

Transition in Chronic Illness

# Self-Care



BOOKLET 10

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

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

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

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

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



Australian Research Council Discovery Grant DP0346092

© RDNS Research Unit – November 2005

This booklet is copyright. Apart from any fair dealing for the purposes of private study, research, criticism or review, as permitted under Australian copyright law, no part of this report may be reproduced or copied in any form, or scanned or stored in any type of information retrieval device or transmitted in any form or by any means, without the prior written permission of the author.

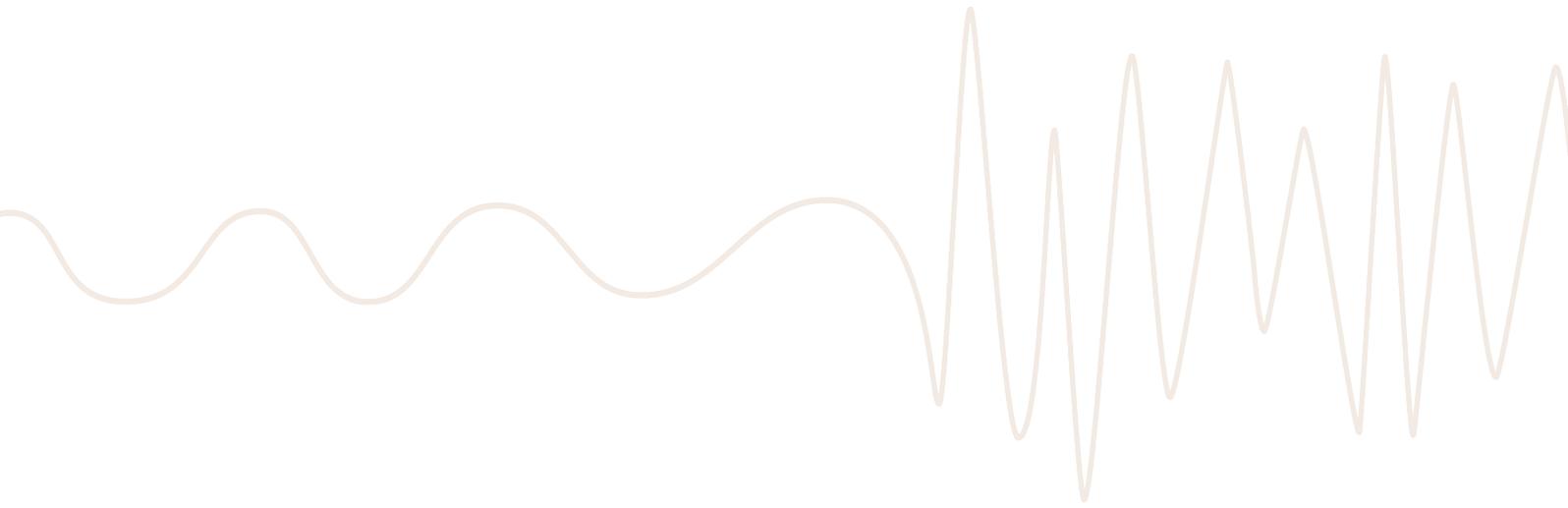
#### **DISCLAIMER**

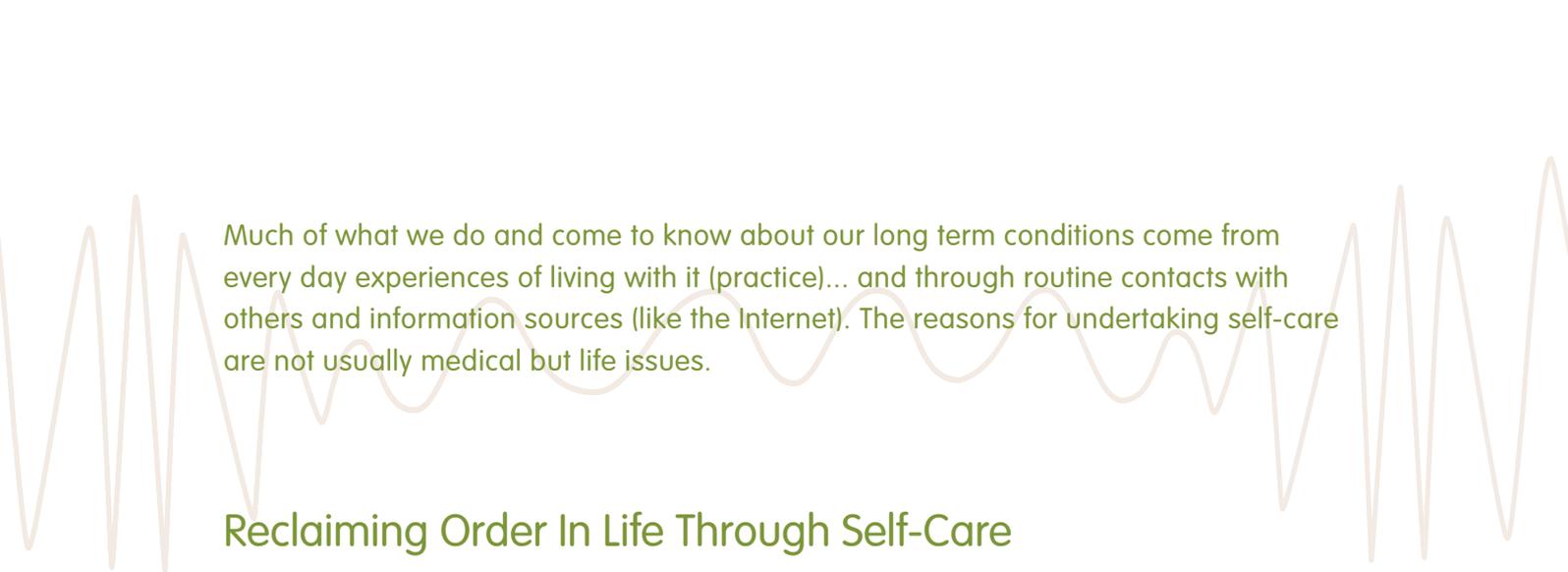
This report is issued on the basis that:

- The information in it is intended as a guide only and should not replace the advice of a healthcare professional.
- You should rely on your own independent advice.
- No representation, assurance, warranty or undertaking is given or made as to the suitability or accuracy of the information for any specific purpose or the relevance, appropriateness, accuracy or reliability of any opinions, conclusions, recommendations or other information (all of which matters may change without notice) contained in this report.
- Save for any statutory liability that cannot be excluded, RDNS and its employees and agents disclaim and exclude to the maximum extent permitted by law all liability and responsibility (whether in negligence or otherwise) for any direct or indirect loss, damage or harm to personal property which may be suffered by any person relying upon this report.
- RDNS does not assume any obligation to update this report or correct any inaccuracy which may become apparent after it is issued.
- Provision of this report does not constitute endorsement by RDNS of any product or organisation referred to in it.
- All information contained in this report is gathered from research participants and academic literature that we believe to be reliable. However we cannot guarantee its accuracy and you should only rely on information and advices provided by your independent healthcare professional. We are passing on this information in good faith.

# Contents

Reclaiming Order In Life Through Self-Care	1
There Can Be Positive Outcomes Too!	4
Reclaiming A Sense Of Order	6
Sources Of Inspiration	8
Fun Is Still An Important Part Of Life	10
Goals Worth Striving For	11
Our Message To You	13
Our Message To Health Workers	14
About Us	15
About The Booklets	16
About The Research Inquiry	16
What Are We Researching?	16





Much of what we do and come to know about our long term conditions come from every day experiences of living with it (practice)... and through routine contacts with others and information sources (like the Internet). The reasons for undertaking self-care are not usually medical but life issues.

## Reclaiming Order In Life Through Self-Care

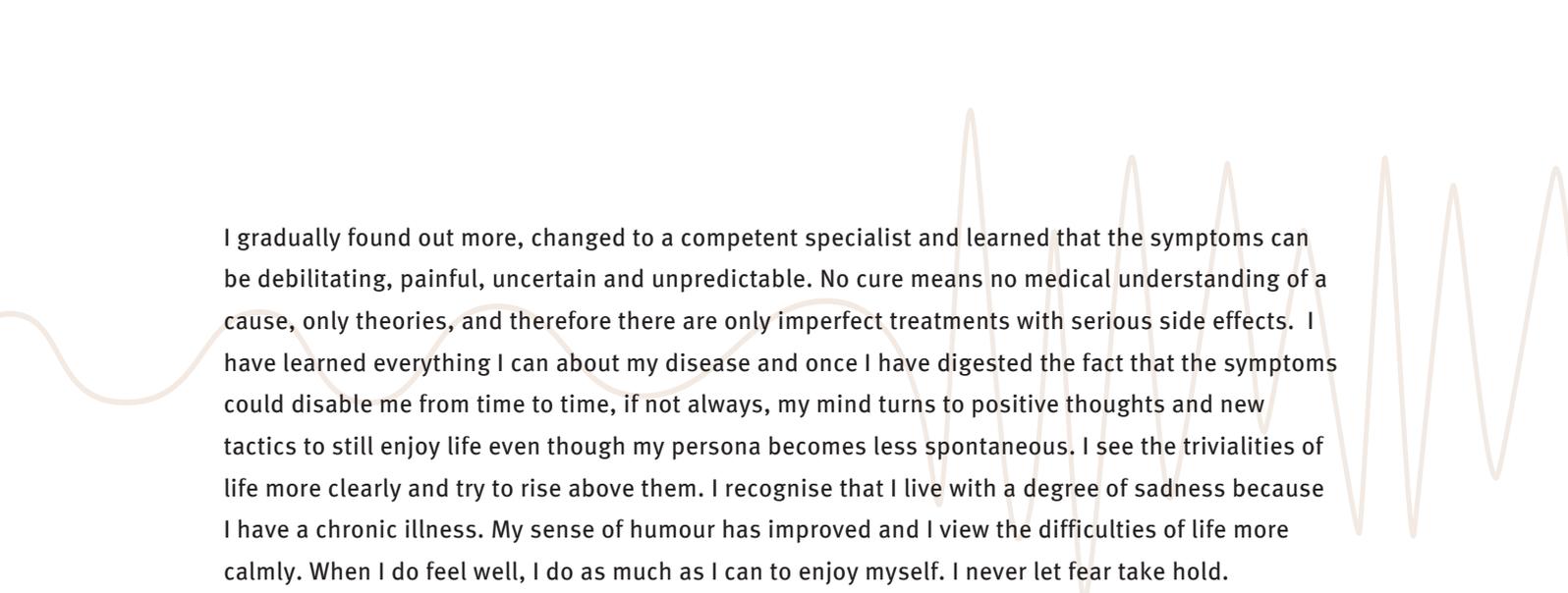
Our experiences with chronic illness can feel like a roller coaster ride with its ups and downs. Sometimes it can feel like all control is lost. We can all relate to the dips, where we felt chaotic, overwhelmed with strong emotions and a sense of nothing being as it was. Reflecting back over our experiences helps to put those times in perspective. We revealed that we have faced these times over and over, found ways to cope, learned what helps and what doesn't, and arrived at a point of understanding about how illness fits in our lives. We now know how to think about the illness, what to do when it interferes with our wellbeing, and how to adjust our lives so that we can find balance between maintaining wellbeing and living life. We have learned to adopt a new vision of ourselves and our life that incorporates illness. During the process of learning to live with illness, we have learnt a lot about ourselves and our relationships with others. Illness no longer stays in the foreground of our everyday life. Rather, it takes a back seat, freeing our mind and bodies up for the experience of living a meaningful life. That does not mean we do not attend to illness symptoms; we simply do what we need, to manage them and get on with life. Here is how we described our journey through the disruption of illness.

