Transition in Chronic Illness

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

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 from 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 advice provided by your independent healthcare professional. We are passing on this information in good faith.
## Contents

Relationships 1

'Back To The Essentials' 4

'Working Out How To Fill The Gaps' 9

'Giving and Receiving' 12

Never Taking Their Care For Granted 14

Our Message To You 16

Our Message To Health Workers 16

About Us 16

About The Booklets 17

About The Research Inquiry 18

What Are We Researching? 18
I don’t see my family much, so other people are more important. Looking back, I think I am more ‘choosy’ about these people. From dealing with my illness I am a much stronger person than I used to be, and this has also changed things. A major change is that I have found I don’t tolerate people looking for sympathy. I certainly will help them with their problems and help get them moving again, but don’t like it at all when they start to dwell. I don’t like receiving sympathy either - support yes, sympathy, no. So the people I tend to gravitate towards now I think are similar: Ones I can rely on for help and support, but won’t let me dwell on a problem. In return, willing to allow me to help them in the same way.

Relationships

Sometimes those of us learning to live with chronic illness can feel different. We may become isolated because we are unable to go outside the home. Even for those of us who are still working or can still participate in other ways there may still be a sense of being set apart. These feelings may be compounded because family, friends and coworkers may not seem to understand what we are learning to live with and we may be reluctant to tell them. We may not have the words to explain, because we may not have worked it out for ourselves.

For some of us, our condition may not be obvious to others, so we may be forced to explain when we are not able to do or attend something. This can prove difficult, because it is often our intention not to draw attention to our illness. Why don’t we feel comfortable explaining to people? Sometimes it is because we receive varying reactions from others. Some of us have been treated with suspicion in the past… people may hint we are being a hypochondriac. When our condition is life threatening, people may feel uncomfortable to talk with you, while others will be full of advice. Just as we don’t talk about other aspects of our lives, we often don’t choose to talk about our chronic condition with everyone. Supportive understanding from family and friends however, is gratefully received and very much needed. It remains up to us to explain how we are feeling and what we are able to do. We may worry that others will perceive us to be complaining so we may minimise our symptoms. We have found however, that the best way is to tell it as accurately as we can.

Without doubt, chronic illness presents challenges to relationships. Existing relationships may need to be renegotiated and new relationships may seem more difficult to develop. We may not be able to participate in the type of activities that may link us with people. We might tend to withdraw from people in the awareness that our lives are different and the fear that others will not understand. Relationships can be demanding and we may not have the energy or physical mobility to fully participate. It may be that life is dictated by illness management and leaves little room for social activities. The development of new relationships might happen less spontaneously. Your friendship network may become smaller. Some people will stick around and these relationships may strengthen. Others may drift away. This can leave us feeling abandoned or rejected by these people.
Chronic illness does not diminish the desire of the human spirit to feel connected to other people. And it does not signal the end of the potential for meaningful relationships. Indeed it might be that some relationships we make when living with chronic illness may be more meaningful. We do need to be creative about how we connect and interact with people in ways without compromising wellbeing. Here we share what has been important to us in linking up with other people. There are two significant themes, these being the Internet and the support of peers. The Internet is clearly an important way of overcoming some of the barriers to developing new relationships. It does not require one to leave home and people can choose to participate at their own pace according to their health. When they do participate it requires less energy than a face to face contact. Being connected to a group of people in similar situations provides support and understanding in terms of the experience of illness. It alleviates fear of misunderstanding or being seen as different.

For those who are able to, attending a class related to exercise, interests or hobbies has been a useful strategy for meeting up with people at regular intervals. These regular contacts provide an opportunity to get to know others whilst enjoying other benefits. Feelings of isolation can be overwhelming and it is important to remember to take one small step at a time in developing a network of friends. There is a delicate balance to maintain between your wellbeing and involvement in relationships. We now talk about how we have managed to connect with people in ways which do not compromise our wellbeing.

