Transition in Chronic Illness

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

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexuality... A Lot More Than ‘Doing Sex’</td>
<td>1</td>
</tr>
<tr>
<td>Our Sexual Selves</td>
<td>3</td>
</tr>
<tr>
<td>Counteracting Gender Expectations</td>
<td>4</td>
</tr>
<tr>
<td>Staying Connected To Our Sexuality</td>
<td>6</td>
</tr>
<tr>
<td>Changing Sexual Needs</td>
<td>8</td>
</tr>
<tr>
<td>Our Message To You</td>
<td>9</td>
</tr>
<tr>
<td>Our Message To Health Workers</td>
<td>10</td>
</tr>
<tr>
<td>About Us</td>
<td>10</td>
</tr>
<tr>
<td>About The Booklets</td>
<td>11</td>
</tr>
<tr>
<td>About The Research Inquiry</td>
<td>11</td>
</tr>
<tr>
<td>What Are We Researching?</td>
<td>11</td>
</tr>
</tbody>
</table>
We are able to talk about this kind of issue. The only time I felt a real sense of guilt was when I was finding it difficult to bring the problem out into the open. John therefore didn’t mention it either. When I did bring it all up (with a bit of humour as I explained in my answer to the question for the booklet) he was relieved as he thought perhaps it was his fault in some way. Therefore he was feeling guilty. That’s why I find communication imperative as it’s the only way to prevent misinterpretation of the problem and misplaced feelings of guilt. Thankfully this isn’t a problem all the time for us but with so many of my hormones defunct, constant fatigue and the pain of arthritis, it definitely is an issue from time to time. From now on when I am feeling a loss of libido I won’t hesitate to talk about it and use a bit of humour if needs be. When all is out in the open, it’s easier to work out other ways of expressing love. Avoidance definitely unnecessarily exacerbates the problem.

Sexuality... A Lot More Than ‘Doing Sex’

We get bombarded from the media with a very narrow perspective on sexuality, one that is about the physical aspects of having sex. The emphasis on the physical aspect of sex neglects the social, emotional and spiritual aspects, which all have a strong influence on how we feel about and express our sexuality. Sexuality is often equated with being young, attractive, fit and ‘doing sex’. Most people do not measure up to these images, yet they are still promoted as ideal. We emphasise that sexuality is about ‘being’ rather than ‘doing’. Many of us may have grown up in environments where sex and sexuality were forbidden topics or were the topics of speculation or teasing. These background experiences may make having conversations about sexuality difficult.

In our view, our sexuality is about the way we interact with others, it is about affection, attraction, and sensuality, it is about who we are. It is about a myriad of small subtle things that happen as we live life, such as the way we talk, move, dress, a gesture or a flick of hair. It is about our values, attitudes and philosophy of life. Sexuality is also about communication between two people that may happen verbally and non-verbally. Sex, sexuality and our relationships are important aspects to our quality of life. A willingness to be in touch with our own feelings and emotions and those of other people is part of our sexuality. If we accept this broad dynamic definition of sexuality then the person living with chronic illness has access to many aspects of their sexuality. We can choose to reject a narrow unrealistic concept of sexuality, and embrace a broader more relevant definition that recognises the complexity and depth of the relationship between who we are and our sexuality.

When chronic illness becomes a part of our lives, surgical intervention and medical treatments may result in our appearance being altered and symptoms such as pain, stiffness, fatigue and depression may change the way the feel about our sexual selves. Here we now talk about what sexuality means to us.
What does sexuality mean to you?

Sexuality, firstly, is how you feel about yourself as a man and confidence in how others perceive you as a desirable person. Secondly, sexuality is the physical and emotional attributes that are considered gender specific.

Graham

For me, sexuality includes affection, willingness to tune in to a partner’s emotions, for example, if there is a need to talk about something or not talk about something, touch, hugs, loyalty and love. Appreciation of the sensuality of movement, hand gestures, a lovely smile, a flick of the hair, sunlight striking shining hair, sudden bursts of unexpected humour.

Di

Sexuality means how I identify myself as a woman with a healthy attitude towards sex, my communication with my husband on what I need and want and his needs as well.

Julie

Sexuality to me means feeling comfortable enough in my body to invite others in, so to speak. I’m not necessarily being literal here. Surprisingly, I felt at my most sexy when pregnant. It was 15 years into my chronic health problems with all the issues swirling around, including the one that said I would not be able to have a baby. I remember one afternoon when I went to a poetry reading of a famous Russian poet. His style being audience participation, during a particularly romantic poem he reached from the stage and looked into my eyes while declaiming the lines, then kissed my hand. Later that afternoon I stopped at the local shop on the way home for milk and the guy behind the counter started chatting me up and asked me out. I don’t know if it was just the hormones, but despite all my chronic problems, and the fact that I had just finished treatment for breast cancer, I felt good about my body and that must somehow have shown.

