

Transition in Chronic Illness

Our Inner World



BOOKLET 9

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

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

Email: researchunit@rdns.org.au
Website: http://www.rdns.org.au/research_unit

Titles in the 'Transition in chronic illness' booklet series

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



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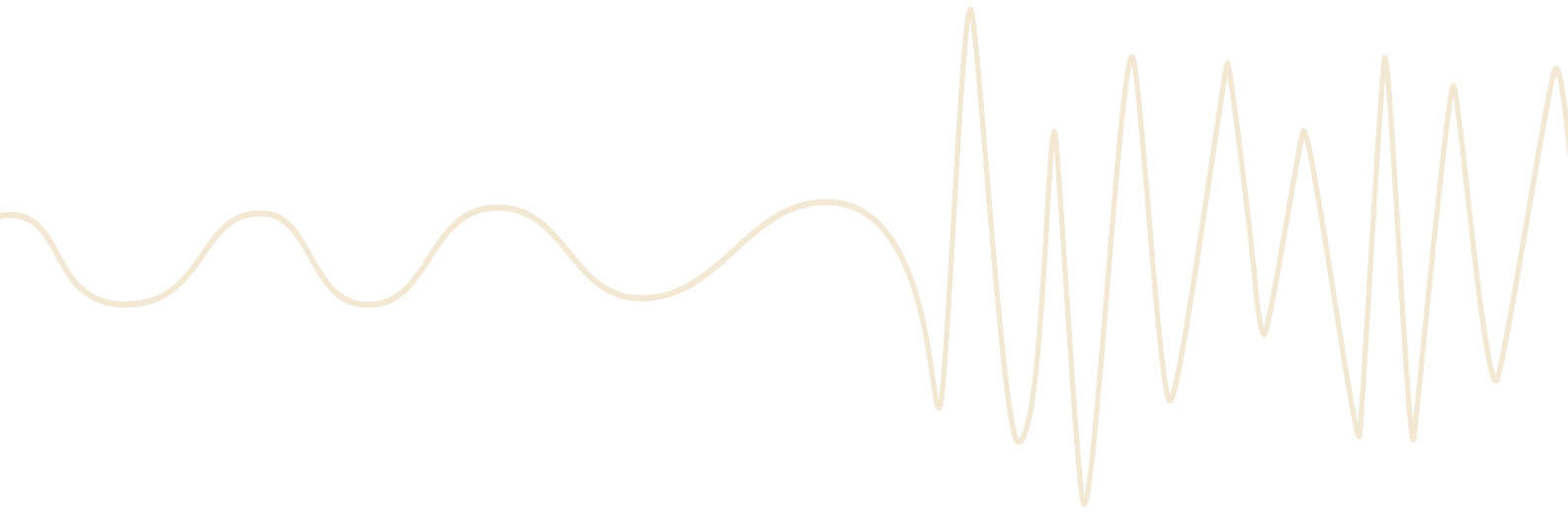
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I've changed a lot. I used to be very volatile and excitable, now life flows by and I do what I can, letting what I can't change just flow past. It suits me now. I may have changed as I've aged... ripening maybe?

A Changing Perspective

The onset of chronic illness may throw our lives into chaos and confusion. Life as we knew it becomes disrupted. Each person makes sense of what is happening to them through his or her own unique value or belief system. We want to recover from the mayhem that illness creates and restore a sense of order. For a period we may be 'all lost at sea' as we try to reconcile the reality of illness with our personal values and expectations. Eventually we will strive to reframe the experience of illness and what it has meant for us, to create a new lifestory, where we have a vision for the future that upholds our sense of self and enables us to continue on with the sense of living a 'normal' life.

When we have a meaningful understanding of the presence of illness in our lives we are better able to cope. It enables us to interpret and make sense of the fluctuations of illness and its consequences. We are better able to weave the experience of illness into the fabric of our world and to reclaim a sense of order in our lives. In doing this our values and attitudes play an important role. When the reality of the experience of illness conflicts with our values we may gradually come to replace them with values that better reflect the situation, and in this way we make meaning of the experience. For example, if one holds the value of hard work as a priority, this may not be relevant to life once illness intervenes. The lack of fit between personal values and the new reality of life with illness causes discomfort and angst. Eventually, we reorder our values so that 'hard work' as we knew it shifts to a lower priority and we replace it with valuing other aspects of life. This reordering might take some time because shifting our values means accepting that the reality has changed. The process or reordering of values is ongoing throughout our lives and is an important part of the way we adjust to life changes. It is central to restoring order in our lives. We talked about how our values and attitudes have shifted as we searched for understanding about illness.

What has been the relevance of your attitudes and values to the experience of living with chronic illness?

Illness has always been something to be endured or ignored ...just carry on with life. This belief seemed to be backed up when I eventually did see doctors to be told it was minor and nothing much could help. It took a long time for me to come to the realisation that the chronic illness was something I could not ignore, and unless I made lifestyle changes it would continue to diminish my life. I had even gone through a 6 year period of continually rupturing spinal disc which necessitated three operations without fully recognising that I had to change life drastically. At that time it was just physical pain and disablement that was the problem, again something that



IS THIS
A cocktail of drugs to get you through the day?
OR
A cocktail of broken hopes & dreams?
OR
Is it both?
Michelle

can be ignored and relieve with medication when necessary. However my current condition is more than just physical pain, but involves my capacity for clear thought, interaction with other people and a general lack of drive and energy. It took me years to actually admit I had to change, and in fact I am still developing a lifestyle to suit my abilities. This was a gradual change as my loss of abilities chipped away at my lifestyle, me giving way a bit at a time. Eventually I found that a total change was necessary as I realised that the illness was not about to 'go away'. This realisation has made life much easier for me as I learn, and still am learning, to live with my abilities rather than fight my losses, which I guess is what I was doing.

