Transition in Chronic Illness

Grief and Loss

BOOKLET 2

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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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Contents

I was at a picnic and after a very ungraceful effort, got to a standing position from being seated on the ground... and started walking (slowly) to the toilet... a young relative came along, grabbed my hand and said she'd come with me... Well, holding my hand is very unhelpful, as I become physically unbalanced, so I gently explained that... and afterwards I realised that she took that as a personal rejection.

On the way to the toilets, I started steering myself along the bitumen path, and she wanted to go across the lawn. I explained that I can't walk on grass, because it is uneven (this is my lack of confidence about being able to physically move around, and uneven surfaces mean that it HURTS when I stumble or even step on uneven or spongy surfaces).

We were going along okay and she asked me about the arthritis, and she said, "Oh, never mind, you'll get better." When I told her there was no cure, she burst into tears... now, there are a whole lot of things going on here, but essentially, I am tired of dealing with other people's grief and fear, and am certainly not up to facing my own. I am fearful of the future... where will I live... how much of my independence will I lose...how will I get around... and the beat goes on...

Grief, Loss and Fear

Chronic illness seems to pervade every aspect of our lives. Living with a chronic illness can have a profound impact on the way we live and may create feelings of grief in response to the changes and subsequent losses that happen in our lives. There are wide arrays of potential life disruptions and changes that we may experience when dealing with illness. Chronic illness is often erratic and unpredictable, and the way we respond to it requires constant readjusting.

We may experience multiple losses such as a feeling of loss of control and personal power, which is important for our self-esteem. We may also experience loss of independence, changes to our identity, loss of financial security and significant changes to our familiar lifestyle. In addition, we may also be confronted with having to change our hopes and dreams and visions for our future.

Changing roles in family, work and social situations that result from a person's illness also can create additional adjustment issues. Family members and partners may also experience similar feelings to us, as well as their own feelings as to how the illness is impacting their life. If these issues are not communicated and worked out, then relationships may falter and leave us with the sense of another loss.

Perhaps the most difficult of these transitions is the loss of the identity one held before illness disrupted our lives. We often have ways that we define ourselves (ie. daughter, brother, mother, father, nurse, mechanic etc). Sometimes illness forces a reframing of the way we define ourselves and the way we interact with others. It can be difficult to feel good about ourselves until we find ways to adapt our illness into a new self-image. The work of rebuilding our lives following the disruption of illness can mean changes to supportive relationships. Sometimes people react without understanding. This seems particularly so when the illness is invisible to others. At a time when we most need compassion, love, understanding, sympathy and support we may be met with suspicion and disbelief.

The changes and consequent losses that we may experience can be visible or invisible, and maybe of a physical, intellectual, psychological, emotional, social and spiritual nature, or a combination of these. Some of what we have lost has been associated with the way we have defined ourselves. We each build our sense of self and life situation on the basis of what we value and what is meaningful to us. The losses associated with illness might mean we no longer have access to important parts of our world. We may need to let go of some of our old ways of being and doing, and learn new ways that are in line with our changed circumstances. Consequently, the way we think about our world and ourselves is altered. This process can evoke strong grief emotions as we struggle with letting go of familiar and meaningful parts of ourselves and our lives. We grieve for the loss of what was and also for what will never be.

There is no time frame for grief; for some it may be life long. As illness progresses or changes we may find we are faced with new losses. Each new loss can trigger the pain of previous losses, especially if we have avoided or suppressed dealing with the grief. Loss is a part of life. Each person, whether living with illness or not, will face loss as they move through life. Our stories demonstrate that the losses associated with a long-term illness encompass every aspect of our lives and are likely to alter our sense of self.

What have been some of the losses that you have experienced as a result of chronic illness?

The multitude of losses due to the chronic illness caused the seeking of a diagnosis. I think it would be like this for most cases. Rarely would you get a diagnosis before you get the illness, after that would be the treatment that creates more losses. There are many losses and not all are tangible. The upfront ones are the loss of mobility and physical abilities, loss of income, career/employment adjustments, the expense of treatment, and cost of making changes to your living environment to accommodate your disabilities. Then the emotional losses of self esteem, stresses on yourself and your carers, loss of freedom of movement by relying on others for going places, having to alter your life to the constraints of the illness. Life can be turned upside down, and what you always have taken for granted and never given a thought to doing becomes a hurdle requiring planning and thought to get accomplished. The strain of living every hour of every day with the illness itself and the emotional and physical impositions from it wear into your soul, causing more

> “I think I lost myself when I was first diagnosed with chronic illness. I didn’t know who I was anymore or what was to become of the real me.”

problems with how you are able to cope with it.
To a certain degree I have lost my self esteem and a sense of who I am. My memory and concentration are nowhere near as good as they used to. I’ve lost my ability and desire to do things, this could be either housework or going for a drive or painting.
Graham

I am uncertain when I commit to going out, or volunteering or working as to whether I will be well enough. This takes away spontaneity and affects natural enthusiasm. My body too of course, is not as strong and healthy as a completely well person.
Di