What have been useful strategies in connecting you with other people?

I have found the Internet to be the most useful method for interacting with other people sharing my illness. It is difficult for me to travel and to be involved in group situations, and conversations are difficult for me to cope with, so the internet provides an interface that I can use when I am able to. The main downside to having cyber friends is that it is difficult to sit and have a cappuccino together at the local café.

Graham

A very important strategy is to make contact with people through the internet and email. It allows a build up of knowledge about each other and an idea of others’ personalities. They in turn get to know me. If there is a face to face meeting eventually, the hurdle of explaining about a long term, chronic illness has often been dealt with. Joining a group or club if the people are friendly and their purpose e.g. quilting, writing, group trips, suits you, can help a great deal in meeting people at regular intervals. If you are able
to walk it is fun to walk with a friend and say hi to others walking, or if in a wheelchair and unable to expend energy, a good friend might push you on a walk. Volunteering to do something that you enjoy, if you are able, can create a situation where you meet more people and are providing a service to the community despite illness.

_Michelle_

The Internet has been so helpful for me in connecting with other people. I have found it to be a great way to meet people and get to know them really well without the usual constraints of a face to face meeting. You can chat to people when you are feeling great, or not chat when you are tired. I have met in person nearly all the people that I’ve met on the internet and because they know of my illness they understand if I can’t go to a coffee night or if I’m not really chatty when I do go.

_Di_

It helps a lot to be in touch with other people who have the same condition as you do. The realisation that you are not alone and that there are other people going through the same things is a very powerful (and empowering) one. Humour can be a useful tool, often people do not know what to say about your condition so if you can make a few jokes about it, it helps them feel less nervous about talking about it. THE most important thing is to communicate with each other. If you both have an understanding on how you are each affected, then you can work out ways in which you can deal with it. This applies to relationships in general, really.

_Andrew_

I joined an arthritis support group but when two women who were in gophers asked what was wrong with me and I told them I had arthritis, they told me that I wasn’t as bad as them so I felt uncomfortable there and left. I joined a friendship group which was starting at the local community centre. A woman who had schizophrenia ran it and when she started to want to see me every day I left as I couldn’t cope with that. I found a craft group. It improved my self-esteem and I was happy. I joined Senior Citizens and now go on lovely day bus trips to areas I have never been to. They are very understanding and supportive of my limitations. I have joined hydrotherapy classes at public hospitals. I went to the local library and joined up their cooking demonstrations. The Internet has many groups of different interests if it’s too much to go out. I once belonged to an Orchid Society as a means of learning more about orchids. It’s a matter of finding something suitable and if it doesn’t work out then find something that does.

_Julie_
The other thing with relationships is that its healthy if you are happy with your own company. I don’t need people to make me happy. I used to need people when I was unhappy in my ex’s relationship. I would ring people up all day to try and forget my miseries. But that was before I began to grow and to realise that I needed to be at peace within myself to be happy. You alone are the only one who can make you happy. Nobody else can do it for you. Brian (my partner) doesn’t make me happy. He’s not here all day so how can he make me happy all day? I enjoy his company and he is good to me. I choose to be happy in his company. There is a difference. What he does for me enriches the relationship.

*Julie*

Staying in touch with and visiting friends and ‘rellies’ (relatives); Trying to keep up with hobby groups and social groups; go to church regularly; engage in exercise where I can (i.e. swimming).

*Ted*

By nature I’m a fairly introverted person anyway but unfortunately one of the symptoms of my condition is an inability to socialise easily and a tendency to become more isolated. Internet support groups are an invaluable tool in connecting me with other people, who are in a similar situation to myself. We share information, advice and give each other support. Such groups become particularly important in keeping in touch with others when getting out and about is difficult. I know it’s important to try and force myself to have contact with others on a face to face basis, particularly now that I’m unable to work and my husband gently encourages me to do so. Hydrotherapy classes keep me in touch with others, helping me both physically and socially. When I’m up to it I intend to take up a hobby. I think joining a class would be the ideal option as this will give me personal contact with others sharing similar interests.