### *Looking back, how do you view your journey with illness?*

The illness was slow coming on and early stages were brushed off as several minor annoyances. As it progressed and increasingly interrupted my lifestyle I still felt it would go away and I could return to as I was. Not exactly denial but determined that my life would not be severely disrupted for long. Over time as the disruption of it became chronic and I had to learn to change my life to suit the illness, it became a very depressing time until I learned to accept that it was with me for a long time. I needed to adapt to it to survive.

*Graham*

My journey began with the diagnosis of an inflammatory bowel disease about eight years ago. First there was a colonoscopy, a vague amount of information from a specialist, no information from a GP and wrong information from a nurse. I searched the internet and found information on rather horrific symptoms. I thought I could not possibly have this dreadful disease, not me! So I began with fear, disbelief and ignorance of its potential affect on my lifestyle and me.



I gradually found out more, changed to a competent specialist and learned that the symptoms can be debilitating, painful, uncertain and unpredictable. No cure means no medical understanding of a cause, only theories, and therefore there are only imperfect treatments with serious side effects. I have learned everything I can about my disease and once I have digested the fact that the symptoms could disable me from time to time, if not always, my mind turns to positive thoughts and new tactics to still enjoy life even though my persona becomes less spontaneous. I see the trivialities of life more clearly and try to rise above them. I recognise that I live with a degree of sadness because I have a chronic illness. My sense of humour has improved and I view the difficulties of life more calmly. When I do feel well, I do as much as I can to enjoy myself. I never let fear take hold.

*Di*

Because of my memory loss I can't comment on what's happened to me on a first person basis. But being sick is just something that happened. Sure, it's stopped me in my tracks, but these types of things happen to others too. It's how you react and deal with it all that's important.

*Iolanda*

My illness has been a bumpy journey, rather than a steady one. It's often a case of "two steps forward and one step back", but generally I feel I am moving forward in a positive direction. Here is my journey as I see it:

- **Despair and fear** when I became really ill.
- **Hope** that in swallowing the prescribed pills, I'd get better again. I did improve for a time but gradually my condition deteriorated.
- **Lack of control** over the future and of the unknown.
- **Alienated** because having a rare condition made getting information near impossible, on top of having no ongoing specialist care.
- **Huge learning curve** when I finally had access to the Internet and to information.
- **Relief** in finding support groups and knowing there were others out there just like me. I no longer felt completely alone.
- **Self-respect and confidence** as I learned to trust my own judgement and to expect quality care and respect from health care workers.
- **Self-reliance** in realising for a vast majority of the time, I'm responsible for my own health care.
- **Acceptance** of my illness and its limitations, but at the same time not letting illness defeat me.
- **Reassessment** of my priorities in life and discovering what really is important.
- **Appreciation** of the many gifts life has to offer, an appreciation I doubt I would have developed had I not become ill.
- **Determination** to have as much control over my life as possible and to live life as fully as I can, even if it isn't exactly what I'd planned.