I think I lost myself when I was first diagnosed with chronic illness. I didn’t know who I was anymore or what was to become of the real me. I couldn’t wear high heels any more because of my lack of balance and difficulty in walking due mainly to Fibromyalgia (lack of co-ordination) and osteo-arthritis, B12 deficiency (nerve inflammation and again lack of co-ordination) and a bad back. I couldn’t wear make up anymore because of the itching on my forehead due to psoriatic arthritis. I get very embarrassed if my forehead is in flare up. It’s so red and the skin is flaky. No more loud music because of my blinding migraines. No more going out at night because I would get so tired that it depleted all of my energy and took a few days from which to recover. I used to love dressing up to go out now my wardrobe consists of comfortable clothing that is easier to put on.
No more curries or hot spices. I couldn’t work anymore because I had to get up and down from the computer. Getting to and from work was impossible because I couldn’t get up the steps onto a bus easily and standing at the bus stop would have been impossible. Standing in the bus if it is full is virtually impossible for me now. All this activity would mean that I would take a few days to recover. I miss my work.
I can’t drive very well now and only use the car every now and again. Reversing is near impossible because of whiplash I can’t turn my head in a hurry and changing lanes is difficult. I rely on taxis and have a disability voucher. Going to the theatre is out as going up and down so many stairs is also impossible. I just can’t coordinate properly and take so long to manage just a few steps. Walking up and down the mall in town would just about kill me. I haven’t been to town for years now. Crowds worry me as the bustling and shoving scares me. They could easily push me over and because of osteo-porosis I could easily break a limb. I have broken two bones already. I now have to think about the things I want to do and how taxing it would be on me physically. Long bus trips leave me exhausted and in pain.
Julie

I suppose my experience is slightly different in that I had an acute illness, the treatment of which led to various chronic conditions. When first confronted with illness, the immediate response was to fight. That was not going to happen to me. I was still the same healthy, strong person I have always been. Gradually I had to build in accommodations, as I was on crutches for over a year and had hip replacements. Found out about the Hep C, which explained the fatigue, coped with the breast cancer, and the joy of being pregnant when I'd been told I'd probably never have children. Its all such a welter of emotions I can't pinpoint one point at which I felt a loss.
Brumby

I've lost a lot but I try not to dwell on the losses or I try to change my way of thinking about them. I'm not successful at this all of the time, and it requires e-f-f-o-r-t. For example, it is my choice not to consider ever getting married and having kids. Whilst based on the need to do what's best for me, I try to view it as what I'm going to "gain" from not getting married. At least I won't be contributing to the 48% general divorce rate in Australia and the much higher divorce rate for those with chronic medical problems. The loss of friendships and independence are other major losses that have had a dramatic effect on my life.
Iolanda

I never really said anything about losses that are a side effect of my illnesses, but there are two main losses - the first being the loss of energy. I know I could cope with the pain and the other problems better if I just had the energy to get out more, to keep up with my interests and pastimes. The other major 'loss' has been the loss of memories of the past, and loss of the ability to make many new memories. So I don't have any real memories to "keep me company" as I age. For example, no memories of my life, people or achievements before diagnosis. I know a lot of people won't think this is important, but it is because, to quote the lyrics from a popular song, "you don't know what you've got, til it's gone".
Iolanda

I've had various losses. Thankfully many of them have occurred gradually over time, making coping a little easier. I've lost the ability to really live life, but rather just exist, as I'm too exhausted and fatigued to do anything which isn't deemed essential. I therefore avoid joining in many activities. I've lost friendship and companionship due to an increasing inability to socialise. I've lost my mind (ha ha)! Well not completely but my memory, concentration and organisational skills are increasingly poor. I've lost my career, which I enjoyed but became too ill to keep working. I've lost a marked degree of my mobility which has severely limited what I am able to do. This is the one loss which may not be permanent, so I have hope this will improve.
Chrispy

Gradual deterioration of function; reduction in ability to exercise actively; walking distances reduced; bird watching curtailed; severe restrictions on long/medium distance travel; reduced mental and physical energy; reducing range of activities that I can use to compensate for these losses.
Ted

- An immediate loss in my perception of the world. I was the centre and nothing else existed.
- MS had entered my whole being and took up a lot of space. That has shrunk considerably 3 years down the track, other stuff old and new have resumed or taken up space.
- A loss of the familiar, how did my body and legs feel before the sensory loss, a loss of fluid flowing movement and control of my body.
- The loss of thinking that what I had was a given
- The loss of a sense of security and knowing what I thought I had
- A loss of self worth and ability. Why did I let this happen to me????
- A loss of new possibilities, dreams, plans.
- The loss of my familiar, preferred habitual ways of doing my life.
- A change in the way people know and view me
- The loss of how I was in the world

Olympia

I used to do volunteer work, which was pretty important to me. As a result of my illness I can't do this work anymore so I also miss out on the 'social' aspects of this - mixing with other people etc. so I have become somewhat withdrawn.

Andrew

Loss of job, friends, social life, recreational activities e.g. couldn't read for years; loss of self-confidence.

