity and self.

Julie

Self is four-dimensional - it's in our being. It's not only what we are and who we are but also our essence. Identity is what people see and hear of us. It might even be what we CHOOSE others to see and hear. For example, I followed the euthanasia debate for a while before I ever told anybody. This may or may not have changed what people thought of me; my identity, but until I told them they were none the wiser. There is also a more profound difference between self and identity - self is something we personally see and feel every day and it dies with us. Identity however lives on in those who knew us during our lifetime, even if it's decades after we die.

Iolanda

In the past I have tended not to think of these two concepts as separate, but rather as one total objective account of the true, complete inmost 'me' as viewed by some objective external being (like God in heaven). Self and identity describe me fully and accurately in an objective framework outside of any subjective view that I have of my 'self'. I realise such an objective account will undoubtedly not be the view that others (and I myself) will have of me given that I am continually putting on a mask which I hope will allow me to be seen in some other light which suits my need as the occasion

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arises. So I do really have to consider a parallel subjective view of my self and identity which centres mainly on how I understand and feel about me. Maybe this framework would include positive and negative aspects describing: happiness, satisfaction (with me and with my life), confidence, abilities/talents, social skills, fullness (or otherwise) of mental and physical health, ethical beliefs and behaviour, how I think I 'come across' to others, personality, spirituality, coping skills etc.

Ted

Self: My sense of self is that I am a fun loving person. I like to have fun and I like making the people around me laugh or have fun as well. I am a good hostess and a good cook. I'm a good Mum, wife, friend and confidante. I'm loving, kind and friendly. I love my family and my friends and am always willing to help them out when they are down. I can't help physically anymore but have found that I can help counsel friends in time of need and they have all told me that they love that about me. They have said that I am non-judgemental and they can talk to me about anything and everything.

Identity: The image that I used to have of myself is of someone with endless energy. I used to be able to work tirelessly for long periods of time. If anyone ever needed help with anything then I was the one that was always there to help or assist. Once my illness came along and the fatigue set in I was no longer the one that could be relied upon to help out. I was now the one that had to rely upon everyone else. I also used to see myself as the fun Mum. The Mum that used to take my kids on big long constitutionals (walks) and discuss the soil and how plants grow and lie on the grass and find pictures in the clouds. I can no longer do simple things like that anymore either. I felt and still feel that I am letting everyone around me down because I can no longer do these things. My sense of identity is now of someone who is no longer useful.

Chrispy

Experience Informs Self and Identity

A diagnosis of long-term illness sets off many changes in the way life and self is experienced. As we cope with a changing body, abilities and shifts in wellbeing, many of the things we took for granted may present as challenges. Our familiar body and/or mind may become unreliable. In our desire to live a familiar life, we attempt to minimise or downplay the effect of these changes. Inevitably, we are met with the reality that familiar life has changed. The experience of coming to terms with illness consequences, such as inability to work, mobility restrictions, less ability to participate socially, loss of a lifestyle etc. can leave us with lots of time and gaps in our life. The contrast between our situation and that of others who are carrying on with life is stark and painful. It can leave us feeling disconnected from society and withdrawn from others.

When we can no longer participate in community activities, visitors must come to us. Such visits require extra time and commitment on the part of the visitor, and past reciprocity becomes altered and we may feel left behind. The inattentiveness of former friends and relatives sometimes shocks us. We can become intensely sensitive to the reactions of others, scanning conversations or

situations for signs that may indicate our feelings and fears. These experiences all influence an ongoing dynamic process of creating and recreating images of our self and identity. It can be easy for people with illness to drift into isolation, unintentionally. Time, energy or concentration needed to sustain relationships may no longer be available. Here we talk about some of our experiences that have led to changes in sense of self and identity.

What are some of the experiences that have changed your sense of self and identity?

I do not appear ill to others just by them looking at me, so the questions, looks and comments made by others in which I can see the disbelief has had a large effect on me. It has made me turn more inwards than I was before and feel even less the need for contact with anybody, or should I say less contact than I am able to cope with.

I forget things very easily like being given a few things to do, I can forget anything after the first item. My memory of things can be wrong as I can clearly remember something I did, that I never did. This can be a simple thing like I remembered telling my wife something one day and later wondered why she never responded to it. She told me I had never spoken to her about it. These things change the confidence I have in myself. Visits to doctors have made me feel weak and inadequate in not being able to live a normal working life.

Michelle

The main thing that has changed my sense of self and identity is getting sick, the uncertainty of my illness and all the related conditions that come with it. When I am in the throes of a flare up I feel useless and inadequate. I start to doubt my abilities, and myself and feel low in my spirits.

Graham



My illness doesn't show like a broken leg, so when others listen and look at me with a sense of disbelief, their thoughts that I am exaggerating or that I 'should get over it' was an ongoing irritation. I have changed and no longer let this irritate me or erode my sense of self as a decent 'good as anybody else' human being. In fact, they can 'get over it' - who are they to judge?

Di

Struggling with limitations. The most confronting have been during acute phases of illness. They are the instances one can pinpoint, but the lasting changes have been the more gradual ones. Like learning to say no when I don't feel up to doing things and realising people will not suddenly change how they see me because of it.