*Chrispy*

After I was diagnosed I felt grateful to be living where I was with my family physically intact, all living under the same roof. After an eight month separation I was having time out from my work and social life. My time was spent learning /talking /thinking about my life with MS at the forefront and visiting doctors and other health people. It all felt a bit surreal. I remember working hard to keep a sense of the familiar everyday in my life. I remember staying as active as I could in different ways. People kept saying I needed to change my ways of doing things. I knew I needed to change also but I don't think we were thinking about the same things. I wanted to reprioritize and check in on the values and meanings I had on/in my life. That was a process I had already embarked on before MS. Once diagnosed I knew I needed to commit to and integrate that change I was seeking more deeply. ....My spirit was calling out louder for peace and harmony. So I needed to stabilize the MS to get to a physically optimal functional state where I could get on with the real job/task at hand. Living well with integrity and greater clarity around what was good for me! I looked at my life style, nothing drastic or over the top, created what I felt and deeply inside knew would be good for me i.e. diet, activity, friendships, interests etc.

My MS became less at the forefront and took up less space in my life. It moved in and out of the front seat according to what was happening with it. But it's never stood alone since. It feels so integrated and part of me. That may change again but I don't give it much consideration. I have been and want to continue dealing with life as it arises, with the qualities and skills I have in my life.

*Olympia*

What other journey was there?

*Frank*



I started my life with diabetes with much hope and determination. Yet my body seemed to defy usual diabetes explanations, causing frustration and disillusionment. Subsequently my illness provoked some of the saddest times in my life. I questioned my worth and value as a human being because illness is all I saw in me for a long while. Now that I have found my place in this world, I see my journey with illness as something that has allowed me to conquer through challenge. While there is nothing inherently pleasant about illness, I can see how I've grown through the experience. This journey has been one of self discovery - physical, psychological, emotional and spiritual.

*Mari*

## There Can Be Positive Outcomes Too!

Some people may be surprised to find that living with chronic illness can have some positive outcomes. When we are confronted with a challenging or adverse event we can learn and develop as a result of experiencing the difficulties it presents. It is no different with the experience of living with an illness. The demands that illness makes on our lives causes us to become more in tune with who we are and what we are really 'made of'. We might discover aspects of our personality that we had not been aware of prior to illness, such as courage, determination and resilience. We learn to appreciate ourselves by listening to the needs of our bodies, and realise that adaptation to new life circumstances means a process of trial and error. For some of us this is the first time we began to focus on ourselves as a priority. Our attitude toward life may change with greater appreciation of the small things, or moments or interactions in everyday life. We find that these things inspire us and make life joyful. We may endure hardship as a result of illness, so we feel that we have developed compassion and sensitivity to others who are vulnerable or experiencing difficulties and disruption. It feels good to open our hearts to others and to empathise with their situation. All of these changes improve our enjoyment of life and of ourselves. This does not mean that we see illness as a 'gift'. We would rather have achieved these life learnings by other means, but since illness is what we have been faced with, we choose to acknowledge and appreciate that there has been personal growth, insights and new dimensions opened up to us. Our conversations now turn to our experience of positive outcomes:

### *What have been some positive outcomes of learning to live with illness?*

Never thought that having an illness could provide any advantages. If nothing else it has given me a better understanding of what others go through with severe illnesses, however it has given me less tolerance for anyone who whinges excessively about minor complaints.

*Graham*

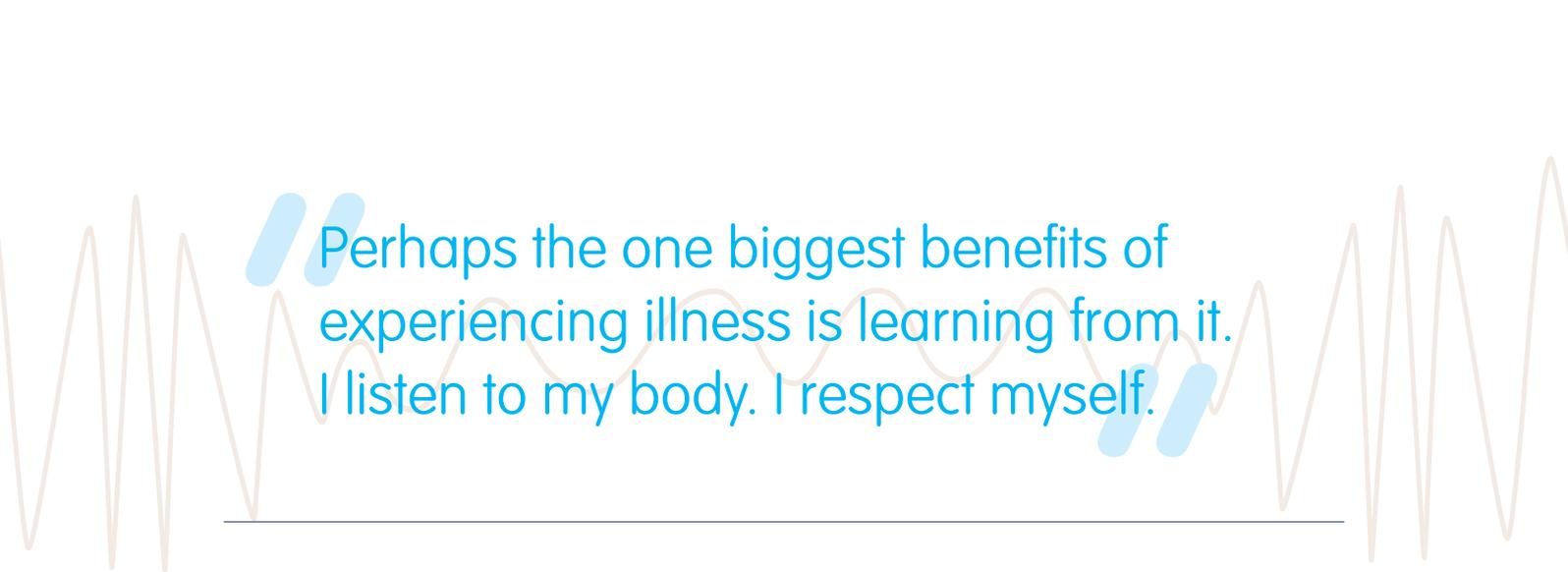
I have found out a great deal about myself. I know that I am not invincible and that illness doesn't just happen to other people, yet my character and personality have strengthened with much less reliance on worrying about what other people think. I have gained a better understanding of other people's illnesses, the impact on individual's lives and a much more real compassion for others.