Graham

I have the attitude about most things that looking for information and knowledge helps me to adjust to whatever is happening and in this case, it is my chronic illness. I value good information and also hearing about the way other people with the same illness cope and what happens to them. I am filled with admiration often about other people who have been through much worse times than myself and still have a good sense of humour and help others by telling their story.

Di

I believe I have achieved much since my journey with chronic illness. I can empathise greatly with others through learning, experiencing and achieving which I wouldn't have been able to do if I had never had chronic illness. Makes me more aware that I'm not alone with chronic illness and that helps a lot to keep it in perspective. I have looked at others who have been spared heartache and to me they do not seem understand what others go through.

Julie

It is not so much attitudes and values that have influenced my life with chronic illness but transformations to my understanding of the social construction of life. It was chronic illness that led me from electrical engineering to the humanities and to the particular interpretation of environment that I have developed. That understanding builds on the notion that if one recognises that we create our structures of interpretation then we are responsible for them and the actions we make with them. We are responsible (i.e. we care) for the way we deal with the environment. This has in turn transformed the way I interpret/live with chronic illness, the health system and indeed with health itself.

Frank

Probably my strongest value - or belief - is in the importance of our psychological standing and reactions to what happens to us in our lives. And this is applicable for everybody, not just those facing chronic illness. I've always maintained that bad things happen to everyone, but the important thing is how you cope with it all. Although I've been commended by members of the medical profession for the way I've reacted, coped and adapted to my many problems, it's been easier because of a few things. I'm living with great parents that would do anything for me, I have access to the internet which feeds my heart and soul, and I have peace in the knowledge that my future is free of suffering or degradation because I'll be able to access voluntary euthanasia should the need arise.

I've also always been a hard worker, trying to do the best that I can in whatever I do. And this attitude has been very necessary and very useful in recovering from the encephalitis and trying to make the best of what I've got left. I've also got a greater appreciation of everything, including the smaller things. For example, I'll go out of my way to take a small insect that I've found in the house and put it outside in the garden. And I feel good because I may have saved its life.

Iolanda

Becoming progressively ill over a long period of time has probably helped me cope better than if I had suddenly become very ill. As a result I don't feel I have been robbed of my life, as I might have done, yet my attitudes and values certainly play an important part in coping with chronic illness. Everyone has to deal with adversity, be it illness, disappointment, sadness, grief, hardship or any other experience that life may 'dump' on them. Many [people] have to cope with far more than I do. Feeling sorry for myself, feeling hard done by or angry, giving up completely, or any of the other negative emotions we all feel when confronting adversity, for any length of time is pointless and counterproductive. I can't change what has happened, so what is the point. A positive attitude doesn't come naturally to me, but I try to make the best of what my life is now. This isn't a consistent thing and sometimes I feel negative for a while, but I keep trying. I aim to value the important things in life, such as my husband, family and friends and all the special little things I once didn't have time to appreciate. I try to make the most of the good days and get through the bad, knowing things will eventually improve again. I refuse to allow illness to dominate my life.

Chrispy

Illness is something that I have lived with, either secondarily through my parent's illnesses, or in a primary way through my own illness. Through reproductive health difficulties I faced regular pain and have endured many losses throughout my other illnesses and health issues. I guess my attitudes of having courage and living life because it was all there to be lived caused the pain to go onto the back burner. But after a series of further health problems the pain really increased in a major way causing upheaval and change to my life. My whole life and future options changed, so following the pattern

I value good information and also hearing about the way other people with the same illness cope and what happens to them.

of my life I turned to Him [God] to make sense of it, to enable me to cope with and address the pain wisely and to know what to do and what not to do. Illness and its consequences resulted in losses related to my career as well. Now I look back and see that God did a lot with the time I had due to ill health. I had opportunities to learn different skills and to complete my journey as a daughter and be with my Mum in her last days. I have learnt the value of silence, rest and living at my pace not the pace of others. I have shed a lot of false guilt about not doing things. The answer to this question is in looking back and seeing that He [God] has led me well and wisely through a path I would not have chosen but has given me good things along the way.

Glenice

I think I have always been a 'practical' person but my illness has made me more so. I find that sympathy is much less important to me - either giving or receiving, but rather want to get on with finding a solution. It has made me harder and stronger and probably made me somewhat detached from people emotionally. I still value people, but in a different way.

Andrew


When I came 'down' with MS I wasn't really surprised ...I'm not really sure where that came from. There was a deep familiarity with what I was experiencing, 'a knowing' of the experience. Had I dreamt it, was it from a previous life, were there signs that had been appearing for some time that I hadn't connected together? Was there an emotional process that I was experiencing that in retrospect mirrors my now current physical experience? Does my interpretation of the disease, a hardening process of the nerves relate to my lived experience of loss and grief from an early age??? Whatever there is a strong familiarity. I grew up with 'Life wasn't meant to be easy!' 'You deal with what comes your way' attitude. I was raised believing that I was ultimately alone in the world and that I had to deal with it the best I could. I had significant people around and in my life that were just getting on with it. My family was like a collective. We all had our jobs and roles. There was always something to be done. Play came last and sometimes never. We actively lived off the land, lots of people and animals in our life to care for and consider. This has all contributed to my attitude and values in living with MS. I have a 'get on with it' attitude. In my latter years I have chosen to incorporate gentleness in the caring and getting on with it. In my childhood there was harshness in the attitude. That harshness still surfaces particularly in the ways I judge myself and others. I have learnt to value and work with what comes into my life with a belief that I'm growing into a better person with the experience.