Brumby

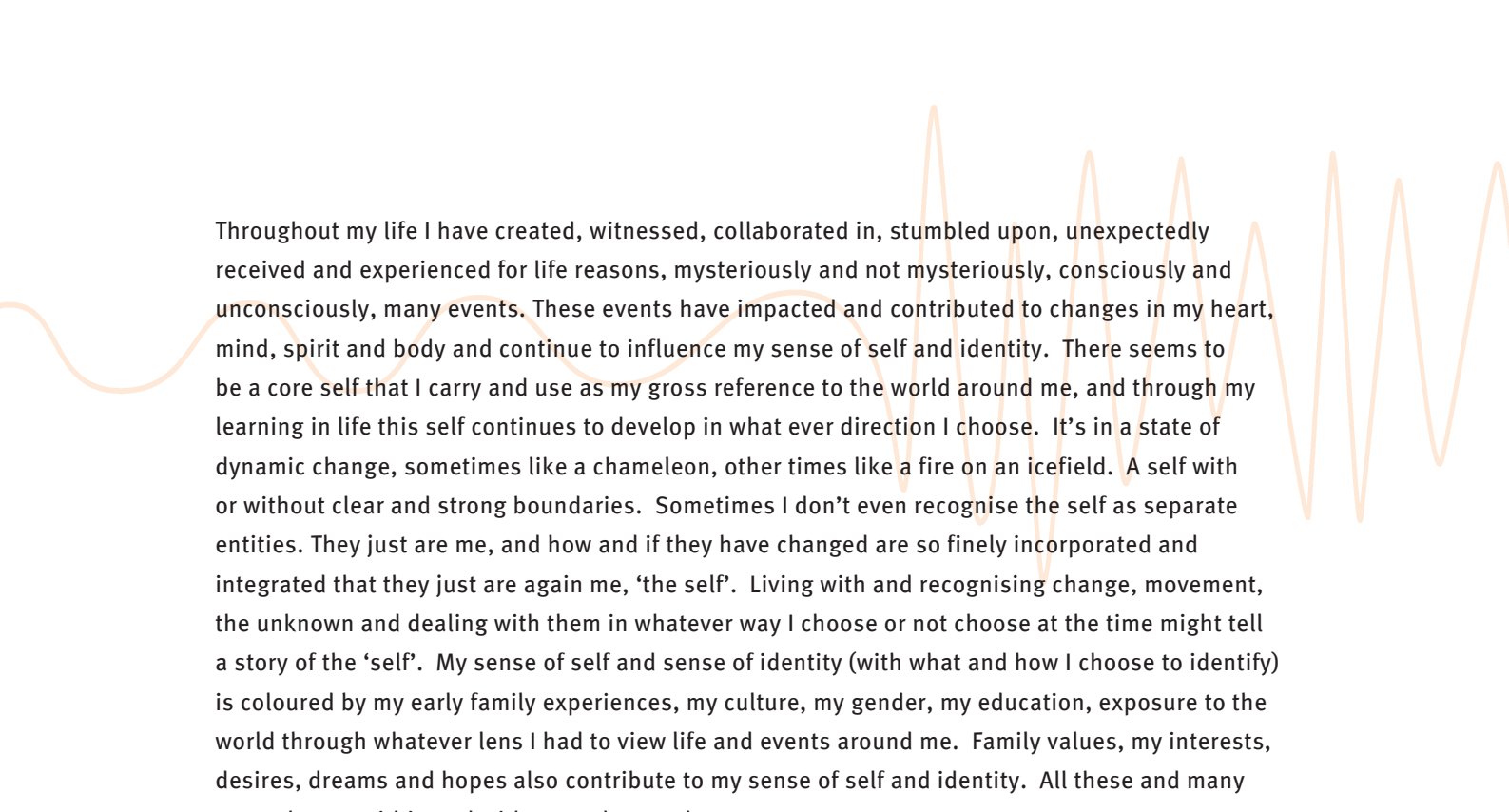
...the questions, looks and comments made by others in which I can see the disbelief has had a large effect on me.

Being abused by my Dad and my ex-husband changed my self-esteem, self-love and self-worth as did other events in my life e.g. my divorce. All my life I felt I was no good. I felt nobody else would love me. Being teased at school because of my voice and ears left me in tears on most of my school days. Later on in my working life I had to prove that I was the best typist in Adelaide so that I would be chosen for the job on my abilities alone. I loved my legal secretary days as it seemed I was accepted by some people and it made me feel good about myself. When I was young I was forever active, the life of the party. I had a good figure and other girls were jealous as I was always dressing in black hot pants, the craze of the 1970's, white lace up boots and anything that was sexy. I needed to be this way knowing others would see a different self. Having two children with disabilities caused a lot of changes in me. I had to stop thinking that people saw me and then saw my children and labelled me as having a disability as well. One event in my earlier life stayed with me forever and that was when the love of my life at 18 told me that I would end up having abnormal children and that's why he didn't want to stay with me. I had a real battle to prove that I wasn't abnormal as I felt that other people saw me this way.

Julie

As my illness progressed, my physical stamina, organisational skills, memory and overall ability to function productively decreased. Over time adrenal crashes became more frequent and severe, limiting my ability to perform even further. I began to avoid what would bring on these crashes, including being outdoors in the hot sun, going on school excursions or participating in extra curricular activities which were often expected of me. Coping with work, and the constant chronic fatigue, took every ounce of strength I had. I existed just so I could keep going to work. Progressively I needed more and more time off work due to illness. Due to arthritis my mobility became more and more restricted until I found walking very painful and going upstairs near impossible. To keep working, my husband took over all the housework as I could no longer cope with both. Work was so all consuming, I didn't have the strength or energy to play an important role as a grandmother. Finally I was unable to work at all. Even then my health didn't improve and I became so immobile, I still couldn't do much around the house, depending more on my husband.

Chrispy



Throughout my life I have created, witnessed, collaborated in, stumbled upon, unexpectedly received and experienced for life reasons, mysteriously and not mysteriously, consciously and unconsciously, many events. These events have impacted and contributed to changes in my heart, mind, spirit and body and continue to influence my sense of self and identity. There seems to be a core self that I carry and use as my gross reference to the world around me, and through my learning in life this self continues to develop in what ever direction I choose. It's in a state of dynamic change, sometimes like a chameleon, other times like a fire on an icefield. A self with or without clear and strong boundaries. Sometimes I don't even recognise the self as separate entities. They just are me, and how and if they have changed are so finely incorporated and integrated that they just are again me, 'the self'. Living with and recognising change, movement, the unknown and dealing with them in whatever way I choose or not choose at the time might tell a story of the 'self'. My sense of self and sense of identity (with what and how I choose to identify) is coloured by my early family experiences, my culture, my gender, my education, exposure to the world through whatever lens I had to view life and events around me. Family values, my interests, desires, dreams and hopes also contribute to my sense of self and identity. All these and many more change within and without and around me.