*Di*

Like a lot of others in my position, I appreciate the smaller things in life. On occasions I've also been able to connect with certain people on a 'deeper' level and this is beautiful. I'd like to think I'm more compassionate.

*Iolanda*

I appreciate  
the smaller  
things in life.



Perhaps the one biggest benefits of experiencing illness is learning from it. I listen to my body. I respect myself.

---

- A deeper understanding, empathy and compassion for other people's illnesses and/or problems.
  - Appreciation of the many wonderful things in life, not taking life for granted, nor good health as my right.
  - Developing a strength of character I never knew I possessed.
  - Discovering who I really am and developing a different but important purpose in life.
- .....Oh and having a good excuse for sleeping half my life away :-).

*Chrispy*

I've learnt to be more compassionate and tolerant. I've also become more understanding and patient.

*Michelle*

- Some time out, seeing how life goes on internally and externally.
- The internal resilience that grows/develops, the receiving of people's generosity, gratefulness
- The activation of a keen eye for the simple, rich and beautiful gifts that surround me
- An experience and understanding of my way of dealing with great change and challenge.
- A reprioritizing of stuff in my life, people, things, thoughts.
- Some of the concessions that come from living with an illness, disabled parking ticket
- A connection with courage
- Valuing the experience of being the 'other', Greek, and living with a chronic illness
- The learnings. A re-ordering of expectations and taken for granted

*Olympia*

Self and systemic insight.

*Frank*

Perhaps the one biggest benefits of experiencing illness is learning from it. I listen to my body. I respect myself. Illness has also broadened my worldview, taught me about compassion, forgiveness and dealing with imperfection.

*Mari*

## Reclaiming A Sense Of Order

A symptom and diagnosis of illness typically throws life into chaos. It may seem as if we are at the mercy of the illness and have little power to influence our life. Unfortunately there is no traveller's guide for the journey with chronic illness. There are, however, alternative ways of living. When we learn to think of ourselves in nurturing ways and learn about what is helpful in minimising and managing symptoms, we gradually regain a confidence that, whatever happens, we will be able to manage. We learn that wellbeing relies upon using the knowledge we have gained to make decisions about how to make adjustments in life to enhance our sense of well being. We also learn that there are times when we are willing to risk not being as well so that we can enjoy things that are important to us and for us. Gradually we regain a sense that we have some choice about the way we manage life incorporating the experience of illness. It is a sense of control within the limits that the unpredictability of illness imposes, but it is none the less a feeling that contributes to a sense of living an ordinary life.

### *Have you regained a sense of control? And if so can you identify the key elements of regaining a sense of control?*

I don't know that I would have gained a sense of control of the illness. I am in control of my life provided I stay within the capability limits of what my illness allows.

*Graham*

I'm not sure that I ever had a sense of control, life has so many unexpected happenings. I have a better sense of myself in that if people can't or don't want to understand the limits placed upon me by my illness, then too bad. I have a much better understanding of how to deal with the unpredictability, uncertainty and the guilt from having to impose on loved ones when I am ill and somewhat disabled. In general I have become aware of my ability to be determined and resilient. Key elements would be a growing confidence in my ability to deal with illness and unsympathetic acquaintances; staying calm and putting life's events into perspective; knowing that everyone is going to die some time and fear not; enjoy everything that gives you joy, a good laugh, or wonder at the beauty of a flower, leaf or the full moon. Do your best whether you are ill or well.

*Di*

I don't have a lot of control over my health situation at all. Some control, yes. But not a lot. There are only two ways that I can control my medical issues. The first is by pacing (and not overdoing things) and trying to work around daily problems as they arise. The second and most important way is by showing an interest in my health, being proactive and getting online to research and communicate with others. This has been absolutely ESSENTIAL. I couldn't have come out of everything I've gone through so well without the internet.

I'm not sure that I ever had a sense of control, life has so many unexpected happenings.