*Chrispy*

I have particular interests in life and in attending to those as I am able, at the time I’m connecting with people. I would love to be always feeling well and have the energy to connect but my need and biggest challenge is to make time to be on my own, rejuvenating, tending to the things in my life that I enjoy and prefer doing alone, reflecting, and relaxing.

*Olympia*

‘Back To The Essentials’

Some of us have found it difficult and painful to talk about relationships. Our experience since living with chronic illness, is that relationships have changed in ways that have been disappointing. For example, some people may not include us in activities any longer. Some of us have had hurtful experiences when being open about illness and have developed ways of protecting ourselves such as being selective about to whom we disclose information or what situations we expose ourselves
to. We might change our attitude to relationships as a result of a changed experience of life. This process happens for all people as they age. We value different things as our experience of life changes. The goals and dreams that grew out of a relationship may need to be renegotiated to accommodate changed needs and abilities. Maybe they are not possible any longer and new ones have to be found.

There are challenges to be overcome and adjustments to make for both people. We may begin to appreciate the qualities of people who stick around and demonstrate genuine commitment. These may be qualities we once took for granted or did not see, such as respect, loyalty, trust, or unconditional love and care. Some people feel that the experience of long term illness has strengthened their close relationships.

Whilst the challenges of illness are likely to place stresses on relationships, there is also the potential for deepening of commitment and understanding. We emphasise the potential for a mutual exchange of caring and support. As people living with illness we can still provide a depth of understanding and care. We can still be fun to be around and contribute meaningfully to relationships, but we may have to do it differently than in the past. It is common to have developed clearer ideas about what we want and do not want in relationships. Where once we were happy with casual relationships, we now look for relationships of substance and sustainability. When we think about what is important, it gets back to the familiar building blocks of relationships such as honesty, trust, communication etc. It is evident that we hold a sense of responsibility for demonstrating these qualities too, and for being sensitive to the other person's situation and needs. In other words, we see relationships as two way exchanges. We find we are more attentive and appreciative of relationships.

It is difficult to face the need to review and renegotiate the terms in relationships but this process can have positive effects for both people. There is a sense that two people being prepared to work through challenges together have great potential for a closer bond. Here we talk about changes to relationships since living with illness, these being changes in our own attitudes and in the relationships in our lives.

How has living with long term illness impacted on your attitude to relationships?

Long term illness has made me more aware of how lucky I am to have a relationship with someone who cares for me regardless of whether I can fulfil all the normal “manly” type things. Who can accept that plans we have made for years, of the things we will do after the kids are independent can not be carried out. Illness brings you back to the essentials of a relationship where just being together means more than what you can do together, and when you are able to do something together you appreciate the moment as special.

Graham
With a close relationship or partner type relationship I expect their reliability; continuing loyalty; willingness to try to come to grips with understanding the symptoms and how I feel; I try not to frighten anybody with the fact that it is long term and won’t go away. Also, I try to understand others expectations, and try not to become so self absorbed about illness etc. to avoid selfishness and to keep a good sense of humour.

Di

I think I tend to look more long-term, and focus on people who are more likely to ‘stick around’ when things go wrong, rather than people where you have to go out and enjoy something. This has probably narrowed my circle of people a lot and I probably miss out on some activities that may be of benefit (getting out to unwind is important).

Andrew

Because my first husband was not supportive to me because of my limitations (he wanted everything perfect) I decided divorce was the only answer. There were other issues as well. Whenever I had back pain he was not there for me. My husband now is very supportive and helps with tasks I can no longer do such as vacuuming and washing floors. Sometimes I do them when the pain isn’t too bad. He has helped enormously with my self-esteem as we have talked on this for years. I had no dreams, goals etc. with my first husband and I now know why. I have found love, trust and understanding to be the most important attributes in a relationship. I am there for my husband and he is there for me.