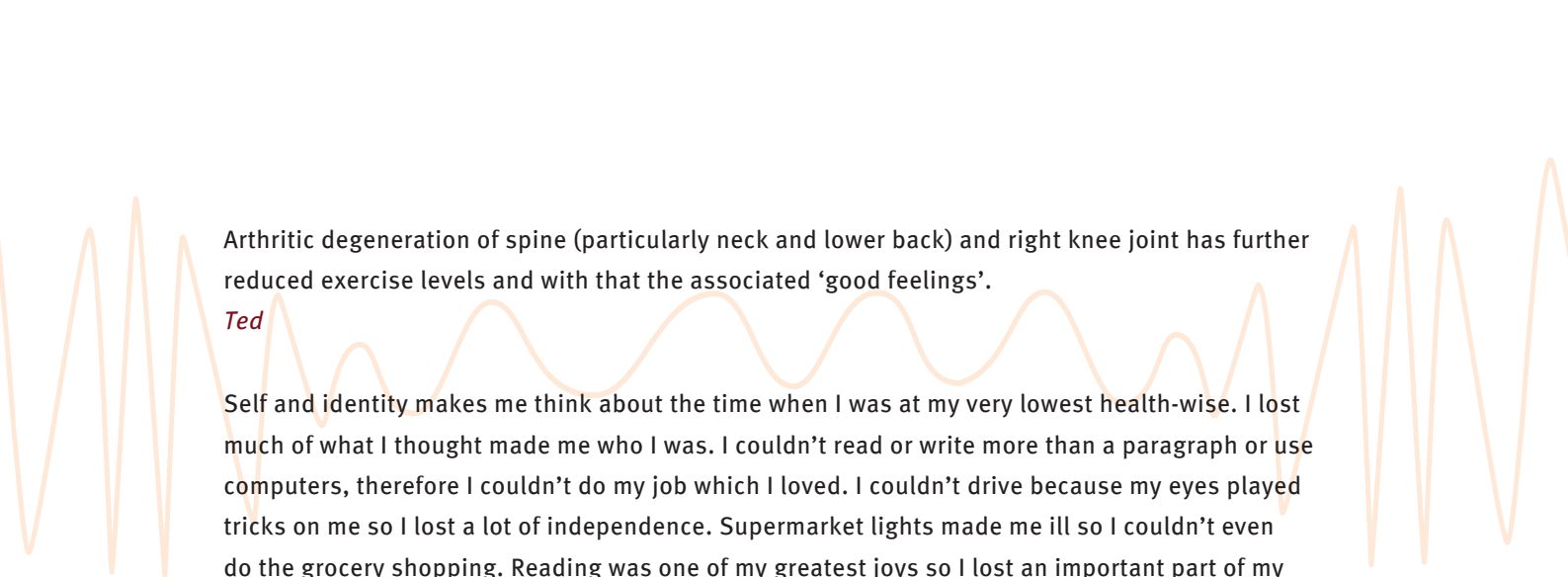
Olympia

I can't talk about any changes in "self" or how my health problems have influenced it, because I don't remember what I was like before being sick. I can only rely on what OTHERS have described to me – family, friends, employers and school teachers. So I can only talk about past identity. But family and friends have described me as a loving daughter and friend, determined, positive, creative, thorough, studious and a good organiser. I was very very busy, energetic, bubbly and cheerful, and always organising everyone's social life. Some of these qualities are still there, but have had to be drawn on for totally different reasons. For example, my organisational skills are required to try to help me try to cope with my poor memory. My positive outlook has had to be drawn on with unscrupulous repetition both for my benefit and for the benefit of others.

Iolanda

Depression and anxiety were a variable but significant impact over about 20 years since about 1980. They were a constant nagging influence which, on and off, eroded my self-confidence and self-esteem, caused frustration, stress and depressed feelings. All this affected my behaviour with my immediate family - I was ill-tempered, picky and suffered bouts of misery. The heartening aspect was that I did not lose my bundle but pressed on with medical treatment, social life, work and professional development.

Heart disease has been a concurrent and increasingly more invasive influence since the early 1980s. Initially I wondered how significant these irregular heartbeats were, whether the condition would deteriorate quickly, how soon would it kill me etc. Amazingly, I was generally optimistic and went on receiving whatever treatment was needed (medications, aortic and mitral heart-valve replacement, cardioversion, pacemaker, more drugs). Fortunately, all the treatment has been effective and has kept me alive thus far but with significant loss of physical wellness (out of breath, chronic tiredness, reduced libido, inability to exercise enough).



Arthritic degeneration of spine (particularly neck and lower back) and right knee joint has further reduced exercise levels and with that the associated 'good feelings'.

Ted

Self and identity makes me think about the time when I was at my very lowest health-wise. I lost much of what I thought made me who I was. I couldn't read or write more than a paragraph or use computers, therefore I couldn't do my job which I loved. I couldn't drive because my eyes played tricks on me so I lost a lot of independence. Supermarket lights made me ill so I couldn't even do the grocery shopping. Reading was one of my greatest joys so I lost an important part of my recreation as well. At my lowest all I seemed to do was sleep and cry. Not good for self-confidence and pretty hard to live with too.