Olympia

My attitudes and values are very relevant to living with chronic illness. They give meaning to my life; they remind me that there is more to life than this earthly life and give me the promise of a heavenly body that works perfectly.

Helen

“My attitudes and values are very relevant to living with chronic illness. They give meaning to my life...”



I have developed an appreciation of the smaller things in life and how wonderful relationships can be when you can concentrate on the smaller aspects. A very enriching and rewarding experience.

My attitudes and values are closely entwined with my spirituality and faith, all of which play a central role in the way I view my experience of living with chronic illness. They provide me with meaning for living with diabetes, and allow me to view life beyond the limitations of my physical illness.

Mari

A Changed Perspective

Illness is an experience that is likely to cause a shift in our attitude and belief system. The complete upheaval to life is challenging and may lead us to think differently about our situation because it no longer fits with long held values. Ultimately our perspective on life shifts.

For most of us, these changes in perspective have been viewed as ‘positive’ because they enable us to live well and to attain a sense of control and order. The changes mean we can view our situation and ourselves positively, upholding our dignity and self worth. We may make some dramatic changes to the way we relate to ourselves and the way we manage illness. For example, some of us have learnt to prioritise our own needs and take better care of ourselves than we did prior to illness. This is in keeping with living well with illness and reclaiming a sense of order. Life becomes less chaotic and unpredictable when we attend to our needs.

One other example of a shift in values lies in the attitude to employment. Participation in work and community are highly valued by most people, but when living with illness, many of us has found this to be exhausting and counterproductive. Therefore we have developed a deeper appreciation of the smaller things in life, a ‘taking time to smell the roses’ attitude. Priorities have been reordered to value the aspects of life that may usually go unnoticed or are taken for granted. Along with these changes there is a sense of enlightenment and of knowing what’s important in life. We discussed the changes that have occurred to the way we view the world and ourselves.

Have your attitudes and values changed throughout the experience of illness?

I have come to realise the importance of the small things in life. When you are feeling well your life horizons are those of dealing with the outside issues of life, work and relationships. Illness has reduced my horizons due to the exclusion of external work influences, and now I have developed an appreciation of the smaller things in life and how wonderful relationships can be when you can concentrate on the smaller aspects. A very enriching and rewarding experience.

Graham

Yes, my attitudes and values have changed. I find that I am much more compassionate towards anyone with problems or disability, older people with walking frames in particular. I don't just look and brush the sight of them out of my mind thinking that could never be me. It could be me, it could be you. I value friends more and also the little things, like a lovely flower, the fresh air, wonderful gum trees, little living things like animals, lizards and insects and that Australia is a free country. I cherish myself more. I don't push myself as much to do things I really don't want to do. I don't stay friends with people who are rude and really not true friends. In my mind I stand back and observe people more than I used to, and I am calmer. I understand myself better than before and have adapted to the fact that nobody except those with a chronic illness, can really understand how we have to pace ourselves and deal with fatigue, pain and remembering to take medications.

Di

I can't answer this very well because I have had pain all my life.

Julie

Again, changes to my understandings of the social constructs underpinning my life have led to a total transformation in my approach to life and therefore to chronic illness.

Frank

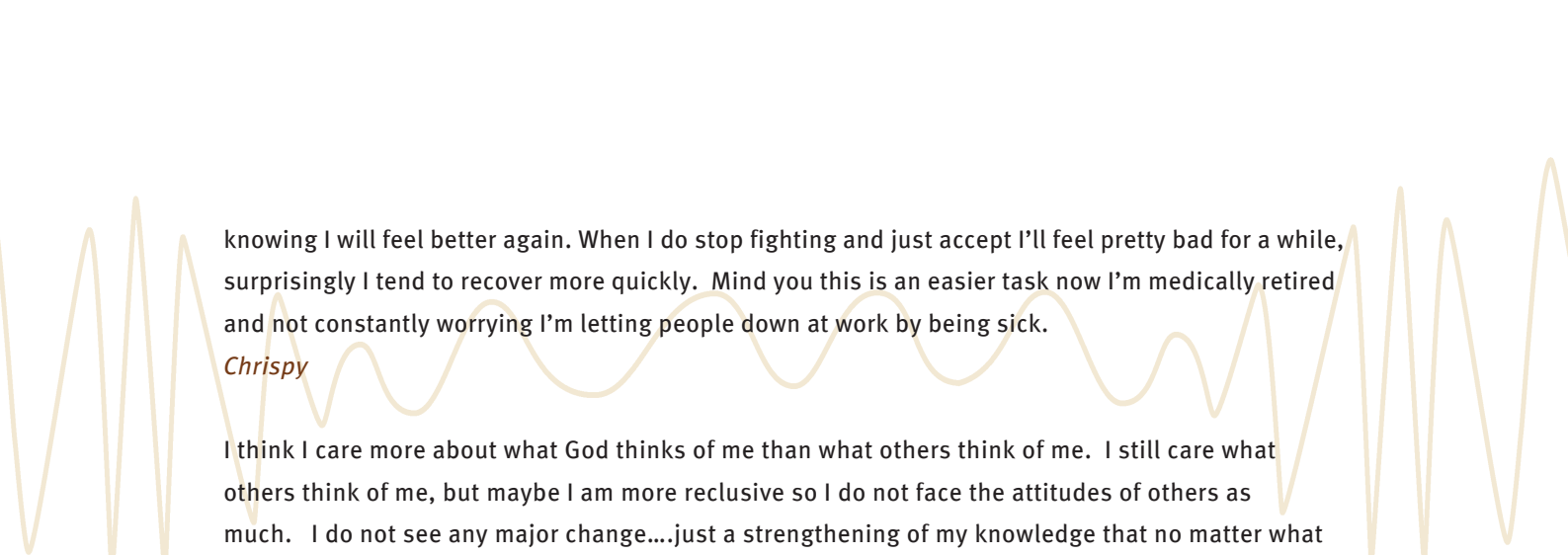
Unfortunately I can't answer this because I don't remember how I was before getting sick...