On non-health issues, control is easier since I'm my own person and not a wife, mother or carer. So I have greater control over what and how I want to do things or think. For me, a key element is routine. Routine, for example, in how I dress and what I do with my day. And a psychologist once told me that wanting and even needing to have this control and creating routine is understandable given my situation - it's my way of creating a safe zone and coping with the trauma of what's happened. And I suppose my support of voluntary euthanasia is an extension of the principle of control. It's giving me a sense of control over an unknown future.

*Iolanda*

Yes I have definitely regained a degree of control over my life. I'm convinced the main key in attaining this has been through access to the Internet and the vast network of information and support groups it provides. "Knowledge is power", in that I better understand exactly what is happening to my body and why, the best available treatment options, but above all that I'm no longer alone. Communicating with others in a similar situation, learning from their experiences and gaining comfort from their support is invaluable. Being more in control has given me back confidence and self-respect, helped me find a different purpose in life, helped me to discover who I really am and hopefully made me a better person. During bad times I may spiral downwards for a while, but I now have the strength to fight my way back and move on. Another important key in gaining control is being fortunate in having a very supportive partner and family, as well as an excellent GP who really listens and cares.

*Chrispy*

I have less control over life than I ever had. But I have control over the essential me, if that makes any sense. I do go nuts having to sleep all day or lie in bed and read a book but I learn to do what I can when I can.

*Glenice*

I don't know! Some days I feel that I have some control and then other days it all just seems completely out of my control. So I guess that I am still working on gaining some sense of control.

*Michelle*



#### BED LEVEL

Raised bed level so it is better height for getting on/off.

– Graham

Yes I have regained a sense of control:

- Maybe not worrying about what others think
- Having people in my life to share the tragedy/comedy
- Being able to delegate tasks and ask for assistance
- Believing that I will deal with the change whatever it may be as best I can at the time
- Being organised and a good planner
- Being financially able
- Having a positive /happy disposition
- Having a greater awareness of self and others
- Having a great sense of independence

*Olympia*

Yes, I've gained it - although getting the disease so early I never 'lost' it.

*Frank*

I find this a continual challenge. Over the years I was taught about 'diabetic control' - something that has been clinically defined as 'poor' for the 15 years I have had diabetes. This definition does nothing for my sense of gaining control over my health. And I can let it ruin my self-efficacy and the belief that I am actually doing OK. I guess I am learning to look at other ways in which I've gained control, e.g. I don't let my health worry me, despite its obvious metabolic flaws; I am in control when the diabetes is not controlling me; when diabetes no longer drives me to obsessional lengths to get the sugars 'right'.

The key elements for regaining control in my experience have included a dose of realism, shaking off perfectionism, and appropriate support. I also found I had to forgive those whose expectations of me were too high, including myself.

*Mari*

## Sources Of Inspiration

Inspiration is still an important part of our landscape when living with illness. But what inspires us has changed. We now find inspiration in familiar places and relationships such as family, good friends or within ourselves. The ordinary is inspiring to many of us whether it is a bird singing, people living their life despite hardship, natural beauty, or merely life in general. Once we may have taken these things for granted. Living with chronic illness has opened our eyes to the magnificence of people, places and things, that were right under our nose. We see them in a new light and they stand out to us, 'like threads of gold' woven into the fabric of our lives, giving us inspiration to continue our journey. We want to share with you some of the 'golden threads' in our lives.

## *What inspires you?*

There are no external inspirations, I have developed in myself the satisfaction of when I have been able to complete a task, and use this to inspire me to try more.

*Graham*

I am inspired by the Transitions group as well as those who have the same disease as mine with worse symptoms who just keep going and support others. Also, people like Louise Sauvage, the Paralympian and my mother, who despite great odds lived a good life and used her intelligence in the best way possible to cope with life. The sounds of birds in the morning create a joyful start to a day and this inspires a positive view of everything.

*Di*

Over the years, what or who inspires me has changed so much it's unbelievable. For example, motivational thoughts, people living with disability who are role models for others and religion inspired me during cancer treatment and shortly after. Now they are the furthest things from my mind. Some of the things that might inspire me include natural settings and certain friends. But to be truthful, the thing that really inspires me on a regular basis now is \*me\* - for example, the happiness or pride that I'll feel by saying that I've achieved something or looking at things I've done in the past.

*Iolanda*

Ordinary every day people who struggle to overcome adversity such as illness, poverty or hardship. People who go out of their way to help others who are less fortunate than themselves. People who give, in whatever way they can, simply because they care, but who don't expect anything in return. These are the real heroes, not the rich or famous.

*Chrispy*

Eternity at the moment.

*Glenice*

My husband, my children and friends. The Transitions group.

*Michelle*

People, nature, love, beauty, positive thoughts, balance and harmony.

*Olympia*

Life in general, nothing in particular and certainly no person. I have a problem with idolising anyone.

*Frank*

Healthy relationships inspire me. The people who are close to me, my parents, my brother, my friends. Some of my clients also inspire me. They teach me so much more about living with illness than I will ever discover through my illness experience alone. Art inspires me. Nature's beauty and serenity inspire me.