Helen

Shifts In Self and Identity

Most of us agree that we are not the same person as we were prior to illness. While some of us acknowledge that our core self has stayed the same, other aspects of self and identity seem to be dynamic and shifting. We each perceive our self according to experience of such things as our interests, roles, values, philosophy of life, social interaction and educational and cultural background. Some of these things may change with illness and we find that parts of our self no longer fit our circumstances. A different self and identity evolves as we live with changed physical health and review our priorities, goals and interests. There may be very personal changes to our sense of confidence and mastery with increased anxiety about taking on tasks or activities. Where once we were carefree and spontaneous, now we are cautious and measured. There is a sense that what we once took for granted can no longer be relied upon. Some of us have changed the way we think about ourselves to accommodate the uncertainty and unpredictability of life lived with illness. Loss of certain roles such as work, parenting and/or social roles can mean that we not only see ourselves differently but also perceive that others see us differently too. This can result in changes to the way we present to others e.g. we may be less talkative and outgoing, more sensitive to what others think etc. We may not feel as useful and purposeful as we once did.

The process of creating self and identity is ongoing, even when we experience what we see as negative changes in our self, there is always the potential for this to change again in a more empowering direction. Some of us report changes in self and identity, such as seeing oneself as more dependable and strong. A shift in attitude toward being more compassionate and tolerant to others has been experienced by some. Other positive changes experienced relate to valuing of self, e.g. prioritising our needs and looking after ourselves, changes in our approach to life, and learning to say no. Illness is one of many disruptive events that will occur during our lives. All people experience shifts in self and identity whether they live with illness or not. With chronic illness however, shifts in self and identity will be ongoing. Our sense of self and identity is a 'work in progress'. Here we share our perceptions of how self and identity have changed since illness became a part of our lives.

How has your sense of self and identity changed and/or shifted since living with chronic illness?

Loss of self confidence, learning to be more dependent on others.

Michelle

I am no longer quite as confident as I used to be. Prior to illness I never doubted that I would be able to do whatever I set my mind to, but I now find that I worry more about whether or not I can do things. I also find that I seem to be hyper-aware of changes and feelings in my body. If I feel ill I wonder if its just because I've got a 'bug' or if it's more to do with my illness. This is annoying and frustrating but I don't feel able to stop it.

Graham

Mainly I've realised what an intolerant callow @\$%^# I used to be. I'd like to think that I'm a gentler person because of my experience. I've always seen myself as a strong, capable person there to support others, and find it very hard to say 'no, I can't, could you help me'. But over the years I suppose I have accepted that I can say those things without it meaning that I'm no longer those things, and that people around me will not think less of me.

Brumby

When I was diagnosed with chronic pain (i.e arthritis), degenerating back, body shrinking, my bottom sticking out because I couldn't walk very well, my awkward gait and my jerking legs, I felt as if I was being punished by God for my youth days. I didn't like this new me because I was frightened that other people would see my added disabilities, my two kids and label me "Oh what do you expect she's always appeared to be a nut". I guess my sense of self has changed since I was first diagnosed with chronic pain. At first I denied it and pretended that I wasn't getting worse. In the end after each diagnosis of another condition, I began to look at others who were worse off than me and to realise that they had to battle even more than I did. I began to do little things and then I could see that I could still function if I paced myself. This helped enormously to realise I had conquered the pain. I began to find other things I could do (i.e craft, gardening), rather than just saying 'Poor me I can't do it.' Now even little things give me a feeling of accomplishment and therefore make me feel better.

Julie

Confidence has always been a problem for me, and the diabetes has not helped. Part of the problem is that many of the people around me are in manual labour types of work while I am in a much more of a 'thinking' job. My illness tends to highlight this difference, as it is more difficult for me to do much manual work (such as in the garden) as I tire much more easily. However, I still don't know how much of this tiredness is physical and how much is emotional (stress).

Andrew



A CHANGING BODY

I know I am staring and at risk of rudeness
But today again in the mall
My eyes are drawn to a group of women
Perhaps twenty years older than my forty three
Intently I watch as they walk arm in arm
Their limbs moving freely with strength
No falter in their step, no stagger in their gait
No hint of pain on their faces as they laugh
and talk and enjoy...

I remember and feel the confidence of
movement

In my own dance through life prior to MS
The joy and the pride I felt in a strong fit body
That is now a prison of pain and discomfort
– Kerry

My 'self' remains much the same except that empathy and understanding of others has improved through having to cope with my own illness. This group has been a great help to my gaining deeper understanding. My identity has changed on the surface in that I no longer work. I have a different financial, work and social status, and can't spontaneously volunteer for things (I used to be very enthusiastic and a very committed worker). But I can be enthusiastic about other things, like educating myself about my illness, other people and different activities. Being retired is a different status apart from any illness. I think if I hadn't left work I would be dead by now.


Di

My sense of self and identity have become very poor. I feel incompetent, inadequate, useless and often guilty for my inability to cope. I feel others see me as weak and lazy, especially as I look normal and don't have any obvious physical disability. When I'm at my lowest ebb, I guess I see myself as a 'complete waste of space'.

Chrispy

I'm not sure that anything is fixed in relation to self and identity. Since MS I've probably thought more about what it is that I need to care for myself. I think my relationship to the outside world, my work, my attachments to things other than children, family and good friends became tenuous. I was more consumed with the 'why did I deserve this disease?', 'What do I have to learn?', 'What do others think this says about me?', 'How will others view my value in their life?' Because I have no control over other's thoughts I have focused on 'What do I have to learn?' and I keep coming back to loving, caring for myself and my children, staying open to truth, clarity and compassion for self and others. That's a lifetime journey, and I'm sometimes grateful to MS for bringing me here, if I am indeed here. I confess I very consciously struggle with it.

Olympia



...most of us seem to have discovered a “new me”; a stronger, more confident and also more patient and tolerant person, largely because of what we ourselves have undergone.

I find it difficult to think of myself as having complete control of my future - there is always the need for my ‘medical support team’ who overall have a significant impact on what I attempt to do. I have had to accept that I can only have limited aspirations. However, I think that I have developed more self-reliance. I am more relaxed about what I think I can achieve so I am less uptight. Thus, overall I think I have become more accepting of my physical and psychological limitations.