My goal now is to look after myself as best I can so that I don’t become too much of a burden for my husband even though I know he will be there for me no matter what. I don’t expect my friends to be there for me because they have their own lives. I don’t expect my parents to be there either. They love and understand me. That is important. My brothers are not there for me. I know that my husband will look after me into old age and I will do what I can for him as well. This has given me great peace.

Julie

Because long-term illness has severely limited group exercise and travel experiences, I’ve tried to compensate by valuing and working at remaining relationships.

Ted

I don’t believe illness has had any sudden or obvious impact on my attitude to relationships, at least not with my husband and family. My symptoms came on gradually over many years and long before my conditioned worsened, I battled with other debilitating physical and emotional problems. Love, trust, respect and understanding have always been important to me, but a supportive and caring relationship is increasingly important now. Over the past decade my husband and I have had to support and help each other through the losses and changes wrought by long term illness. This has strengthened our relationship, despite the strain. We better understand each other’s needs and if anything have become closer.

Chrispy
Illness has I think had a positive impact on my attitude and attendance to relationships. Particularly in the valuing of individuals, self, others, nature and experiences in life, the preciousness of sharing, the learning to accept and be grateful for the support and caring received., acceptance. Gratitude, I feel I prioritise more than ever before with a positive awareness on my and my family’s needs. My focus and interests are less scattered and ‘conditional’.

*Olympia*

**How has illness changed relationships for you?**

When I was diagnosed and I told people about it, all I got was blank stares, and after some more explanation I was advised to rest and I will feel better. Those around me, except for my poor wife and daughter who have to live with me, just could not comprehend my problems no matter how many times I tried explaining. I learned very quickly not to say anything. This is one aspect of the illness that has changed the way I act within relationships outside the home. I have learnt to keep my mouth shut, and if asked how I am just say, same as always. I have become adept at saying this in many ways to add variety.

Secondly because I find any noise or travel makes my condition worse I tend to shy away from situations where there are groups of people. I can withstand a couple of people for a short time, but even maintaining a level of concentration on conversation becomes very taxing after a short time. So I have become somewhat reclusive.

*Graham*

I find I am tentative about ringing people who I feel might not want to meet me for coffee for example, or who keep suggesting activities beyond my physical capabilities and who refuse to understand my illness and its impact on me. Others I might meet insist on a long outline on what is wrong with them and all of
their relatives and friends, as if to suggest that I am complaining about nothing. I was just trying to explain so that the friendship can continue and develop based on understanding each others’ limits without the insidious inference that I, somehow am the only one without an illness. Then, there are others who utter for example, ‘Oh, my Aunt Hepzibah had that, she couldn’t eat bread’ and whatever else I might try to say to correct the wrong impression of my illness just slips over their heads and any information is just not taken in.

I mention occasionally to good friends that I am not feeling well and I make sure they know I take tablets, some of these have to be taken half an hour before meals. I take from 10 to 13 tablets a day so I shake, ‘rattle ’n’ roll.’ (Having a chronic illness has not changed me from loving rock ’n’ roll, Elvis Presley, swing, jazz, blues, rhythm ’n’, blues because I think music is one of the important human activities in the world!) The result of others not listening, not wanting to listen or seeing illmess as a competition as to who has the most to bear, is that some so called friendships will fizzle.

Di

I think that I am conscious that as my condition progresses, I am going to be more reliant on others. I am also less energetic and outgoing as well. So I am tending now to have a smaller circle around me, but it tends to be more people that I feel will be more long term and willing to help me in later years.