Helen

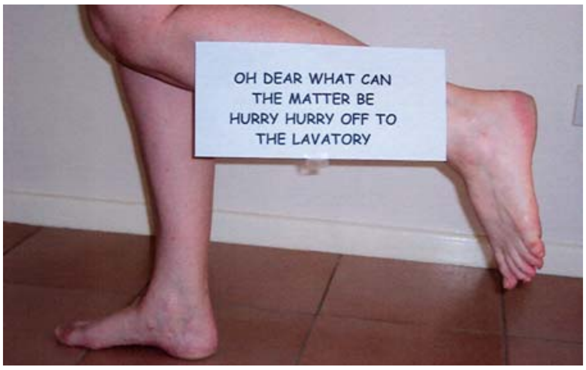
The Experience of Loss

Each person is unique in the way that loss is experienced yet some common themes stand out. Grief can be a lonely and isolating experience. The strong emotions of grief can be overwhelming and diminish our self-worth and confidence in life. We may feel uneasy talking about our loss or the emotions associated with it. Loss can be triggered by many of the ordinary situations that one encounters in living; for example, seeing mothers and children at the supermarket, hearing songs about love on the radio or having friends who are achieving at work. Since we are often exposed to situations such as these, we may have feelings of loss repeatedly. A change or deterioration in the illness experience can also be a trigger for previous losses. It may feel as if grieving is never finished. We live in a society which values being fit and strong, being successful at work and being independent. This context can emphasise our sense of loss as we continually receive messages about what is valued through the media and social interaction. It can make us feel as if we don't fit. It is painful to be aware of how illness has changed us. Yet life goes on and we can each find a way to endure our losses according to our familiar life patterns. Our different experiences of illness related losses reflect our differences as individuals.

How have you experienced these losses?

Experience of these losses is for every hour of every day. There is no respite, only some occasional lightening of the load. Good times do not become like the good old "normal" days, they become a lessening of the effects of the illness. I have felt a large loss of self esteem and self confidence which is taking a lot of effort to regain. There is a sense of isolation as the rest of the world seems to be moving on as I sit and look on. Stemming from this I have been very depressed for a long time. Due to my inability to withstand noise and movement, and the effort it takes for any conversation or reading I am virtually stranded at home. The world is something only to be glanced at occasionally. I get sad or down sometimes, especially when there is something that I particularly want to do but can't because of fatigue or pain. I also get angry about the fact that my health is so bad and I am now so restricted in many things. There is a feeling of unfairness about it all and also uncertainty about the progress of my illness.

Graham



Sometimes helpless because I can't for example, stop flare ups and diarrhoea that is, having little control and a lot of uncertainty; a sense of disappointment in not being able to work or whatever with no worries about the affects of my condition; and at the same time a sense of not letting it take over my life.

Di

I am not a person who gives up easily. I try to meet the challenges head on. I cried for awhile but then I realised there are others worse off than me and this kept me going through all the changes I had to make. I learned to ignore people staring at me because I walked awkwardly or I used a gopher and being young, people tended to look even more. I learned also to ignore those who were ignorant when it came to parking in a disabled car spot. They thought I was normal until they saw me get out of the car and walk.

Julie

I don't know that I have ever accepted the losses. I still try to prove that I can do anything others can, which does not help.

Brumby

How I experience the losses is very cyclical and sometimes depends on things that are out of my control. So I try to minimise my "risk". For example, I don't congregate in places where there are a lot of mothers and children or families. I don't watch any Sydney Swans highlights as it immediately reminds me of my pre-encephalitis football fanaticism. I don't listen to music on the radio because the songs are generally on subjects that I may be sensitive about at the time. But unfortunately a lot of things can't be avoided. It's hard to be enthusiastic and not grieve when you're looking at

someone's holiday photos - grieving for the holidays my body won't let me take. And what's the point anyway since I won't remember much of it anyway? It's hard not to be upset that your friends aren't calling anymore. Sure, our lives are now headed in new directions, but should this matter anyway with long-time friends?
Iolanda

> "I am not a person who gives up easily. I try to meet the challenges head on."

At times when I'm feeling my worst I do get depressed, but I try hard not to let it get too big a hold on me. At best I feel regret for what I've lost. I often feel excluded, isolated and alone, as I seldom socialise with friends. Not being able to cope with many activities makes me feel guilty that I've let others down. I was once so organised and efficient, but now I feel inefficient, incompetent and often downright stupid. When I had to stop working I felt cheated as I'd lost a career which gave me much satisfaction. I often experience frustration with what I can no longer do and fear for what the future will hold.
Chrispy

Uncertainty about how long I will last; sadness as reality of losses gradually dawns; being forced to accept the reality of the situation.
Ted

- The experience of these losses has varied depending on the particular loss and again would vary according to time and space
- Deep sadness and frustration around the sensory loss of parts of my body.
- A strong desire to try and even remember/re-experience the past.
- Feelings of great aloneness in my experience of it all "if only they could experience it for a fleeting 5 minutes, then they would have a better understanding."
- My short lived moment of not being able to walk was frightening but fortunately I never really went to a place in my mind of not being able to walk and I have worked my body back up to a level of strength and endurance. I want to believe that I'll always have that motivation, determination and ability to come back. My history supports that thinking.
- I have experienced some shame around these losses.
- Lots of questioning why? Why do I need this experience.?
- The experience obviously slowed me down and this gave me a chance to see and appreciate all the precious things in my life, and the preciousness and fragility of life.
- I have continued to mostly feel determined not to let it take me down. I've probably been too driven to quickly pick up on my previous life with some small rearrangements.
- The reprioritising of my life and the listening into my inner world is slow and eclectic but I feel over the last three years I've made some good progress and in some ways there has been some growing up.