Iolanda

Illness has
taught me
compassion,
caring,
understanding
and tolerance.

It's hard to remember the person I was before battling with chronic illness but I know I was more negative, shallow and self centred. Illness has taught me compassion, caring, understanding and tolerance. I've become less critical and judgemental. I better like the new me.

An attitude I am still grappling to change is "fighting it" when I'm having an adrenal crash, in pain or feeling particularly ill. That doesn't mean I turn up my toes and decide to die, but rather try to accept it and flow with it,



knowing I will feel better again. When I do stop fighting and just accept I'll feel pretty bad for a while, surprisingly I tend to recover more quickly. Mind you this is an easier task now I'm medically retired and not constantly worrying I'm letting people down at work by being sick.

Chrispy

I think I care more about what God thinks of me than what others think of me. I still care what others think of me, but maybe I am more reclusive so I do not face the attitudes of others as much. I do not see any major change....just a strengthening of my knowledge that no matter what happens, God is faithful. I would love to be fit. I have to get back to gym. My rheumatologist said the other day, 'you have been this low before Glenice and you will get back up again'. Now I guess I have to find the courage to drag myself to the gym in the new year and push through pain barriers when it is easier to stay in bed and read. And I guess I do it because I see my life as belonging to God and available to Him, and therefore if I am told I will be better if I push harder and exercise etc. then it is a response of obedience first to God, then to the medico to do it.

Glenice

They haven't really changed, maybe grown stronger particularly the caring of/for myself, through being more available and conscious to my needs and not others. I used to spend so much time on the needs of others or wanting to 'make their lives good', give others what I would have wanted for myself. Now I give to myself before others, mostly! I have also grown up with a belief /thinking that life is a quest and the quest was always focused outwards before I got sick. Now it feels more like an internal quest to find peace and harmony with in. In fact that feels more like my challenge in life as opposed to my chronic illness. I guess I ultimately believe that my chronic illness reflects my loss from a true self, a happy self, a playful self. I value the hard working busy self and my life so far and truly now want to add balance to my life.

Olympia

I don't think they have changed much.

Helen

It is difficult to imagine the adult I may have become without chronic illness, given that I was diagnosed with diabetes as a young teenager. I believe diabetes entering my life at such a formative age has made me a different person to whom I otherwise might have been. In the time I have had diabetes, the experience of living with chronic illness has 'softened' me. I have developed more compassion toward myself and toward others. This embraces love, forgiveness, openness, honesty and integrity. Life is more than the physical experience and our material environments.

Mari

Values Inform The Approach To Coping

Values and attitudes play an important part in the response to chronic illness and the way we cope. Some values may constrain our efforts to cope and we may have difficulty with the gap between what we believe and the reality of life with illness. We might resist letting go of our values and continue to place unrealistic expectations on ourselves. This is an understandable reaction that we have all experienced but over time we have learnt that this path makes living with illness more difficult. It can have a range of adverse consequences for the way we experience illness and the way we cope with its challenges.

The experience of chronic illness is a process of ongoing learning and development. Usually the desire to cope and live as normal a life as possible will eventually lead us to maintain or acquire values that are supportive of adjustment and coping. This process takes time and is different for each person. We learn to create a value system that enables us to live as best we can, and to do that we let go of values that hinder our efforts to cope. There are expectations attached to values and we have referred to and internalised them as we have worked out ways to incorporate the daily challenges of illness into our lives. For example some people refer to the valuing of courage and positive attitude, spiritual faith and taking time to appreciate smaller things as lynchpins to their coping. When we embrace a value, we modify our attitudes and behaviour to be congruent with that value. A shift in our perspective can have a ripple effect in terms of the way we think about and manage illness in our daily life. Here we share some of the values or principles that have enable us to cope with illness.

Can you give an example of how your attitudes and values have influenced your ability to cope with chronic illness?

Some attitudes and values can have a negative effect, especially those related to relationships, external to your close family. The lack of understanding of my condition by many people has had a very negative effect on how I have been able to cope. However the pulling back to the smaller issues of life and relationships has given me true help in coping. A saying I think would fit how I am learning to cope is to “stop to smell the roses.”

Graham

I admire courage and value strength and a positive attitude. I am not sure as to whether I am courageous but I like to think I have some strength in coping with my illness and not caving in, whingeing or expecting others to pander to me. I believe that I should live my life, really believe in the Divine who will always be there within me and do the best I can always even if the best isn't much. I am more willing to adapt and adjust to the fact I have to choose carefully what I become involved in rather than enthusiastically rush in and volunteer.

Di



THE TRANSPORT DEVICE FOR THE INCONTINENT

There is no other means of getting around a city that so quickly and conveniently gets one into a toilet. I am non-visibly disabled and the bike just complicates people's failure of imagination. The reality is that my bicycle is my "two-wheeled wheelchair".