Andrew

For me, slowly but surely there has been the dawning of clarity in the world of relating. Relating to my self, children, friends, family, work, community, a slowing down that was imposed and with some struggle embraced, strengthening of boundaries and purposeful relating. On a good day there is even some fun, spontaneity, a cherishing of those times. Sometimes I think and do some letting go with a trusting that all that is meant to be will be, while simultaneously I do life the way I do it. I participate at some level most times. I'm getting better at being a passive recipient of life. Getting stronger about not carrying expectations, asking for what I want when I want it in relation to others and then dealing with receiving or not receiving. Trying hard to keep the location of control within my abilities, the heart, mind and body. Accepting of my mistakes and those of others. Some days it runs smoothly, some days not.

Olympia

Making and maintaining face to face friendships, isn’t something that comes easily to me. Illness has made it much more difficult to join in many activities. I’m so fatigued that it’s a real effort to
even bother going out at times. There are certain activities such as being out in the heat or playing golf which are now impossible. I am more likely to have adrenal crashes which are not only frightening and debilitating, but very embarrassing. Arthritis has limited me even more in the last couple of years. If I do force myself to do something which is a bit too much, I’ll be wiped out for days afterwards. Some friends are understanding of my limitations to a degree, while others never will be. With the latter I prefer not to bother explaining my illness and its limitations, as I feel they won’t get it anyway. It’s therefore easier to avoid meetings, although I try not to do so. It’s much easier to make an excuse and say no, than to worry about possible negative reactions to my limitations, whether or not these are real or just perceived. I worry I may put a dampener on the meeting, particularly when there are a few people present. I worry about what they may be thinking about me.

Michelle

When you really suffer a hardship or long-term illness that is when you find out who your true friends are. You don’t have to live in each other’s pockets to maintain the friendship either. We have some friends that we only see every 4 months or so and every time we meet up its as if we hadn’t even skipped a day. They are true friends who have always been there for us.

Chrispy

‘Working Out How To Fill The Gaps’

We each bring different things to a relationship, for example, our personality, experience, philosophy, interests, skills or spirituality. Usually we develop patterns in relationships that reflect these characteristics. For example, a person with lots of energy may be an instigator of activities, fun loving and extroverted. They come to be seen in this way and people expect this behaviour from them. With the experience of chronic illness there may be diminished energy and withdrawal from social activities that mean that the roles played out in relationships may need to change. Other people may want and expect us to be the same. We might feel guilty, fearful or angry that we cannot be the same person in the context of a relationship. We may not be able to do the things we once did, such as housework, driving children to school, shopping, employment, playing ball with children, gardening, house maintenance etc. This can make us feel as if we no longer make a worthy contribution or, as if we are a burden to the relationship.
The challenge for us is to find other meaningful ways to contribute to the relationship. We may not be able to contribute in physical ways, but there are many other things we can do to be a great friend or companion. We can listen, talk, provide emotional support or draw on humour. We may need to find new activities that fit with our changed abilities and needs. The process of redefining roles in a relationship doesn’t just happen overnight. It is a gradual process of letting go of past roles and confronting consequent changes in our self and identity. It is helpful if the people around us are sensitive and supportive of what we are experiencing. Here, communication is important to let them know what we are experiencing and how important it is to maintain the relationship despite necessary changes. We acknowledge that it is futile to continue trying to meet another’s expectations when we are no longer able. It is important to allow yourself time and space to gradually let go of past roles that do not serve us well any longer. This can evoke a range of emotions and trigger feelings of loss. Sharing these feelings with others in similar situations may assist us to move forward.

There is work to be done by both people in the relationship. The other person may also experience feelings of loss and need to change their perception of the relationship. Some may be unable to adjust to the changes in the relationship and may continue to expect us to fulfil past roles. Sometimes we might have to let go of these relationships to protect ourselves. Our network may become smaller and we may need to develop new relationships that are more compatible with our changed situation. We acknowledge this is a difficult consequence of illness, but one that must be overcome if we are to live well. Now we will discuss our experience of changing roles.