I'm tuned in to my needs more than ever before.
Olympia

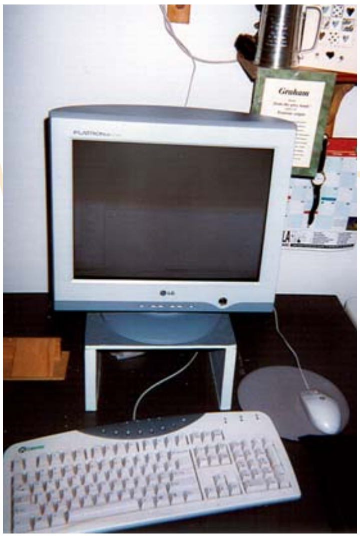
ISOLATION
I sit alone, exhausted.
Outside my pain,
the world goes on without me
– Helen

Probably the main effect on me has been a loss of confidence as I cannot do the things I used to. However I have also gained confidence as the experience has made me a stronger person. I am confident than I can deal with things in my life but there is also more for me to deal with. Confidence has always been an issue for me anyway. It is easy to accept that you can't do some things - when in fact you can. A chronic condition can easily become a dark cloud over your life, and it takes some effort (and confidence) to see that the sun is still shining.
Andrew

I think it gave me a sense of isolation, lack of self-worth, feelings of uselessness and not contributing to household, community or marriage.
Helen

Dealing With Grief Emotions

The strong grief emotions such as guilt, regret, anger and sadness can be intense and may make us feel isolated and alone. Grief emerges at a time when we are dealing with illness and may not be well placed to cope. Depending on our familiar pattern of dealing with emotion we might avoid or suppress the pain of grief. For a time that will protect us from the harsh reality of loss, but eventually the pain re-emerges and we are faced with intense emotion. Grief is not an easy topic to talk about or to listen to. We are rarely given permission to do so. Having access to support and understanding from trusted others appears to be most important in working through feelings and reducing the sense of isolation. Being connected to a network of peers who live with long term illness provides a safe place to speak about the difficult experiences of grief. Many of us have found the Internet has provided this opportunity to share feelings and information with others, without having to leave home. Some of us find it hard to talk about grief to others and we tend to avoid it. However, we don't give ourselves a hard time over this. Instead we try other, more personal strategies, such as relaxation, writing, body-work or prayer. We all learn that painful feelings lessen with time and we each learn what is most helpful in facilitating that. It is important that we do it in our own time, and avoid comparing our experience to others or to rigid frameworks about adjustment to loss. Grief is a complex process that goes back and forth and is highly individual. The uniqueness of the journey is highlighted by our voices about what we have found helpful.



COMPUTER
My window to the world.
Talking with people or being amongst crowds and noise results in me becoming extremely tired and often brings on migraine – Graham

What have you found helpful in dealing with and working through strong grief emotions?

I guess I become a hermit in these circumstances by creating an orderly life of routine and thus reducing new problems to more manageable numbers. I try to keep myself occupied with tasks I am able to do without too much trouble. I have also found that I have a capacity to try to help others and find this process helps myself. I received a lot of support within an internet group of fellow sufferers with the same illness as myself and wanted to pass that type of support on to others, so I started a website group myself. The knowledge as reported by some members that being able to express themselves to others who can understand what they are trying to say is a great help and assists them to cope. This gives me a great feeling that in some small way I have facilitated the support to others.
Graham

I'm not sure that I have actually found anything helpful. I often have a rant and rave to [my partner]. I don't often cry about it as that doesn't really achieve much. I tried writing in a diary but that didn't last long as most days I couldn't be bothered or couldn't concentrate for very long.
Michelle

I am not a person so far, who feels a lot of anger about life however I have suffered from regrets and guilt. Regrets take time and relaxation to gradually leave my mind and no longer bother me; guilt takes the same i.e. time and thought. I have a strong relationship with God and the divine world and this helps me a great deal. I have expected a lot of myself and so my expectations have changed and in fact, are probably more realistic. I accept myself as I am much more. Also, being in this group has helped me come to terms with the affects of my illness more than any other thing.
Di

I have always had my faith that has kept me going. I have a strong spiritual side and I have learned to love me for who I am. I am not going on about why me. It happens, you have to learn to deal with it. I never give up and try to keep positive.
Julie

What has helped me most is a friend who has gone through some horrendous experiences and we talk often. Writing it out of my system also helps. Somehow, the more I communicate it all helps.
Brumby

"Somehow, the more I communicate it all helps."