Brumby

To me sexuality includes perceiving and expressing loving feelings between my husband and myself. It’s showing affection in a myriad of ways, such as being close, holding hands or a hug. On a personal level sexuality is feeling as feminine, graceful and attractive as possible. In broader terms sexuality includes pressure in living up to the role of the perfect modern woman or man. A woman should be able to successfully work full time, manage the household and raise her children. She can do it all and still have the energy to be lover as well!

Chrispy

It’s part of my whole being that I feel very much connected to. My sexuality is me. How I dress, how I relate, alone and or with others, its connected to my interests, my politics, my work. The connection varies in intensity and positivity. It’s connected to how I feel about myself physically, intellectually and emotionally. It’s influenced by the current context and the external dynamic. It’s a moving feast.

Olympia
Our Sexual Selves

The person we are may need to change when living with chronic illness. We may not have access to parts of our self identity that were important in defining how we expressed our masculinity or femininity. For example, it may no longer be possible to play sport, wear certain clothing or undertake paid work. We may not be able to move as we once did. Pain or fatigue might affect our energy levels and limit our activities. These effects can lead us to feel as if we are not measuring up to the expectations of others. Our gender (being male or female) is closely linked to roles, and not being able to fulfil certain familiar roles can feel threatening. It is important to remember that most people do not fit gender stereotypes.

The challenge for us is to find new ways of thinking about and expressing oneself, which are compatible with wellbeing and which enable us to feel okay about ourselves. People do sometimes prefer to reject gender stereotypes and to find their own individual style. Chronic illness provides an opportunity for us to learn about our own style and redefine what is important to us about the type of person we are. As you will see from our responses, some of us have been learning how to create new priorities and visions for ourselves. The consequences of illness bring us back to priorities of wellbeing and of looking after ourself. We can learn to listen to the needs of our body because we know from past experience that this pays off in terms of wellbeing. We can also learn to protect ourselves from external pressures and expectations.

Occasionally we do compare ourselves to others, but it seems to worry us less. The experience of learning and incorporating illness as part of our lives enables us to keep focussed on what's important. Our expectations are that illness will constrain our lives and we work with these constraints rather than ignore them. We emphasise the importance of nurturing the self and valuing our unique characteristics. While we may not be able to express ourselves in the same way as others, there are still many options open to us. While we are not able to change our illness, we can choose to honour ourselves as individuals and to shape our lives according to what feels best for us as people, rather than stereotypical expectations of gender. We now talk about our perceptions and experiences of being male or female while living with chronic illness.

How does the experience of illness impact on how you see yourself?

The symptoms of illness combined with side effects of medications can reduce your self image of being a male. The normal range of man-type activities becomes reduced and I went through a long stage of feeling less of a man. I have gone through this phase until I learned to accept that the limitations placed upon me by my illness/medication are now a part of me and the realisation that if you cannot change something then you may as well learn to live with it. I still have occasions when I feel “inferior” to other men but these have less impact on me.

_Graham_
I sense no impact on my female self, except that on days of fatigue I can't be bothered with thinking about anything too intensely and physically my energy is very low. Feeling like being sensual or sexy would be far from my mind on those days.

Di

My looks had changed from the normal look before chronic pain took its toll to the woman I am today. I have had to relearn self-esteem, self-love, self-worth. If I didn’t love myself how could I expect others to love me? Once I relearned this I smiled more, I had more confidence and I had regained my positive attitude. Easier to love this person than one who was complaining of pain.

Julie

I have never felt particularly feminine, being quite tall and an outdoorsy type. I was always regarded as one of the guys at school and despite having a big chest was often mistaken for a guy. So illness has not made any difference to this.

Brumby

Once I was able to do it all, raise my kids, work full time and run the house. Illness gradually took away my ability to do so and now I’m no longer able to work at all. I’m grateful my children were in their teens before I became really ill, but find illness impacts on my ability to do the things I feel I should be able to manage with my grand-children. I used to dance and moved gracefully. Now I often move like a ruptured duck and much of the time I look more like “Jake the Peg with My Extra Leg,” when either the elbow crutch or walking stick is needed. Hardly the best way to look one’s feminine best.

Chrispy

It's so far never challenged how I see myself as a woman, or maybe other issues have not over shadowed its existence although it may have taken space and time from how I am in the world. I am not out and about as I was before Multiple Sclerosis. I have been curious about how others would now view me.