Ted

I’ve been told that my identity has changed significantly since being sick. I’m quieter and calmer, kinder and more mature. I don’t worry so much about etiquette and social niceties. I’m much less talkative, and not good in groups. I’m also more budget conscious. These changes have come about because of the limitations imposed by my health problems - I have little or no energy and try to keep mentally rather than physically busy within the four walls of my room and inside of the house. I’m not socialising much both because of my limitations and because friends are too busy with their partners and children. And my visual presentation has lost the energetic-type of cheerfulness that comes with health and youth. Now I’m more mellow.

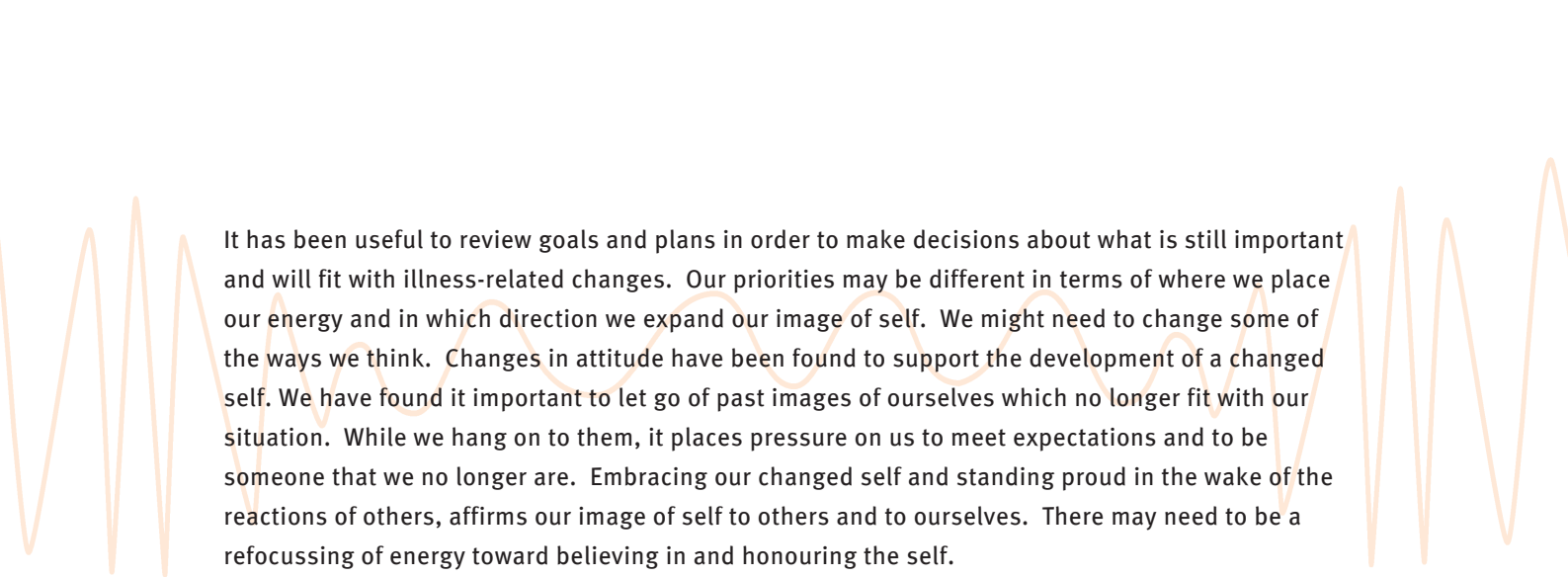
Iolanda

One thing I’ve noticed over the emails is that most of us seem to have discovered a “new me”; a stronger, more confident and also more patient and tolerant person, largely because of what we ourselves have undergone. Sometimes this is just the result of our health problems and sometimes at the hands of others.

Helen

Rebuilding Self and Identity

Inevitably, we will form an image of self which fits with our circumstances. To do this we will sort out which parts of our past self are still relevant. We will also develop new perspectives of self which fit with our changed body and abilities. As a result, we piece together a different view of our self for the future. These shifts in self and identity influence the way in which we express ourselves and experience life.



It has been useful to review goals and plans in order to make decisions about what is still important and will fit with illness-related changes. Our priorities may be different in terms of where we place our energy and in which direction we expand our image of self. We might need to change some of the ways we think. Changes in attitude have been found to support the development of a changed self. We have found it important to let go of past images of ourselves which no longer fit with our situation. While we hang on to them, it places pressure on us to meet expectations and to be someone that we no longer are. Embracing our changed self and standing proud in the wake of the reactions of others, affirms our image of self to others and to ourselves. There may need to be a refocussing of energy toward believing in and honouring the self.

Activities such as reading books on personal development and having the support of spiritual faith are seen to foster self love and valuing. The development of a different attitude to handling the ups and downs of the illness experience enables one to stay positive during hard times and to be encouraged. Perhaps one of the strongest points to make is the positive influence of a supportive network of people. The love and understanding of family and friends is undoubtedly a benefit to reclaiming our own personal power and rebuilding confidence. Access to groups of people experiencing similar situations provides encouragement and understanding for the journey toward realising an altered self. This might happen on line or face to face. For others, becoming involved in activities such as part-time study, interests or hobbies has assisted us to develop different aspects of who we are. Negotiating shifts in self and identity is complex. We might find out things about ourselves that we did not know. We hope that our stories about what has helped will be useful to you and we emphasise the exciting potential of this process.

What has been helpful for you in rebuilding your sense of self and identity?

The love and support of my wife and daughter has given me the strength to face the changes in my self. The other helpful thing was to provide some support to (and receive support from) others facing similar problems to myself.

I have had to look at my life and goals and decide what is most important to me. I do not bother with what isn't important. I also set myself some new goals. These are things that I can do without wearing myself out and may eventually help with the finances. I get a great sense of accomplishment when doing these things.

Graham

Realising that I don't have to fulfil the roles others have cast me in. That the world will not fall apart so to speak, if I acknowledge my weaknesses and speak them. Just letting people be accepting of what you are now, and going with that, rather than trying to hang on to what you used to be able to do.