– Frank

My faith in God has helped enormously in dealing with the pain. I know He will not give me more than I can handle even though I feel I have been dishd out enough. I must be a very strong person to be able to deal with all I have. I know that my attitude is that live is each day as it comes not look at the past or the future. This helps me to cope. I know that God suffered more than we ever have. Dying on the cross would have been the most horrific death, He was different but He never let that stop Him believing.

Julie

The "bike path to continence" or the transformation from a pretence of "normalcy" to "being my disease".

Frank

Being a hard worker has really helped me. Whether it's in the form of attending a few memory courses or a cancer survivor's conference. Whether it's learning how to use the Internet or trying to learn more programs including web design, all in the quest to feed the brain cells in one way or another. Whether it's seeking the medical opinions of international pain specialists (via email and fax), or seeking support groups. To quote Janine Shepherd, "Never tell me never". I'm also more compassionate, but this is probably something that I share with a lot of other cancer survivors. I also try not to worry about anything because worrying won't get me anywhere. The fact that I don't worry about any future is best exemplified by a cancer recurrence scare in 1999. I literally didn't waste ONE moment worrying about it as worrying wasn't going to get me anywhere. And of course I had the ultimate 'safety net' in voluntary euthanasia.

lolanda

One example of my ability to better cope with illness is that I've developed more self-respect and confidence. For over a decade, I knew little about my rare condition and could find precious little information or get adequate support from doctors. I felt very alone, insecure and anxious about the future. Finally I gained access to the Internet, was able to help myself by researching as much as possible and for the first time received the support of others with similar conditions. I now feel less alone and vulnerable, rather I'm progressively developing belief in myself and becoming a stronger person. I can now formulate the questions I need answers to and feel confident and knowledgeable enough to ask them. I respect my own judgement and expect medical professionals to respect and

“...I’m progressively developing belief in myself and becoming a stronger person.”

listen to me. No longer will I accept my concerns being brushed aside or my symptoms trivialised. If they won’t listen, though my access to medical professionals is severely limited where I live, I’ll look elsewhere for support and treatment.

Chrispy

I guess the best example I can give is that I would have taken my life by now if I did not believe it was not mine to take, but a gift to be used, and that as my days go by, so will my strength be

diminished. If I end up in a nursing home, then yes I guess I will hate it but if I am to reach people and communicate God’s love to them I can do it just as well there as anywhere. I recently actually defined my goal for the rest of my life. And that goal is not dependent on my physical abilities. It can be achieved wherever He [God] places me.

Glenice

Becoming more practical is a bit of a survival skill. Living with a chronic illness that requires continual monitoring means I cannot afford to ‘fall in a heap’; somehow I just have to continue to look after myself.

Andrew

I think because my focus hasn’t been my chronic illness I have stayed connected and in pursuit of all my ‘other’ needs. I’ve integrated my chronic illness. Naturally that has changed in perspective and/or intensity depending on my needs at the time and over time. For example I remember a time when I couldn’t walk and was taken down to the beach and I looked over my shoulder and saw the most brilliant moon rising. I felt so happy to be able to experience something so beautiful at that moment. I also remember thinking that if I can’t play with my boys I can at least hold them and talk with them and I truly felt so happy, with that thought. I remember often my thoughts going to what I could do as opposed to what I couldn’t do, maybe because I’ve always been a ‘doer’ and I would also think that when I no longer ‘could do’, I ‘would be’. But in fact I’m trying to learn ‘to be’ now before I no longer have the choice. I’m also not spending a lot of time in the future, in fact I have worked hard on that very consciously and feel good about it.

Olympia

They have influenced my ability to cope in many ways. The promise that God is with me in this as in everything else and that He will enable me to cope with whatever comes is a big help. Knowing that I do not have to cope on my own means a great deal. It means too that any tendency I might have to end it all can be overcome, just because I know I am not alone.

Helen

There have been some dark times in my experience of illness. My attitudes and values have kept me from finishing life prematurely, although part of me has sometimes wanted it so badly. My faith has given me strength and insight to persevere through or overcome difficult circumstances.

Mari

I remember often my thoughts going to what I could do as opposed to what I couldn't do...

Reframing The Experience Of Illness

Values and attitudes also inform the meaning we attach to the experience of illness. We are constantly attaching meanings to events and situations that happen. This is how we make sense of our world. There is no doubt that the illness experience is difficult and challenging. Yet many of us have interpreted the experience of chronic illness as an opportunity to learn about ourselves and to improve our attitude toward others. Our perceptions are that the process of adapting to living with illness has developed us as people. We recognise that the experience of chronic illness has given us a perspective on life that we may not otherwise have. With this meaning, the illness experience has been reframed as an opportunity to develop personally and to gain insights into others and ourselves. Consequently the journey is viewed as worthwhile and each challenge is tackled with a sense of purpose in mind. We are able to experience a sense of achievement, pride and continuity with life. This perspective enables hope and a vision for the future. It develops resilience to endure and move through the difficult times. Each of us has developed a meaningful perspective on the experience of illness that we are comfortable with and we discuss that now.

What meaning do you attach to the experience of living with chronic illness?

I guess I am a fatalist at heart. Things happen because they are destined to be and you have little control over these things. I went through a period of 'why me' at the beginning, but that has passed as I realise that it has happened and nothing can reverse it.

Graham

I suppose I am a less judgemental person. Before my illness it never occurred to me that I would ever have a chronic illness. When I look back I had little understanding of what some people with illness had to deal with. I had compassion for people with disabilities in wheelchairs for example, or people with an intellectual disability because of having worked with people such as this. Also, I studied disability and independent living for my Masters degree. Despite this, I had that usual arrogance of most people because I didn't think that could ever be me.