What's been 'helpful' has been dependent on what stage I've been at with each illness. During cancer treatment, I was surrounded with support from family and friends. Motivational reading and religion gave me peace of mind. Now I am seven years post-cancer and encephalitis (brain injury) diagnoses, and a few years past the brain tumour and Fibromyalgia diagnoses. Motivational reading and religion do nothing for me now and I get the most help from being online - being able to surf on topics, email medical communities and not feel "alone" in the world. I don't tend to express my emotions much to family, friends or even online. I tend to talk about physical things like my pain and fatigue or my lack of sleep. So in this respect it can tend to make the illness-process a bit more "isolating". I don't think people want to hear me 'whinge' too much, even if it's irregular, and online communities are generally for information sharing, not for plain, ol' 'complaining'.
Iolanda

I found a couple of Internet support groups for people with the same condition. Discussing issues has not only helped me find better methods of coping but allows me to feel I'm no longer alone. Having a supportive family, particularly my husband has been essential in helping me cope with what I've lost. Having a GP who listens, understands and treats me with respect is very important. Not fighting it is important and trying to accept it when times are bad, knowing things will eventually improve again. This is easier said than done, but I do try. A sense of humour is helpful. If I can laugh at some of the silly forgetful things I've done, it helps me keep it in perspective.
Chrispy

Acceptance of the facts; making the most of the time and facilities that I still have; finding (and distracting myself with) alternative activities (eg more music, radio, reading, concerts, movies, U3A/WEA classes, etc); accepting the support and encouragement of friends and relations.
Ted

- Staying with feelings, feeling them in my body which is easy with my condition. My body has become an excellent barometer of all emotions.
- Talking, attempting to do things differently, keeping physically busy, walking, body work
- Sometimes I write. I spend more time thinking about writing and composing things in my head, yoga stretching, hanging, massage, nurturing myself
- I wish I could cry more easily
- I work in a great place very supportive and stimulating where I have a lot of flexibility, feel loved and appreciated.
- Strong sibling and friend relationships
- Have found some good practitioners and peers along my journey

Olympia

It's not the most 'blokey' thing to do, but yes I cry at times (just don't tell anybody). Part of the process involves realising that we are undergoing significant changes in our lives and that it is normal to have these feelings. People around us play a significant role - it helps for them to understand the changes we are going through.
Andrew

Grief doesn't go along a continuum - grief emotions arrive in random order and you can go through the same stages several times, especially if new symptoms occur or you have a relapse. I have learned to develop new recreational activities, i.e. book tapes instead of reading, develop new friendships. This group has been a great help - talking to others who experience the same ups and downs and the same emotions.
Helen

Grief Is An Opportunity

Loss takes us down a path that requires much of us. At times it may seem there is no end in sight because the loss is often ongoing. We may anticipate more losses in the future and dread the re-emergence of grief feelings. Yet we do usually find that these feelings become less intrusive over time. Our feelings can be an opening into greater awareness of oourselves and our lives. This is especially true when we have had an opportunity to talk about our feelings and the personal meaning of the loss. We will eventually make sense of the loss through our own frame of reference and incorporate it into a changed self and life. We may then find that we have more energy for life and seek new involvement in relationships and activities. Life might be different but fulfilling and meaningful, never-the-less. Eventually we might begin to see positive outcomes of the journey in terms of changes in how we view our life situation and ourselves. Grief is a difficult experience but it can be a rare opportunity to find out what we are capable of and to get in touch with our humanity. It seems that the sadness and turmoil that grief brings may lead to a greater awareness of our self and re-evaluation of our attitude to life. There is little doubt that grief will bring the opportunity for change. We have some power and choice in whether we make it change for the better. Experiencing loss is part of our challenge to adapt to the changes that illness brings. It is also part of the opportunity that illness presents, to know ourselves better and to develop more meaningful ways of interacting with the world. We now share our insights about personal changes in our lives.

Has the experience of grief changed you?

I don't believe this has changed me, just changed the scope of my life to enable me to manage it. I am still me regardless. I would not say I am any stronger or weaker for the experience. I have been battling health problems for so long (16 of my 48 years) that I could not say if I have changed due to health problems and learning to cope with it, or whether any personal changes are just due to the natural maturing process over the years. Maybe some factors of my person have developed more or

less due to illness, but I cannot isolate them. My life has changed and I have had to adapt to this change. I am me regardless of anything else that life has thrown at me. Life carries on and I have learnt to keep myself moving with it. I do not like change and being ill has possibly brought this out in the open.
Graham

> "…I am a stronger person for all that I have been through."