**How have you felt about letting go of past roles and what has helped you to make these changes?**

“Making changes in a relationship can be difficult when those changes are not part of the natural progression of the relationship. This is made harder when the changes are necessary because one person requires the changes to be made, as is the case when chronic illness occurs to one. The major relationship in my life is with my wife, and we have always been a partnership full of give and take, and sharing with each other. This has made the time of changing to incorporate the limitations of my illness a bit easier. Stresses do occur due to these necessary changes, mostly as a result of other external influences that stretch our personal energies and resources.

_Graham_

Several friends who I have known for years, expect me to be the energetic career person I used to be and so I have had to ease out of those friendships. They expect me to be very
accommodating and I just can’t fit in any more so those friendships will gradually fizzle. It is painful to let past roles go however, that’s life and I am happier not trying to meet other's expectations constantly.

Di

It really comes down to being open with other people and discussing the changes that occur. Everybody can make a contribution so it boils down to working out what we can and can’t do, making the most of the things we can and working out how to fill the gaps.

Andrew

I believe that I am now stronger because I have dealt with my past. I have let go and now look forward to the future in whatever capacity I am left with. I think you have to deal with letting go early on so that it doesn’t fester inside you and make you angry. An angry and miserable person does not make for a happy relationship. I am not the me I was, say 14 years ago when I first started to become worse. My husband saw me as fairly normal when he first met me. When he realised I was getting worse he told me to accept it and just do what I could. It took me awhile but in the end I realised that I was not doing him or myself any favours if I was trying to prove I was something I wasn’t.

Julie

I have felt sad, disappointed and frustrated at times; in some cases where maintaining links has been somewhat demanding, I have felt relieved; overall, I think I have accepted that my illness (is going to) reduces relationship opportunities and therefore I need to make the most of those that remain.

Ted

I’ve never found it easy to make friends and illness has made it harder in either maintaining old, or forming new friendships. Perhaps I fear a change in their attitude towards me resulting from my illnesses. Perhaps I fear unfair judgement. My few close friends live interstate, but the telephone helps me keep in touch. Most of my few local friendships were made through my husband, rather than instigated by myself.

Increasingly being unable to fulfill the roles I once played has resulted in feelings of sadness, regret, loss of self-worth and isolation. Having an understanding, supportive partner and family has helped immeasurably. Internet support groups are also valuable, in learning how others cope in similar circumstances and knowing I’m not alone in this.

Chrispy

Mostly I feel good about the changes. Other than doing a thousand things at one time and being everywhere at the same time, I’m not really missing anything that I once did that I can not any longer do. I have long breaks from ‘things’ and more often than not I’m thinking “Isn’t it amazing how once upon a time that “thing” seemed so important in my life and now I have no interest or energy for it.” Acknowledgment and acceptance of my state of well being have helped make these changes as well as the people in my life and their love and support of me, the strong will and determination that I carry and have nurtured all my life. Mostly with time and all the other things about me and my life context and history, my ability to let go happens and continues to happen.

Olympia
‘Giving and Receiving’

Given that the unpredictable and changing nature of the experience of illness can place strain on relationships, we may worry about maintaining relationships now that we live with illness. The answer to maintaining relationships as we see it, is about understanding and mutuality. Our view is that the responsibility for educating our family and friends about the effects of illness and our changing needs rests with us. Their understanding and awareness is seen as vital in terms of the ongoing relationship, since it enables expectations to be realistic and attitudes to be supportive. It also enables insight into our changed experience of life. We will need that level of understanding to see us through the ups and downs of living with illness. A style of open communication is important in keeping the other person informed about what’s happening for us, and enabling them to understand.

There are some practical things we can do to facilitate successful interaction. It is seen as useful to organise time spent with others to ensure that it is not too tiring or compromising to us. Shorter periods of time at points in the day where energy levels are optimal are more likely to be successful. Having a back-up plan should you feel unwell or lacking energy is also helpful. In our view we need to take responsibility for having a back-up plan. Accepting help is difficult for some of us, but we may need to find a way to graciously allow others to be helpful. These actions are often well intentioned and provide a means of friends feeling as though they can be useful. Whilst we might strive for independence within a relationship, this may be something that is achieved gradually with gentle education of others. We now talk more specifically about our experience of maintaining relationships.