I am not as sensitive about the things other people say or how they act, because I know in life, it is not very important. Living as full a life as possible as best you can is important and the experience of having a chronic illness has taught me that. Just living your life as best you can, accepting yourself and not comparing yourself to Einstein or some famous movie star. We were all born to be here.

Di

I went through a period of 'why me' at the beginning, but that has passed as I realise that it has happened and nothing can reverse it.

I believe it has helped me form a closer bond with God. I believe faith helps because you are not alone with your thoughts. I believe God does perform miracles I have witnessed first hand since the death of my daughter. I keep being positive with my thoughts I don't dwell on the negatives. It doesn't help and in fact creates more stress. More stress on the body creates more pain. My spirituality is deep as I feel God is with me as I go about my day. I leave my life in His hands. Only He knows when my time on earth is up. When people complain they are in pain I try to help them. I ask about their beliefs and if they don't believe I pray for them and they seem thankful for that. I never question why anymore. It's not important.

Julie

Probably the same liberation inherent in any trauma for any personnoting that what is traumatic for one may not be traumatic for another.

Frank

Meaning? Well, if it was supposed to make me a better person, then I'd gladly go back to how I was before getting sick, warts and all. By all accounts I was a great person. In my opinion there's no meaning to it all. Some people will get sick, some won't. I got sick. Full stop. The thing that's important is how you deal with it all.

Iolanda

I didn't think my illness had any particular meaning. I don't blame God, anyone or anything. It just happened. On contemplating this question, now I'm not so sure. Perhaps it's up to me, to make sure my illness does have meaning. If I let it, illness can leave me embittered and always pining for what might have been, or I can use it to discover a new meaning and give my life worth. We can't all be famous, brilliant, talented, or invent or do something for which we will be remembered, even if we are in perfect health. Illness is teaching me, it doesn't really matter what I can no longer do. What is of far more importance is the person I can be and how I can make a difference in the lives of others by giving love, time, care and support rather than commiserating over what I can no longer do. Much of this I probably wouldn't have thought about or found the time for, had I been healthy.

Chrispy

Living as full a life as possible as best you can is important and the experience of having a chronic illness has taught me that.

I don't know that I have thought about attaching meaning to it but there is a verse in the Bible that says let patience have her perfect work. I can see that just as silver is refined by heating and the scum is taken off until the refiner can see his face reflected in the clarity of the silver, so I have handed my life to God to shape and refine according to His divine purposes. So there is an acceptance, a serenity of faith in His purposes if you like. I guess that gives some extra meaning when the tough times kick in.

Glenice

The positive side of making me stronger and more practical is that I can help other people as well.

Andrew

Very similar to the meaning I attach to experience of living. I am here to learn, some lessons are harder than others, its an ongoing process backwards and forwards. I feel blessed, privileged, loved and loveable. Some days I go with strength and fire in my belly both negative and positive, other days I go slow with love or sadness. Often depends on how in control I feel of my choices. Living with MS reminds me of how strong I am.

Olympia

I am here to learn, some lessons are harder than others, its an ongoing process backwards and forwards.

I think I have become a better and stronger person through living with chronic illness. I am also much gentler and easier to live with. It has made me rely on God more and to realise that I can't do it all myself.

Helen

Inherently, having illness is not enjoyable. Therefore it is important for me to find meaning in my illness that provides me with some assurance and life perspective. For me, the experience of living with chronic illness is an example of life's journey, full of learning, ups and downs. It's a journey that teaches me more about myself, my Creator and my place in this world.

Mari

Ways Of Coping

The meanings we have for our experience affects the way we cope. The challenge is to arrive at a meaning that feels right and enables us to move forward. We have some power in how we view our situation. The old cliché ‘its not what happens to you that is important but how you deal with it’ really does apply to the illness situation. It is helpful to find ways of feeling good about ourselves and our lives with illness. We usually cannot change that we live with chronic illness but we do have a choice in how we deal with it. There is no need to hurry or feel pressured to find meaning. It usually happens as we learn and develop throughout the illness journey. When we find the meaning that is right for us we may also find that it helps us to cope with the challenges of living with illness. As our responses indicate we have found new ways of relating to others, and ourselves and new ways of thinking about what happens to us. Our hopes and dreams have had to be recreated to fit with the reality and we have developed new ideas about life, which accommodate a changing body. All of this has become incorporated into the way we see ourselves. Most of us are able to problem solve the challenges and look to the future. This does not mean that we do not ‘hit the pits’ at times but our perspective informs our thinking about the hard times and gives us resilience and the ability to move on from it. Let us now talk about how our perspective has affected the way we cope.

What implications does this have for the way you cope with illness?