I don't think that I can answer this as I think that I am still working my way through the grief. Until I joined this group I don't think that I had really faced up to much. Having a support base is good but often they don't truly understand. I've discovered that I'm a lot more patient than I ever used to be.
Michelle

I am much more empathetic to others with illness or troubles. I understand my own personality and illness much better as time goes on. I found that I didn't recognise or understand the impact of my illness for some years and blamed myself for not being strong enough and thought that perhaps it was something to do with ageing. I couldn't understand why I was not as strong as others when rushing down the street to catch the train, or walking up stairs. I wondered why suddenly I instinctively needed to know where the toilets are, do they have solid walls and whether a new workplace would have enough toilets. I found that I thought that nothing like this would happen to me, only to other people and now it really has happened to me. I am much more 'mellow' about the twists and turns of life's journey; I have had to develop a particular kind of confidence in that if I can't go somewhere or do something other people have to accept this or too bad. I do not worry about little things as much. They are just the trivia of life.
Di

The experience of grief has changed me in that I am a stronger person for all that I have been through. I feel I am able to help others through all my life experiences. I am now a whole person not a shallow person. I have found another me and I like the new me. I have learned to stand up for myself more. I have gained respect from others i.e doctors and friends because they know now that I am a genuine person and I fight for what I believe in. I am not scared anymore.
Judyth

I do feel I've become calmer, less judgemental, and more tolerant. I've found a lot of things that I don't like about the me before I started to go through this. I've found that I'm both stronger and weaker than I thought. I've lost any sense that there are absolutes in this life.
Brumby

..the most marked change has probably been that it's made me more insular as I don't really go pouring out my emotions much. I've also lost a lot of self esteem. Because of my blatant lack of memory I personally know nothing of who I was before my illness. Apparently I'm still the same hard worker I once was. Just a lot less energetic and much more quiet, stubborn and "cyclical".
Iolanda

‘Patience is a virtue’ and this was one virtue I didn’t have. Grief and loss have made me more patient with both myself and others. I have more caring, understanding and empathy for others who are experiencing illness or emotional turmoil. I better appreciate what I am able to do, rather than taking life for granted. I think I am a far stronger person emotionally than I was before I was ill, and hopefully a nicer one.
Chrispy

I think I have become more accepting of the increased limitations in life; less striving; less uptight; more relaxed. I do have periods of depression and resentment though. I am less afraid of death; whereas I used to be very task-oriented, I am now more able to go with the flow; I can feel loved and accepted by others in spite of being less bright and active; I can still get depressed even though I tend to be coping overall.
Ted

- I feel that the experience of grief is ongoing, and that I have learnt and continue to learn…that it’s 3 steps forward 1 step backwards.
- I feel greater compassion
- I feel more tuned in to the micro and macro suffering in and around me
- I crave for simplicity with great admiration for the complexity of life
- Lately feel okay almost relieved to concede fault or acknowledge another way
- Maybe embracing the darker parts of my self, wanting to accept the whole me
- Greater awareness and embracing of movement, difference and changes in life.
- Maybe a desire to off load and not get into attachments

Olympia

Things that I have found out about myself are:

- That I’m strong, hard, soft, scared, determined, obsessive, needing love and acceptance
- That I’m wise and silly, and love routine and spontaneity
- I struggle in trying to keep harmony between all the opposites
- That I over analyse and then leap without thinking
- That I’m a bit crazy, loving and generous, worldly and insular all at the same time with maybe a breath in between
- I’m lots of things and I’m on a journey and will no doubt collect and shed along the way
- I’m searching for inner peace and sometimes I’m with it and that always feels like a gift

Olympia

I do feel more ‘empty’ than I did before. Because of my illness there are things that were important to me that I cannot do and I have not filled this gap yet. I am more withdrawn than I used to be - tending to stay home more. It is important to accept that change will occur, and to find new activities in order to maintain a sense of worth. I think that I am stronger and more adaptable than I thought. Before I was diagnosed, I used to think how hard it would be to live with this condition. It is hard, but I get along pretty well. It is surprising what we can do when we really have to.
Andrew

I have learned to acknowledge and accept the losses - to grieve for the person I used to be and I have learned to be more or less comfortable with the person I am now. It has made me more tolerant and understanding of others. I have learned to expect less of myself and expect less of others - hard for a perfectionist to do. I'm stronger than I thought. I know who my real friends are.
Helen

Moving On From Loss

There will come a time when we find a place for our loss, even if we do not deal with it. We might still have memories and thoughts about what we have lost but we will find a way to move on with life. The way we perceive our situation and ourselves will change to accommodate the loss. We may then be able to invest energy into new ways of living and find new activities and interests that fit with our changed bodies and lives. This does not mean that grieving is finished. Grief emotions will be triggered from time to time, but they are likely to be temporary. Some people might feel that they will always look back on loss, remembering what was and what might have been. But they will also be able to look to the future and create a life that is fulfilling. We are faced with questions about how we will present our self and how we will build our life situation. New activities and lifestyle may assist this process and provide a new focus for the energy that was invested in grieving. Developing a meaningful life doesn't just happen. We have to create it. It may mean putting time and energy into new hobbies and new relationships or looking for opportunities for personal development or spiritual growth. All of this may be constrained by the limits imposed by illness but we can do this at our own pace, one small step at a time if need be. Our ways of thinking about aspects of life seem to have an important role in being able to move forward. We can change negative self-talk or images of ourselves that are not useful. Attitudes that focus on personal strengths and positive outcomes of the illness experience, rather than limitations, seem to be conducive to moving on with life. We each need to honour our grief journey, nurture ourselves as we grieve our losses and reach out to others to share the burden of loss. This is where having access to a network of people experiencing long-term illness can be so helpful. Feelings can be shared in a supportive understanding context. Here, we share our stories of what has been helpful for us in moving on from loss.