Brumby

Learning to believe in myself more. My faith has helped me to do this and therefore it portrays a more confident human being, more self-assured. I have read books on the subject, learned through experiences, either to sink or swim, and I chose to swim. Changing my attitude was most influential in adapting to an altered sense of self.

Helen

I actually feel that I have a long way to go in rebuilding myself. I wonder if this is a 'normal' thing. Does anybody with a chronic illness feel 'satisfied' with the way in which they have rebuilt their sense of identity, or is there always some 'shadow' over our lives that we never really do get rid of? It ties in a bit with comparing life to a journey. Our illness has put us on a pretty big detour, and rather than try to find a new path to where we were heading before, we should be looking for new destinations.

One thing that has helped me is to return to part-time study. It gives me a chance to learn new skills and head in new directions and it is also something positive to put myself into. Many places now offer 'external' studies that can be done at home by correspondence rather than having to travel to classes.

Andrew

I've learned to accept the really bad days will end and I will feel better again. I try not to fight the bad days but accept them and when I start to pick up again, be positive and enjoy what I can as much as possible. Having a very supportive, understanding partner is invaluable in improving my sense of self and identity. Communicating with others on the Internet who have the same condition has been invaluable. Being a rare condition, just knowing others are out there who have the same symptoms and problems, lets me know I'm not alone.

Chrispy

My personality, my commitments to family, friends, time, rest, reflection, reading, learning, listening, sharing stories, nature, the moon and sun, particularly my sons. When I'm unwell they make my heart smile. Also my proximity and love of wide open spaces.

Olympia

I have come to believe that I am a 'survivor' (in my limited environment). I am more optimistic than before and feel blessed with undeserved good fortune so far. I have come to realise that I have loving, caring, and accepting friends and relations. I am becoming to see that it is me that is ultimately responsible for my actions and wellbeing.

Ted

I think what is 'helpful' changes over time, depending on your age, health, and what you've experienced during your life. I was a totally different person during and just after cancer treatment than I am now, 6 years post cancer and after 6 years of deteriorating health. I'm also older and in a different stage of life. I think that being in supportive environments has been a necessary tool to rebuilding my sense of self since I cannot be the person I was before being sick. This has come from my family and most importantly, through the Internet and my online support groups. They've given me enormous psychological support that's helped build my confidence and maintain my sanity, both of which are essential foundations for self and identity.

Iolanda

...it is me that
is ultimately
responsible
for my actions
and wellbeing.

Several things stopped me from being stuck in that awful situation forever. One is that I was determined to overcome it or at least learn to live with it as well as possible. One part of my identity that I never lost, fortunately, was my Christian faith. As I could no longer read my Bible, which had the small print so beloved of Bible publishers, I bought myself a Large Print Bible and was able to read small passages, which I found a great help. My family were very supportive, not only my husband and daughters but the extended family, which was a great blessing. I was also fortunate to have helpful doctors who worked with me to sort things out.

Helen

A Valued Self and Identity

Every person wants to feel as if they are valued. A diagnosis of illness can shatter our feelings of worth. We still want to be respected as individuals and to feel that our existence holds purpose, yet we may not be able to draw on the aspects of self that once provided a sense of worth. Further, inaccurate stereotypes and attitudes of others can reinforce a diminished self. Some people may see the illness or disability instead of seeing the person, and make assumptions. It is a situation that can leave us feeling frustrated and devalued as human beings. Yet we have much to be proud of and we encourage you to keep in touch with that.

The challenge is to be creative about how we define ourselves. New activities and interests that do not compromise wellbeing may give our life meaning and bring different people into our lives. The people around us can either support or constrain the sense of being a valued human being. As far as possible it is important to ensure that the people around us are supportive of our inner wellbeing, and that we find ways to contribute to those relationships. Rather than focussing on what others think about us, let's be proud of our achievements. We can develop an inner dialogue that rejects the negative attitudes of people who know little about who we are and what we experience. Being a member of a group or network which provides respect and understanding is a good way of feeling connected to others. Let's not forget that a sense of humour seems to go a long way in terms of staying connected to the lighter side of self. When we are having fun and laughing we feel better in ourselves. This is not to understate the trials of illness but we do have a choice about how we react to these trials. The strongest point we make here is to look after and cherish yourself. Remember to make time for enjoyment and pleasure and to affirm ourselves for things we achieve, be they big or small. By doing this, we are contributing positively to feelings about self and life. We are so much more than the illness we live with. We hope you find some connection with our thoughts about what has assisted us to live with pride and a valued sense of self.

What do you see as important in terms of maintaining or reclaiming a valued self and identity?

You need to be truthful to yourself and to those around you. There is little point in putting on a brave face to others when what you need is their help. Conversely telling them not to help when you feel the need to muddle through by yourself is also important. Always attempt something before you ask for help. Being unable to complete a simple task can be deflating to your ego, but in the



SOCIAL ROLES

Chronic illness often requires a shift in social roles.

–Graham

long run it is better to have tried and need help than to give up beforehand and get help whether you need it or not.

For me reclaiming a valued sense of self and identity was to find other things I could do that would give me fulfilment. I used to be able to do a lot of heavy physical work. I had always worked hard from a young age. I was proud of my physical strength and endurance. With my illness that is no longer possible. I had to find other things to make me feel worthwhile. It took a few years but I eventually discovered these in photography, painting and making beaded jewellery. All of these are fairly passive but I can do them for long periods of time without exhausting myself and at the same time gain some sense of achievement.

Graham

Letting go of anger is in my opinion the number one. There are people out there who make you feel like you're a waste of space, but it is their problem not yours. You have nothing to prove to them.

Julie

I guess the main thing that I want people to see is that I don't give up easily. I battle on no matter what. The pain will always be there so why complain about it? I think people do admire this about me now because I have often been told this. Above all I try to think I am me and I am accepted in society the same as everyone else.