Olympia

Counteracting Gender Expectations

Media images carry messages of what is male and female, masculinity and femininity, and gender roles. For example, males are often portrayed as active, physically tough and in positions of status and power. Females on the other hand are often portrayed as pretty, slim, fashion conscious, and fulfilling domestic or caring roles. Sexuality is often associated with being young, good looking and socially in demand. Men and women experience these messages as pressure to be and act in accordance with these images. Most people do not fit with these impossible standards. They do not reflect the reality of what it is to be a man or a woman. They reflect a very narrow understanding and in doing so, neglect the diversity of sexuality. Yet, alongside these images we may feel inadequate and different.
Most of us have found ways to reject or avoid buying into these pressures. We choose to value ourselves for who we are and what we achieve in everyday life. We prioritise our own needs, wishes and style over external expectations and acknowledge to ourselves that we are doing okay, despite not fitting with stereotypes. The recognition that these images are fickle and unrealistic for most people enables us to trust and follow our own individuality. We emphasise that it is futile to attempt to be someone we are not. There is a strong sense expressed here of having come to terms with the reality of illness and having re-focussed on valued aspects of self. For the most part we do not pay attention to stereotypes. This is managed within the individual and is a result of learning from past experience. It is a way of thinking about self, of honouring one’s journey and of choosing to nurture self above all else. There is a comfortable familiarity with our imperfect bodies and the reality of the limitations that illness places on our lives. Here we talk about our perspective on managing stereotypes.

**Can you talk about how you manage the pressure to act and be a certain way in terms of gender and sexuality, when chronic illness makes this impossible or unrealistic?**

I try to ignore others and what I imagine they are thinking. At one time I would try to keep up the activities of a normal male, like doing all the heavy work. It took me some time to learn that I must not be concerned if others perceive me as weak because I have limited abilities. This learning process was mostly enforced on me as I continued having bad physical after-effects from doing things.

*Graham*

I ignore the pressure to act and be a certain way. I find many of the advertising images boring but admire the physical beauty of some people, for example David Beckham, the face of Catherine Zeta-Jones or the attraction of Bruce Willis. Advertising images are always extremely heterosexual, although some androgynous looking models do appear in ads and movies and homosexuality is camped up, so that it is rare for the general public to see images of normal, people who happen to be homosexual. I like my own style. I enjoy doing what I want to do for example, not always having to wear make up when going out. The life span has become shorter and wasting life on trying to be something the media or other people want is a waste of my precious time.

*Di*

I never act. I am me. If people don’t like me the way I am then that is their problem.

*Julie*

I suppose the scars I got from the various surgeries at 19 made me realise I’d never be a catwalk model, but I was also very self-conscious about them for many years. At 46, the surgeries now total 18, so I have many more scars, but am less worried about them. Sometimes I try to see them as a badge of honour, ‘Look, I have survived’, but mostly I cover them as much as possible.

*Brumby*

*I try to ignore others and what I imagine they are thinking.*
Realising stereotypical images of gender and sexuality are anything but typical, helps me see things in perspective. I look at younger healthier women who are trying to live up to the pressure of managing work, raising kids and running the home. Many women don’t find this easy, no matter how healthy they are. I look at how my children have grown into successful, decent young adults and tell myself I played a part in that. I try to be realistic about being a good grandmother by spending quality time with them doing activities such as reading or drawing.

*Chrispy*

I feel this has not been an area that I have had to consider on a personal experiential level. I am in to beauty and aesthetics and am drawn to it and find it on many dimensions. There exists an energy I believe that is unique to each and every individual and it often shines when one is simply connected or happy in some way. I am not sure what becomes unrealistic or impossible, I guess that is very self defined.

*Olympia*

**Staying Connected To Our Sexuality**

Sexuality is an important aspect of our lives. Our sexual orientations, needs and preferences will differ, so overcoming sexual stereotypes is important. It may also be possible that other forms of closeness and sexual contact may feel better than sexual intercourse. Each person is different and it may take some trial and error before you find out what suits you.

In our conversations it is clear that we want to stay in touch with our sexuality and that this is closely linked with looking after ourselves. Ensuring that we have physical and mental peace and wellbeing gives us a sense of satisfaction with our lives. Staying involved in life as much as we can be and participating in our interests and passions, contributes to our sense of self. We feel connected to our sexuality when we are feeling happy with ourselves. Paying attention to small things, such as what we wear, how we are groomed or how we interact with our partner all contribute to this.

For those of us who have significant relationships we feel a stronger sense of sexuality when we feel closeness with our partner. Relating to our partner in a way that conveys our love, appreciation and affection assists us to feel close, as does communicating openly and honestly with them. Even if we are not ‘doing sex’ with our partner there is a way of relating which maintains the feeling of each being special to the other. It is about the things we say and how we say them, about showing respect and affection, and about the way we build our life together. The routine of managing chronic illness can lead us to neglect this aspect of our lives, and we may have to remind ourselves to show our partner they are special in the little things we do and say.
Sexual activity does not require a partner. For those of us who do not have a partner, having a network of good friends who we can laugh with and enjoy life with is vital to a sense of sexuality, as is looking after our mind, body and soul. We talked about how we each stay connected to our sexuality.