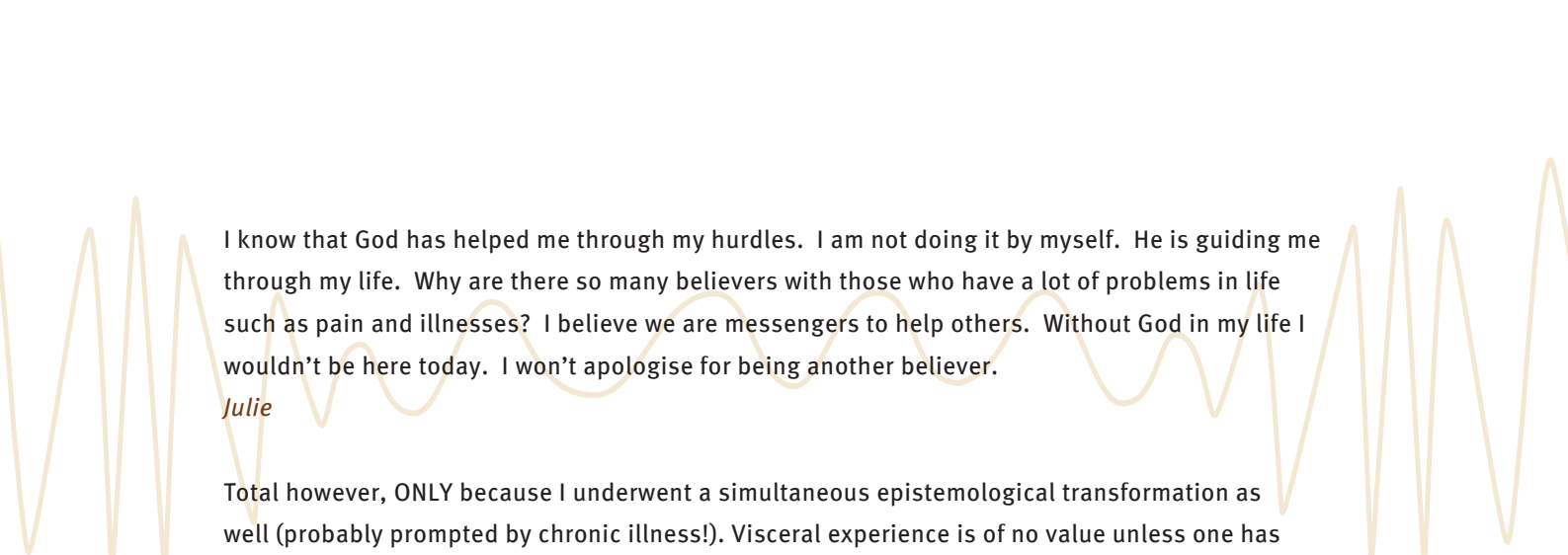
The fatalist feeling allows me to cope by not assigning blame. It has happened and there is no blame on me or anyone. It is just my body that has gone awry. Of course this does not stop the down feelings that occur during bad flare-ups but can help resolving those feelings to logical conclusion that it is just the way my body is acting or reacting.

Graham

I pander to myself a little more. I try to rest when I know I am fatigued instead of pushing myself beyond my limits because I used to feel guilty about being tired. I don't feel guilty now but I know that other people will never understand the need for rest. I resign myself to the fact that friends and other people don't understand and realize at the same time, that they have their own life to live. I recognise now too that my symptoms are not imagined, they are really as bad as I think they are. If a doctor tries to downplay my illness, I ignore this.

I find it difficult to cope with the uncertainty that illness brings to my life. Will symptoms suddenly flare up? Diarrhoea, aching and stiff legs and hips or feeling as if I have been kicked in the stomach by a donkey? Perhaps I'm the donkey! I forgot to mention that I like to use humour as a good safety valve. A safety valve that is, which releases the tension build up because of the constant uncertainty about symptoms. Live a good life as best you can ^ that is my belief and motto.

Di



I know that God has helped me through my hurdles. I am not doing it by myself. He is guiding me through my life. Why are there so many believers with those who have a lot of problems in life such as pain and illnesses? I believe we are messengers to help others. Without God in my life I wouldn't be here today. I won't apologise for being another believer.

Julie

Total however, ONLY because I underwent a simultaneous epistemological transformation as well (probably prompted by chronic illness!). Visceral experience is of no value unless one has a framework within which to make sense of it and which it - the experience - might then test, "confirm" and extend. There will be those who will be resistant to learning itself, i.e. whose frameworks will be of a fundamentalist variety, by definition resistant to change. Experience under these conditions simply confirms pre-existing frameworks of understanding.

Frank

I think that it's a very heavy and invisible burden that we carry. We are having to be always conscious of our physical and psychological states, and be aware if anything is faltering. We are constantly having to battle issues such as chronic pain and chronic fatigue (and probably many others too) but always remain a sociable and loving member of the family and society. And the sum total of this stress shouldn't be understated. And I'm sure people have found friends that haven't understood or accepted us for how we are now, so this adds another dilemma to the situations - relationships with family, friends and the world at large. Ultimately the way each person copes is individual to them, and them only.

Iolanda

Gradually I'm coming to terms with the fact, the person I am now can do many meaningful things the old me didn't have the time or energy for. I can give quality time to my family and friends. I can talk, really talk to them, about anything and everything. I can listen to their problems and offer them love and support. I can do enjoyable little things with the grandchildren and when I'm up to it, I can make them outfits to wear and mind them when their parents need a break. I can play an important role in all their lives, by just being there for them. God willing, next year I hope to volunteer my time helping children with learning problems in my daughter's classroom. This emerging meaning to my life is helping me realise I can make a difference in small ways, but in ways that count.

Chrispy

...the person I am now can do many meaningful things the old me didn't have the time or energy for.

I rest in God. I lay the whole weight of my human responsibility on my faith in His loving plan for my life here and my knowledge that there is a new body waiting for me, that pain and tears will cease. So it is a temporary discomfort, not an eternal sentence. My life is a living walk and relationship with God as my Heavenly Father, my acceptance of Jesus Christ as the only way God has provided for salvation and eternal life, and the comforter, the Holy Spirit who is my constant inspiration and guide. I will fall and fail, but Jesus died because I cannot live up to the standard that God requires of me and I rest in what He has done for me. And I will get up and go on in His strength, but He also leads me beside the still waters.....