Brumby

Keep as active as possible; don't isolate yourself. It is really important to mix (even if by telephone) with people who have a positive influence on you and your sense of worth. A sense of humour can be really helpful. It helps at times to be able to make some fun of your condition (for example, as I take 4+ injections/day I can't go swimming as I will spring a leak!) and it also helps your sense of personal value if you can make other people laugh. If you are fun to be around, you will tend to have (happy) people around you. I have found that I am (emotionally) stronger than I used to be (this doesn't mean that I am not an emotional person) as I know that I cannot 'give up' on this condition, nor do I want to. Despite the problems, I enjoy life. This can be an asset for other people who can find that they can rely on you when they need to.

It is important to actively seek out NEW activities and experiences that fit in with our changed self. We ALL lose something as a result of our illness, and unless it is replaced we will feel somewhat empty. It also gives us something POSITIVE out of our experience - which helps us deal with change, as it is no longer seen as completely negative.

Andrew

There is only one other thing I can add. Having a good sense of humour is imperative. Being able to see the funny side of some of the stupid, forgetful things I do really helps me cope better. I now write many of my little lapses down which I share with others in Internet support groups. Being able to laugh at one's self is good therapy.

Chrispy

I feel really lucky so far that this hasn't been a major obstacle for me. I have a certain amount of self value and strength, good friends, family and networks. Even though my partner has left me for another woman and I hate and am angry about it all I know he didn't leave me because of my illness. In fact I think I would have struggled more if he had stayed with me because of MS and not love. Right now I feel well enough to carry on my own. If I was unwell I'm sure it would have been more challenging.

Olympia

Interact and do things with people I like and value. Join one or two organised groups where I feel 'accepted' and valued and where I can enjoy activity and/or feel creative. Find pleasant and enjoyable pastimes in which I can still partake (eg listening to music, performing music, seeing movies/videos, reading, low-level gardening, eating out with a friend(s), gentle exercise - most important). If I feel down I seek out any such enjoyable distraction. Reflect on the positive aspects of my life and try to ignore the negatives. In so far as it is possible, I avoid situations which I know are likely to be stressful or negative.

Ted

Supportive family and friends are very important. A few years ago I asked my family and friends to write me a memories letter a letter to me about me, anything that they remember about me. In their own way these letters hold a special place in my heart. They give me something to be proud of and show me that I've had a happy life. They help give my heart a foundation. I share some moments of happiness or excitement about achievements with either my parents or my online support groups. These people understand why these small things mean so much. They encourage and congratulate me and help me maintain my sense of self. Unfortunately it's not something that many of my real-time friends see so they have a distorted sense of my identity.

Iolanda

I learned that who I am does not consist of my job, whether or not I can read and write, or even whether I can carry out household duties like grocery shopping. I found I had an inner strength, more patience than I ever thought possible, and a steely determination which I knew was there but which really came into its own during this time. I was also deeply touched by the compassion and love shown by my family and equally frustrated and hurt by people who thought "it was all in my head" or that I was exaggerating, making it up etc. At its worst my life was so tedious, boring

Being able
to laugh at
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therapy.

and painful I don't see why anyone would live that way by choice. Some people never understood that my problems were as real as a broken leg, or any other visible problem, and, like many other sufferers of "hidden" illness I have learnt to ignore and hopefully avoid these people. I feel sorry for them and their lack of understanding. Fortunately none of these were family members.

Helen

Our Message To You

"There is nothing like a serious illness to blow down our fragile houses of sticks and straw. Standing amid the rubble of their lives and thoughts, people with serious illness undertake the task of building a new house, a new way of living..." (The Alchemy of Illness by Kat Duff 2000).

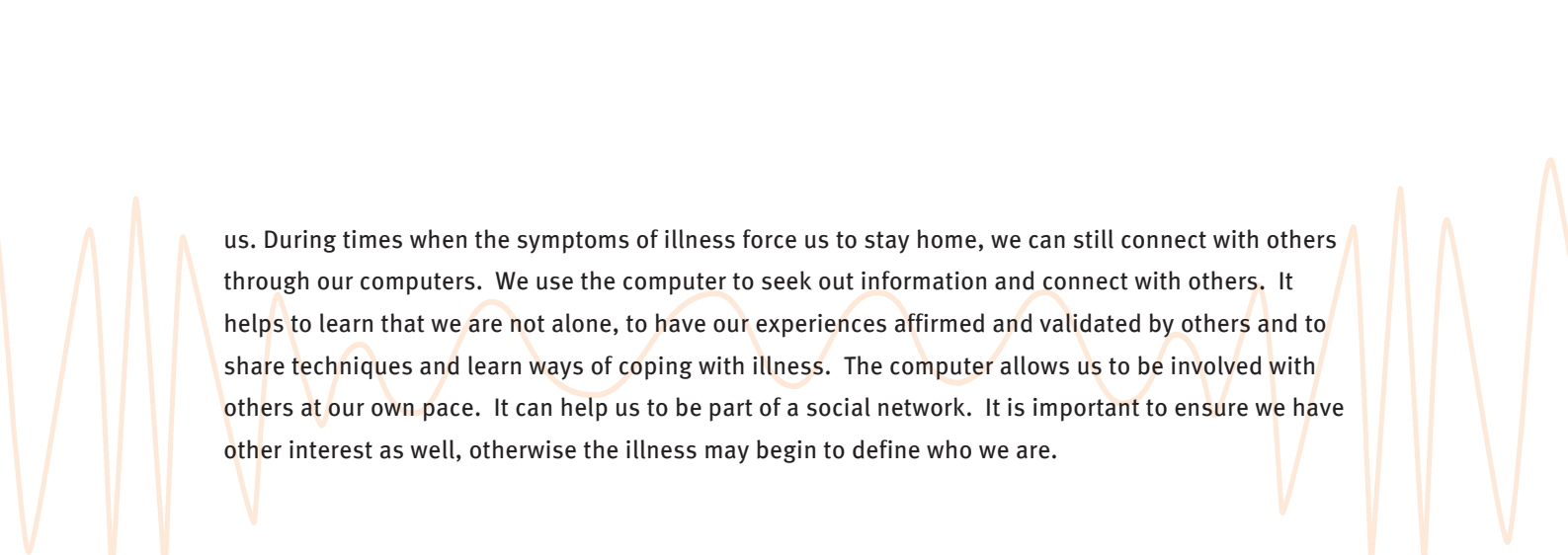
At first, it may seem that we should 'get on with it' and try not to be too concerned with chronic illness. We soon come to realise however that chronic illness has been a significant disruption into our lives and has ended our familiar ways of living. The disorder we can experience can be overwhelming. It is important that we get things sorted and find some order and continuity so that we can find quality and value in our lives. To remain in turmoil keeps us from adjusting our lives so that illness can have a place.