What has assisted you to move from grieving for the things that you have lost because of illness, towards finding new possibilities for your life?

It takes a long time to overcome the loss of being able to do everything as you could before. It takes a conscious effort to make yourself concentrate on what you are capable of doing and to not dwell upon the negatives of "what not". The proverbial "give yourself a kick in the butt" is not far from the mark. I may not be able to do a lot of things, and it can get depressing when you watch others do it, but I try to tell myself that this is life. If I am getting help with something then ensure I am helping that person so that at least I am still part of doing it.
Michelle

> …sometimes the losses rear their ugly head but not as often and they go away more quickly and seem more trivial.

I still look back at what I have lost, especially during a flare up when you are generally feeling down. I think it will be some time yet before I stop thinking about what I have lost. I don't dwell on it constantly but some things just trigger memories.
Graham

I have taken a few years to move on and I find relaxation, understanding fatigue and forgiving yourself have been little steps for me to alleviate the intensity of losses. Like Michelle and others, sometimes the losses rear their ugly head but not as often and they go away more quickly and seem more trivial.
Di

Its a step by step process so that you have really moved on from when first diagnosed. Being with positive people really helps you to follow your goals and what you hope to achieve with the rest of your life. You begin to find new hobbies, new people. When you are achieving new ambitions you find you no longer think about the past but rather look forward to the future because of your new ambitions. I found music to be calming, allowing me to think more objectively about what I really wanted out of life now that I am a different person. Again my faith helped me enormously. I read more about the mind and positive thinking. How you can achieve almost anything if you put your mind to it. I now have no fear in public speaking even though I have an atrocious voice because I believe in me enough to be able to do it. I even read a poem out at my daughter's funeral a thing I would never have thought possible in my previous life. I was so nervous of my ex husband's family and friends. Everyone knew them in the hills town where I lived. I also went on national telly for Fiona my daughter.

When you begin to feel comfortable with the new you I think you can look back occasionally and see how far you have come. I do and I feel so much pride in myself. I have learned to be peaceful about staying home and doing the boring housework and learning to do it with pacing myself. I am not angry anymore. Sure I sometimes wish but that isn't very often these days. I do what I do for now and look forward to learning more about my future.
Julie

I don't think there is a particular point in time where I've stopped looking back at the losses caused by illness. Sometimes if I'm feeling particularly bad or if some event triggers the memories, I'll look back at the losses but then I try to move on again. It's a bit like accepting illness, in that I move on and then take a step backwards for a while and then try to move on again. Forever looking back and thinking about the losses is negative and if I did that, I might as well just give up completely.
Chrispy

I have to make the best of what I have and what life has to offer. If I didn't and allowed myself to just wallow in self pity, then my quality of life would be even less. Life, even though illness has robbed me of some of the things I once took for granted, is to a large degree what I make it. Having a very supportive, understanding partner, has and is assisting me to do this. Having someone who accepts me the way I am, rather than who I once was, helps me accepts myself as I am now. That in turn helps me look beyond the losses and try to find the new gains and achievements that I can make in the future.
Helen

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 myself
Ted

I don't know that I've ever stopped looking back completely. I still tend to go over and over things. That is not to say I don't look forward, because I do, but the two can co-exist. Perhaps this poem I wrote explains my process better than I can.
Brumby

I try to refocus the camera
move further back
but somehow the whole picture
takes on a grey tinge.
I zoom in on one corner
a speck on the lapel of the present
an anecdote that's worth smiling at.
Present pain no pain present
no, there's no poetry in that
and anyway, I should have more self-control
turn an elegant phrase
polish a metaphor
scrubbed clean of self-pity.
Brumby

I think it is important to try and keep up your previous activities as far as possible. It may take some extra effort to work out how to work around the conditions and problems that may crop up as a consequence. So you really need to think things through:
Andrew

- Learn about the condition, how it affects you and what can happen. Gain confidence in your management of the condition.
- Look at activities, think about how your condition and activities may affect each other. Find ways is which you can deal with these potential problems - for example to do these activities with a friend who knows about your condition, have a mobile phone available etc.
- Take the plunge and give it a go, knowing that should things go wrong, you know that it will be dealt with.
- Often, getting out and doing things will help manage the condition. Exercise CAN (not always) help with stress, tiredness etc
- Be PROACTIVE - not only in the management of our conditions, but our lives as well - go and find things rather than sit back and wait for them to appear.