Glenice

Being practical, I am still looking for an outlet for my emotions, and they are building up at the moment. While we need to be strong to deal with the stresses imposed on us, from time to time we need to be able to 'let it out' as well. Sometimes we have had outlets that we can no longer use because of our condition - so we need to find new ones.

Andrew

The idea of a journey helps me to accept that good and bad things happen. The best way for me to cope with my illness is to view it as something to learn from and grow through.

I am determined to cope with it in the best ways I can. I know I have the skills resources, courage and support to cope with whatever comes my way at this moment in time. And the knowing that I have done so well up to now. I can ride the waves, have determination motivation and strong spirit. I have a part time job, children, shelter, luxury items, a knowing of a big world and possibilities, hope extended family, friends, values and an attitude that I embrace and feed/nurture.

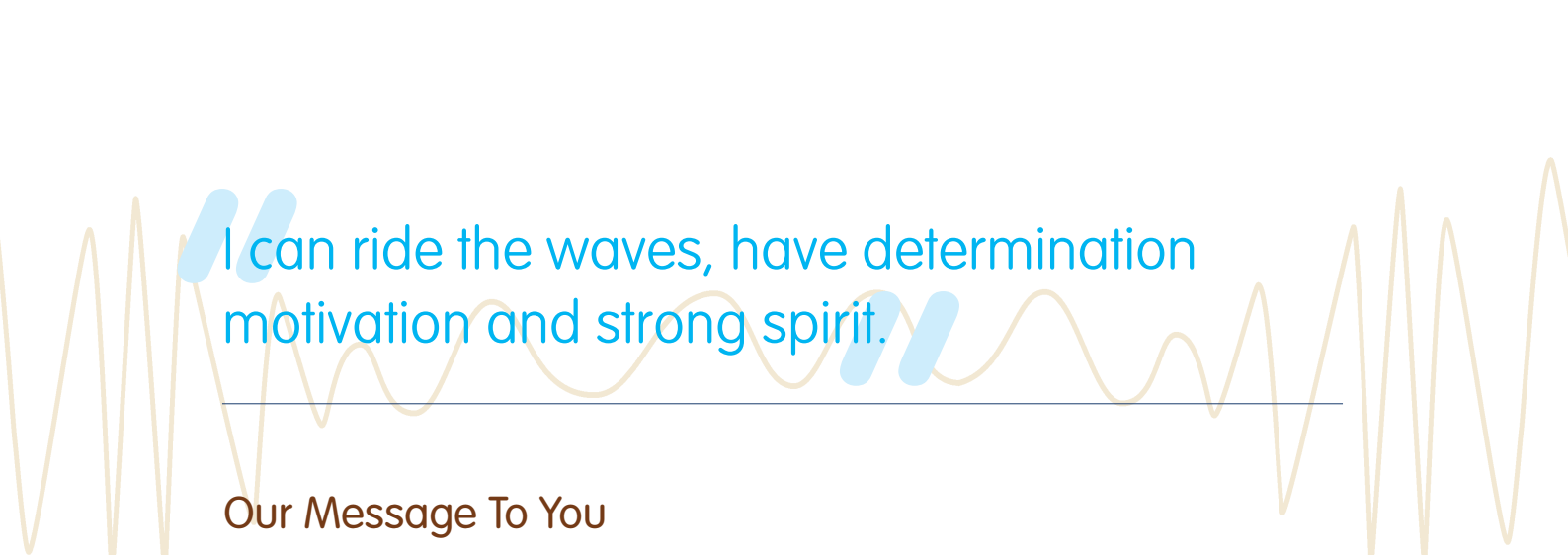
Olympia

I find it helps to think about what I have learnt from the experience of illness. I also know that it is not the question of 'Why?' that is important. The important thing is how you deal with the hand that you have been given. My faith helps me do this.

Helen

The idea of a journey helps me to accept that good and bad things happen. The best way for me to cope with my illness is to view it as something to learn from and grow through. It is something that develops character and has given me a different world view.

Mari



I can ride the waves, have determination
motivation and strong spirit.

Our Message To You

When illness arrives on our doorstep we can feel like we are treading water in turbulent seas... not getting anywhere fast. Life with illness is an ongoing process of learning through trial and error. We learn to shift our values. Learning takes time and time is perhaps one of the best gifts you can give yourself. Learning to incorporate illness in our lives is not so much about how well do you cope with it immediately, but what do you take from it; what do you learn about yourself; what do you decide is important to you in your life. Often the meaningful lessons come from the smaller issues that challenge us. Learning to live with chronic illness isn't going to work for anyone who demands immediate gratification. It is about developing new understandings about what is important, and looking at life to determine the issues confronting you, then thinking about possible responses to difficult situations, not only health situations, but also personal dealings. Good relationships that foster our growth are an important part of life that we nurture because they contribute to the meaning that we attach to our experience.

Our Message To Health Workers

“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...” this quote comes from Kat Duff in her book ‘An Alchemy of Illness’. There is no dress rehearsal for learning to live with chronic illness. We take each day at a time, adjusting our lives so that illness can be a part of it. We begin to be aware of greater depths in both ourselves and existence itself. This is a slow process. Most of us have found that it has taken several years before we could let go of the past so we could value our present and have vision for our future again. During this time we need you to walk with us, we need your support, a listening ear, for you to affirm our experiences and validate our attempts at trial and error. As a health worker, our interactions with you contribute to our sense of ourselves and the meaning that we attach to our journey through illness. When you listen, affirm and validate our experience you will be assisting us to develop meaning for ourselves as valued human beings and consequently a positive meaning for our experience.

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 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.