The identity we have as a person with chronic illness shifts to be based on more than what we can do. To achieve this we need to begin to value aspect of 'being' as much, or perhaps more than aspects of 'doing'. Chronic illness places us into a state of limbo for a while, where we are no longer sure who we were, but remain unsure as to who we are becoming.

It has been important for us to learn that it is not useful to define ourselves based on what we do or what we accomplish. When we live in a society that identifies us by things like our jobs or affluence, this can be particularly difficult. We can feel at odds with the values of the society in which we live. Although a part of us is assured that we matter to friends and family, it can be difficult to shift our own values when we can no longer accomplish what we used to. We may have had to stop work, no longer participate in hobbies or sport, parent in different ways, and even engage sexually with our partners in different ways. This means a profound loss of enjoyment in life, and also fewer opportunities to engage with friends and our loved ones.

Sometimes depression can get us down, because the changes in our lives seem insurmountable. When we feel depressed, feelings of worthlessness come to the fore. If it were your partner or friend with a chronic illness however, you wouldn't consider them worthless, so why punish yourself in such ways?

As our stories reveal, it is possible to reshape our identity following the disruption of illness. It takes time, but we can find new activities that we can value, and we make new connections with others. We can have fun and be fun. Possibilities do open up. Our computers have been important for many of



us. During times when the symptoms of illness force us to stay home, we can still connect with others through our computers. We use the computer to seek out information and connect with others. It helps to learn that we are not alone, to have our experiences affirmed and validated by others and to share techniques and learn ways of coping with illness. The computer allows us to be involved with others at our own pace. It can help us to be part of a social network. It is important to ensure we have other interest as well, otherwise the illness may begin to define who we are.

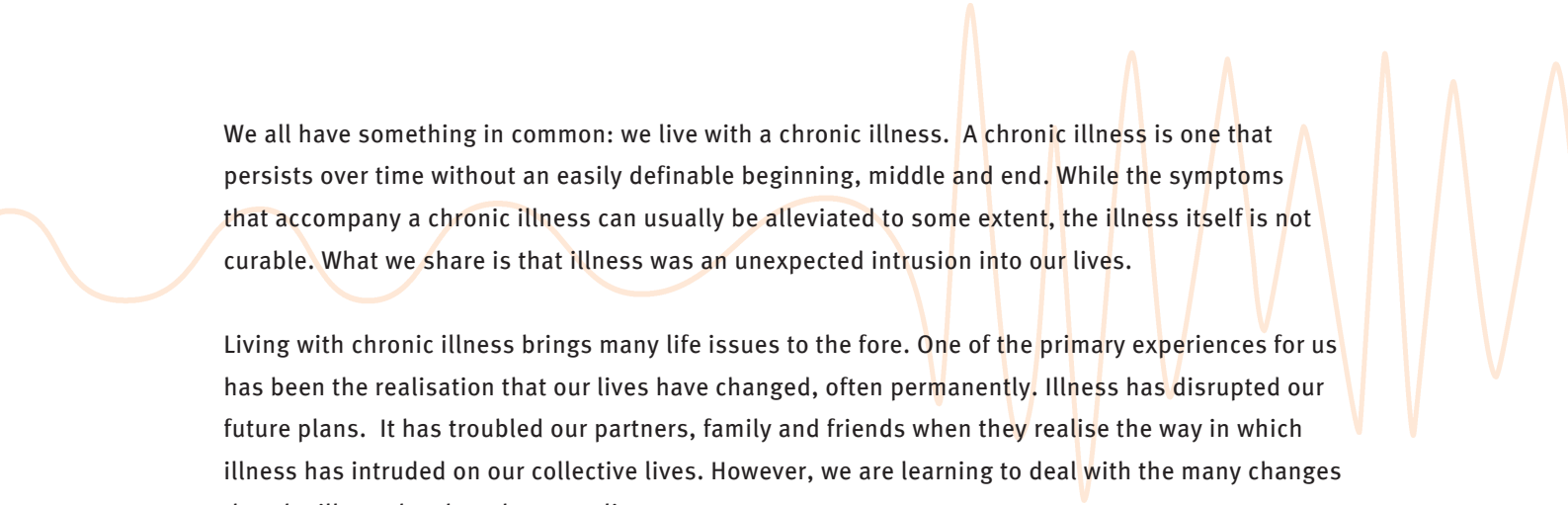
Our Message To Health Workers

Some health workers may feel that it is their role to help people understand what they need to change and how they need to change it. Learning new ways to live with illness is a long-term process. Adjustment to new ways of living does not happen quickly. Each person is the author of their own lives and only they know what changes may be possible. You cannot assume to know exactly what needs changing, nor how we should do it. You can help us to adjust our identity by offering us time, genuineness, being an active listener and, where possible, support us in our search for information, even when that information may not be within the realm of your experience or education. Help us adjust by validating and affirming our experiences and feelings. Help us to find ways to value our changing identity by showing us that you value us. Be fun to be around and greet us with a smile.

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 eleven 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 understandings 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.