Iolanda

I think my feelings, thoughts and experience of grief, and the losses are always there somewhere in me and they travel deep down out of consciousness or just into another realm of my experience then surface again with variations in intensity and need for response. I've accepted my illness in the way I have learnt to accept things in my life, and that's unique to me. Sometimes and mostly I don't think and/or experience many things in life with beginnings and ends. They just are full of daily life activities all of which I mostly do with some passion and purpose. Most things I do keep me connected with life beyond but also inclusive of me. I love to hear and talk about ideas, thoughts, experiences also doing things that keep me earthed and connected to life. ie I love to pick olives and then cure them, and even better is opening the vat 12 months later and enjoying the harvest, collecting and admiring my garden even though it's small. I fantasise about what I could do if I had the strength and then say 'slowly, no rush'. I do occasionally wonder if I'm on track, am I doing it the "right way" only to be quickly reminded that this is my way, and my way is a collection of what I have gathered through my life, part of who I am. I feel mostly confident in being able to assess when something is not working for me, maybe the biggest thing I'm learning in this whole process is that I need to take care of myself and others in the processes I use in dealing with change.

Olympia

I think it is easier to stop looking back once you have achieved a routine. When life is uncertain from day to day you tend to cling to the old ways and look at them with fondness, even if the reality was dreadful. [The devil you know...] I'm not sure that you ever fully stop looking back at the losses, at least I don't. Maybe not in a breast beating kind of way - now it is more of a wistful - "if only,,," An example. Today someone said "I wish I wasn't working" to which my reply was "I wish I still was". I would very much like to be still able to work and times like this bring home to me the costs - financial, emotional, social - that are part of having to leave work at the age of 54. As I said, it is only fleeting and certainly not angst-ridden… more wistful. I think the more you can replace that which is lost with something, the easier it is. If your days are full of nothing it is very easy to be looking back all the time. You need a reason to get out of bed each day, something to look forward

to, and some achievement however minor, to look back on at the end of the day. Some days my big achievement is staying out of bed all day! Also focussing on the things that are possible because of my illness. Some examples are I have more time to spend with family, friends I have made only because of my health problems, things I have learnt and strengths I realised I have only because I have these problems to deal with.
Helen

Our Message To You

Learning to live with chronic illness is not easy and is a process that takes time. Part of learning to live with illness is letting go of the past and valuing the future. It is important to allow yourself to feel and express your feelings, otherwise you may not understand your responses to events that are happening around you. Allow yourself to grieve and acknowledge that grief for what it is. Where possible, find support, whether that be in a support group, a health worker that you can relate to, or a friend. Often people with chronic illness can relate to each other's experiences, even if the medical diagnosis is not the same. It is important to keep communication open with partners, friends and family members so that feelings and resentments don't build up. It is possible that everyone's needs can be met, even if it is not in the same way as before illness.

Avoid negative self-talk. It is not helpful to put yourself down. Look for ways to be proud of your achievements. Think about ways that you may adapt or modify some of your activities, break them down into small parts and work on a little bit at a time. Trial and error will determine the most livable choice (and this means that you will make errors!). Find ways to value new activities and relationships that come into your life.

We need to be informed about our illness in order to manage the physical symptoms as best we can. Educate yourself about your condition. It may be important to find out information about the symptoms you are experiencing in addition to the condition. For example, if you experience fatigue, then search for information about fatigue in addition to information about your diagnosis.

Take the time to pamper and nurture yourself with things that you enjoy. Be kind to yourself, value your own company, become your own best friend and find your self-worth based on inner strengths rather than on what you do. Strive for a balance between work and play, rest and activity, relationships and solitude, and grief and joy. Learning to live with illness is a process that evolves over time. Give yourself the time you need for this learning to take place.

Our Message To Health Workers

Health workers often refer to the terms ‘acceptance’ and ‘denial’ when describing how individuals respond to chronic illness. Those people whose understanding of the illness experience relies upon the acceptance/denial framework may not listen when people with chronic illness attempt to tell their own unique story of how they have experienced life with illness. Instead, health workers may focus on fitting aspects of the experience with stages of adjustment. When the labels of acceptance and denial are used, people who are learning to live with a chronic illness may internalise these labels as reflections of the self. This may be most likely when the person using the label is perceived to have authority, such as a health worker. The internalisation of negative information associated with these labels may obstruct rather than assist the reshaping of self-identity that is fundamental when people are learning to make the transition to live well with chronic illness.

People who live with chronic illness do not want to be seen as diminished. If we understand the fluctuating response to long term illness from the perspective of striving to fit with social norms and maintaining a sense of power and control, it becomes possible to understand behaviours as the individual’s attempt to preserve a valued sense of self and identity. The fluctuating illness experience is perceived as the individual engaging in processes of trial and error and navigating their way through a social context that is often unsupportive and sometimes suspicious. We contend that labels of ‘acceptance’ and ‘denial’ are not helpful and may obstruct this process. Rather, the willingness to listen and to understand what is happening for the person at the time, resisting the temptation to categorise, and honouring their account will go a long way in assisting the person to feel respected and truly supported. This approach is likely to foster a valued sense of self for the person who is learning new ways to live with illness.

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 bought 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 questions 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.