*Mari*

## Fun Is Still An Important Part Of Life

Our spirit seeks fun, and while it may be fleeting, it does us good. There is fun in each of us if we open up to it. It may be a sense of humour, love of pets, love of music or enjoyment in particular activities. We can create fun drawing on these parts of ourselves when we are alone or with others. Getting in touch with the fun in ourselves is infectious. It spreads to others and comes back to us. Reaching out to others with our playful side can reward us with mutual good feelings. We have a choice: to be consumed by the negative aspects of living with illness, or we can provide some balance to this by allowing ourselves to be jovial or to let loose at times. When we do this it nurtures our spirit and fosters positive feelings about ourselves, others and life itself. To have a good belly laugh has been identified as a contributor to wellbeing. Many of us need to be mindful of energy and fatigue, so we have learnt to pace ourselves and make the most of the times when we do have the energy or inclination for fun. But we do not forget the part of us that seeks fun. Where we find fun and the way we find it may have had to change, but we have fun and laugh in ways that are just as uplifting. Our conversations reflect our sense of fun.

### *How do you find fun?*

I can share a joke. I can enjoy moments or situations.

*Graham*

Watching the antics of my toy poodles, laughing at movies and television shows, laughing with friends, going on day trips with friends or the social club, and other activities when I am able. I enjoy email contacts with friends and the Transitions group.

*Di*

For me “fun” has a lot of dimensions - fun alone at home, fun interacting with others, fun getting out of the house. Most of my fun comes from things I do on my own at home since I spend so much time at home, so it’s not the type of fun that’s animated, energetic or friendly. Some things I do at home might include emails and internet, writing, getting on the phone, entering (and winning!) competitions or logic puzzles.

*Iolanda*

Ways of having fun have gradually changed to more passive activities, but still very enjoyable. Despite having very different interests, my partner and I enjoy spending time together, just talking and doing everyday things. We’re best friends really. We both enjoy having dinner at restaurants, sometimes alone and sometimes with family or friends. I enjoy my time on the computer, reading, listening to classical music etc.. I get pleasure from doing volunteer work in schools when I’m well enough.

*Chrispy*

My sense of  
humour still  
holds me  
together.

My sense of humour still holds me together. Singing and being on radio are things I enjoy. I can be fun for a while when with others but I tire too quickly so I do not go out socially apart from Church. I sit and sew when I can. People see me as being fun but I feel that the 'stuffing' has gone.

*Glenice*

Playing with my children; Chatting with friends on the phone, in person or on the internet; Going out for coffee with friends; Spending time with my husband just working in the garden etc.

*Michelle*

I stay as well as I can, sleep, eat, rest, exercise, drink, think and talk. I create fun. I do things /activities I like to do and avoid those I don't like.

*Olympia*

Living, coping, being ... Riding back from the dentist one morning with half a dozen injections in my face (the oral rehydration I take rots my teeth), got to a station & coffee machine didn't function. Reported it and station assistant offered me a cup of coffee from her own supplies! Was so impressed by this that I wrote a letter to the editor, it was published and she got a formal pat on the back from her employer. I love doing such constructive mundane things.

*Frank*

I find fun in immersing myself in music. I enjoy listening, singing, playing, writing, performing, and going to live gigs. I also enjoy the little and positive interactions with people: to smile, to wink, to hug, and to share a laugh, to banter.

*Mari*

## Goals worth striving for

Having goals to aim for and vision for our future is important when learning to live with a chronic illness. Our life needs direction in order for it to feel meaningful and have purpose. Goals are benchmarks that provide structure and feedback about how we are doing in life. Goals are an expression of who we are, who we want to be and the way we want to live. Our vision for our futures has changed, and we have had to develop new visions in line with our changed abilities and interests. For most of us this is related to living the best life we can whilst managing the symptoms and consequences of illness, achieving balance and continuing to develop at a creative and personal level. It is about making the most of our strengths and abilities, rather than dwelling on disability. We do have choices in the path our life takes and we want to create our futures rather than leave it to chance. Whilst our goals may seem trivial to others who can take health and abilities for granted, they are grand in our eyes. To live a life that includes reasonably stable health, enjoyment, creativity, self-development, spirituality and meaningful relationships is a goal well worth striving toward.

### *What are your long term goals?*

To hopefully slow the rate of progression of my illness and maintain a self satisfying lifestyle. This may sound a bit egotistic but if I am not satisfied with the life I am living then depression takes over making it worse.

*Graham*

My main goal is to do the best I can with what I have. My needs are to cope financially with health care needs and growing older, and to live life to the fullest even though it might be a quiet life as judged by some others.

*Di*

In brief and general terms, my long term goals are probably to live, love, smile and be happy. More specifically to try to stay positive and happy, to be creative and keep my brain active, and keep up with others. A long term goal in a medical sense is that I'd like to keep abreast of developments in the treatment of my problems. A corresponding need that comes from this goal is that should there be no treatments available and my situation worsens with time, I'd like to know that voluntary euthanasia is available if my suffering become unbearable.