**What have you found to be important in maintaining relationships while living with chronic illness?**

Any good relationship is built upon trust, honesty, respect, giving and receiving. These form a large part of what is important in maintaining a relationship through the effects of illness. Some examples of what I mean are, when you feel bad and uncommunicative you need to say so and the other person needs to know that you are not pushing them away, but just need some space. There are times that you feel the need to do something for yourself and another person steps in and assists, or does it, as an expression of wanting to help because they know you have problems with doing it. This is when it is necessary to be able to receive graciously, even though it feels like you are being treated as incapable. This acceptance of receiving can be hard to do without feeling inadequate.

*Graham*

Keeping a positive frame of mind; listening to what others have to say more carefully; being stronger in not letting people who are insensitive to my limits impose on me what they want me to do because it suits them.

*Di*
As a result of my condition, it is not as easy for me to just go out and do things as I need to eat at regular times and have to carry medications etc. with me as well. So some spontaneity is lost. This can be frustrating for some people. Fatigue is my other major problem. I can get tired easily. It is important for other people to understand that this is a consequence of the condition that cannot really be controlled and that IT IS NOTHING PERSONAL. Also, develop some strategies for dealing with the problems, for example if I am really tired I have a snooze for about half an hour after I get home from work.

*Andrew*

I have found being honest to yourself and to your partner helps to maintain a relationship. Your partner has to know the truth of how you are dealing with a situation or how you are feeling. Its a lesson in trust when living with chronic illness. Pain can be minimal one minute and out of control the next minute. If you have lied to your partner about what you have been doing he will not know what to expect when he needs to know how you are feeling.

*Julie*

Keeping communications active i.e. meet, chat, be proactive when not feeling depressed.

*Ted*

I know I’m in danger of becoming increasingly introspective, introverted and antisocial. I must make a conscious effort in maintaining friendships outside of my family. My husband tries to encourage me in this, but left to myself I tend to put off contacting them. I’ve found it helpful to allow for the limitations illness imposes on me by planning situations that aren’t too lengthy or physically demanding. For instance meeting friends at a restaurant rather than cooking a large meal and playing hostess, which causes anxiety and exhaustion rather than enjoyment.

*Chrispy*

Sharing the hard and the good times, being positive and loving, generous and interested, looking after myself mentally, emotionally and physically

*Olympia*
Never Taking Their Care For Granted

Chronic illness can also create challenges for people we love or care about. They may experience unsettling changes and losses in their lives as a result of the illness we live with. Like each of us, they are also on a journey of learning how to adapt to loving and caring for someone with long term illness. It may require a change in what we need of them and what they need to contribute in order to continue the relationship. And all the while they negotiate these challenges, being aware of how their lives have changed and being mindful of what has been lost. The people that stick around usually just get on with it and are not given much opportunity to express how these changes and losses feel. Further, it may feel improper for them to express these feelings because of their investment in the relationship. It can be a lonely and painful experience to watch someone you care about suffer.

So how do we, amid our fears of dependency and of being a burden, support them? Illness can be consuming, but there are many other kinds of problems or issues to deal with in daily life. It is important to be aware that the people around us have other life issues to contend with. We think it is necessary to communicate this awareness and to be there to actively listen and talk about issues that are relevant to them. This enables mutual caring and concern. Sharing each other’s ups and downs is seen to strengthen relationships and provide balance to the strain that chronic illness may bring. We see it as our responsibility to educate others about the illness and its effects so that they understand our situation and do not worry unnecessarily. We can also make them aware that illness is a learning journey involving loss for both the person who lives with illness and also the people around them. Relationships are two way, and while we may not be able to contribute in the same way as in the past, it is important to be mindful of finding ways to make the relationship mutual. Communicating openly forms the foundation through which we can express appreciation, foster understanding and provide support. Our discussions focussed on how important it is that the people around us know that we appreciate everything they do for us and that we do not take their care for granted.