*Iolanda*

One important goal is to be as well as I can, as quickly as I can and for as long as I can. To do this I will continue to gain as much knowledge as possible. Had I known a few years ago what I know now, I may have been in a position to prevent a well intentioned mistake made during a minor surgery. That mistake most likely resulted in yet another condition, chronic pain and the need for major orthopaedic surgery. This is an added condition I could well have done without and I have yet to face another such surgery. I will continue to fight for affordable and unavailable treatments, which Australians are presently denied, knowing these can dramatically improve my quality of life and may well prolong it. I aim to live as well and fully as possible with chronic illness. I hope to continue in some form of voluntary work, as well as to take up painting as a hobby. I want to be the best person I can be, despite the limitations of illness.

*Chrispy*

- To get back to the pool and gym.
- To dress every day.

*Glenice*

---

My main goal is to do the best I can with what I have.

- To get better, maybe go into remission.
- To be well enough to work part-time.

*Michelle*

- To be creative and receptive to whatever is, what was and what will be
- To continue to develop the self
- To discover the best course of action in all things
- To be conscious of my choices and actions

*Olympia*

Staying alive of course, what else?

*Frank*

- To maintain balance.
- To appreciate the good days, and accept the bad ones.
- To remain responsible for my health behaviours, but not make unrealistic expectations.
- To give and to receive.
- To work and play.
- To be creative, to explore, and to continue to learn.

*Mari*

## Our Message To You

The tumultuous feelings that we may experience upon receiving diagnosis of chronic illness are the very beginnings of a journey or ongoing process. While the journey may take many different turns, ups and down, convolutions and movements back and forth, we can eventually arrive at a place where there is a sense of order. The transitions that we, as people with chronic illness, experience may lead toward a sense of 'ordinary' in everyday life and it will feel as if there is some control in life again. Negotiating this transition is no small feat. It is a life-changing process, which requires personal resources, balance courage and resilience. Balance is a talented juggling of all your responsibilities and needs.

It does not matter how long the journey takes; it can be taken at your unique pace. It also does not matter how the path is travelled; there is a myriad of ways and you will discover the one that is right for you. What does matter is that it is a destination worth striving toward. The road may get rocky and the pathway unclear at times. There may be times when we falter, lose faith and feel overwhelmed. The landscape is constantly changing and we might need to reach out for the hand of another person or people to support us. Go gently with yourself on this journey and believe in yourself as a person who makes a valuable contribution to our world.

## Our Message To Health Workers

You can make an important difference to the lives of people who are living with chronic illness and striving toward adaptation. We need understanding, non-judgemental health workers. We seek to develop a relationship with you that is about two people coming together to share different understandings and experiences. We have our unique experiences and learnings gained from managing the illness in day-to-day life. We have the knowledge of our body and how illness affects it and our life circumstances and the impact that illness has. This includes the myriad of emotions and thoughts that are triggered by daily events and the feelings toward one self. You as the health worker can bring a willingness to sit beside us and listen, try to understand our experience, and to find places where your understandings can enhance our wellbeing and the ability to manage illness. Perhaps you have found different tools and techniques than the ones we have used. Offer these as suggestions, rather than prescriptions. Be patient, because change takes time.

The skills involved in this relationship are those already familiar to you. You have gained skills in developing rapport, communicating, listening, engaging, demonstrating empathy and concern, offering realistic options and hope, dealing with strong emotions, advocacy and providing practical and emotional support. This relationship is likely to be a crucial resource to the person living with illness and can contribute to positive feelings about the self and the world around. A health worker who seeks to understand and offer options to the person, leaving them space to make their own decisions and choices, is like pure gold.

The process of setting “self-care” goals with those of us learning to live with chronic illness can involve three steps.

1. **Look...** Find the issue. Rather than beginning the encounter focused on test results, begin by saying, “Tell me what concerns you most. Tell me what is hardest for you. Tell me what you’re most distressed about and what you’d most like to change.”
2. **Think...** When you begin to get a sense of our concerns, explore those issues with us. Ask, “Is there an underlying issue? Do you really want this problem to be solved? What’s the issue?”
3. **Act...** Develop a collaborative goal. Once you have worked with us to identify the issue, your instinct may be to try to solve it, but don’t. Instead, validate our feelings and capacity to deal with the issue, and continue asking questions that will lead us to orientate towards our own solution. Ask, “What do you think would work? What have you tried in the past? What would you like to try?”

Following the ‘Look, think and act’ process promotes reflection and evaluation. Engaging in this process also helps us to understand that we are involved in an ongoing transition and even though it can be a bumpy ride, with your help we can find the path that suits us and regain some order in our lives.

## 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 the 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 has been consistently involved.

## About The Booklets

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

The booklets are set out in question and answer format, and are intended to connect you with our voices about our experience of living with long term illness. There are no right or wrong answers to these questions. Our answers reflect our current thinking and understanding about what it means to live with long term illness. Maybe you will find some experiences and ideas that are familiar to you or have meaning in the context of your life. We acknowledge that challenges are part of life and fall within the experience of all human beings. Given this, our experiences may also be helpful to 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.