*What do you think is important in supporting partners and friends in their experience of watching someone they love or care for live with illness?*

Give and do what you can to show that they are still important to you. Be aware that all of the problems of normal life continue and that they still have to cope with them, as well as you with your illness problems.

*Graham*

Ensuring that they have full knowledge of what is happening, reminding ourselves that an ill person is still able to care about and love another person and friends, and that partners can still have lots of fun.

*Di*
This ties back in with grief and loss. It can be difficult to accept that OTHER people also suffer and suffer loss as a result of OUR illness. However, genuine people will be concerned about your welfare, and so it can be a POSITIVE thing as well. Sharing the experiences of the illness, the ups and downs CAN strengthen relationships, despite the additional strain put upon them. The important thing is to help other people to understand your condition and the effects it has on you and your life.

Andrew

Relationships are about two people, how you treat them and how you expect them to treat you. I think that if you whinge about pain all the time a friend or partner is going to get pretty sick of it. It’s hard enough for the friend or partner to see you in pain. They also need your listening ear as to what is affecting them and how they are feeling about it. The person in chronic pain needs to be sympathetic about others’ feelings of loss. The way to do this is not to react negatively over what they have to say, just listen and be sensitive.

I only have two close friends whom I have known since early childhood. They accept me as I am and they live interstate. We still keep in contact and have been to them and they to us. I have another friend who has rheumatoid arthritis and she whinges constantly. She often says she doesn’t know how I do what I do and I tell her I space myself and know what is going to increase pain. I just listen to her and accept her for what she is. She has been there for me over the years.

Julie

Be open with relevant friends and relatives about my illness and its restrictions on me. I try not to burden them with minor or past details; open up when I suffer major setbacks or when I am just not coping, but ideally only to those I feel who can understand and support me.

Ted

Communication is imperative. Never allowing a ‘poor bugger me’ attitude, which could result in loved ones feeling obligated and a building up of resentment. Never taking their caring for granted. Having genuine empathy and concern for their problems and offering support. I may not be able to help as much in the physical sense but I can be there for them by talking things out, being a good listener and a shoulder to lean on. Also letting them know I understand that my losses and limitations impact on them too and how much I appreciate them.

Chrispy

Important that they realise that it’s a normal response. That just as the person living with chronic illness will have changing needs, desires and expectations in response to their managing illness, so too will they as carers and lovers of the people. They could be encouraged to self manage in relationship to the other. For example, address their own emotional physical and mental health needs, not to mention their social economic family, community, work and relationship needs.

Olympia
Our Message To You

Changes to relationships occur throughout our lives. It is ideal if those who are close to us can understand our symptoms, but this won’t occur unless we are prepared to communicate. This doesn’t mean we dwell on our symptoms. Our time and limited energy is precious to us and it helps to plan carefully how we want to use it. When we can, let’s try to just enjoy other people and take pleasure in doing the things that we are able to do with them. Most of us will find our circle of friends and acquaintances may become smaller over time because we don’t have the energy to go out often. Relationships change, and we may find that we drift apart from good friends, while others become more important to us. These are the natural rhythms of relationships throughout our lives.

Our Message To Health Workers

Our relationships with you can be very important. It is helpful when you show us that we are worth the time and effort needed to form a therapeutic relationship. We recognise that we are in charge of choosing our health care team and to do so gives us a sense of control. It is important that we not only have confidence in your knowledge and skills, but that we also feel comfortable with you. We must feel comfortable to raise questions with you, and to ask you to explain results in language that is common to us. It is important that we know that you will explain if you have the answers, and try to seek the information if you don’t. It is also important for us to know that we can contact you at important times.

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 bought to our lives.

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