**What is important for maintaining a sense of our sexuality when living with chronic illness?**

Maintain a warm emotional state towards my partner and be open with my feelings and affections. Communication is probably one of the most important aspects of our relationship, and essential when this relationship has the added strain of limitations due to illness.

*Helen*

I feel it is important to wear nice clothes so you feel good about yourself, looking after personal hygiene, keeping active, mentally and physically so that I am sexually appealing to my husband.

*Julie*

I’m afraid I do not feel like a sexual being at all anymore. Anything to avoid it. I feel so guilty about this, particularly as my husband is so understanding and never pressures me. But I feel I am being unfair, not fulfilling his needs. Most of the time I just hate this body so much and feel like I’d be contaminating him to do it. It is so rare that not even a spark of interest in sexual activity enters my brain, which is, after all, the most important sex organ.

*Brumby*

Making the most of what I have is important. I may feel like someone has run over me with a steamroller, but I try not to look like it. I try to wear clothes which best suit me, take time to put on some makeup and make sure my curly, unruly mop is looking as good as possible. I may often move stiffly and clumsily, but I try to look my when best doing so. I attempt to keep as mentally and physically active as possible, though the latter can be particularly challenging. I show affection for my husband in many little ways, as knowing he is loved, appreciated and desired, is just as important for him as it is for me.

*Chrispy*

Staying as healthy as is possible in body mind and soul. Happiness, positive energy, openness, being in a position to listen and respond to your needs. Good food, exercise, rest, friends, simplicity, staying informed, an ability to share an appetite for living.

*Olympia*
Changing Sexual Needs

Awareness that our sexual needs are changing can feel very threatening. Chronic illness can alter the dynamics of our relationships, particularly if our partner has assumed the role of carer as well as lover. We may not want to confront this with our partner because talking about it may emphasise that life is changing. That can be hard to accept and may feel like a threat to the future of the relationship. People may feel uncomfortable talking about sexual issues and avoid it. These are not easy issues to address. So how do we go about negotiating for our own needs to be met, along with our partner’s needs?

What seems to be important when negotiating sexual needs is a foundation of understanding and honest, open communication between people. This provides the basis for working out how best to meet the sexual needs of both people. Achieving honest open communication can be difficult when, generally, people feel uncomfortable when talking about sex. The most loving partners may feel awkward when talking about sex. It may be helpful to approach the topic of sexual needs with humour and lightness as this relieves tension. It is also important that we ensure that our partner understands how illness can affect our sexuality and libido. A willingness to listen to each other and to problem-solve together seems to convey the message that both people are committed to finding an acceptable solution and that both people’s needs are being taken seriously.

Pre-existing relationship issues may be exacerbated by the challenges of illness. Some of us do not feel like being sexually active and may avoid being sexual with our partner. This can lead to feelings of inadequacy and guilt. Not wishing to be sexually active is a very common issue in relationships. It is an issue that brings us back to the foundations of a relationship, respect, trust, communication and commitment. We are clear that it is not acceptable to participate in sexual activity unless we wish to and that is each person’s right to have their wishes respected by their partner. There are many ways to feel intimate with a partner, so let’s be creative about finding options that enable people to feel close. Most important is that we seek assistance with a trusted health worker if we are unable to work this out on our own. Counselling from specialist sexual and relationship therapists can help us to adapt to, and communicate about issues around sex and sexuality. Here is what has been helpful for us.

**What has been helpful for you in terms of negotiating for your sexual needs?**

I try to let my partner know what is needed and listen to my partners needs. It becomes even more important that I am fully aware of how my illness is affecting my partner. This can be difficult as I am not always fully aware of any problems, so when I am able I try to be as attentive as possible.

*Graham*

Ensure that a partner understands as much as possible the effects of the illness and talk about what that means physically and emotionally and work towards ways of dealing with that together.

*Di*
Communicating honestly to my husband as to what I am feeling at the time. If I am feeling pain, I tell him and we work it out together.

*Julie*

Unhealthy as it is, I have built up an amazing retinue of avoidance strategies. I do not like myself for this.

*Helen*

By being completely honest and up front. There is nothing like feeling exhausted, ill and / or being in pain to lower ones libido. I used to bottle up my concerns and sometimes avoid intimacy, which left me feeling guilty. Once, when my husband was initiating sex, I got up and started looking under the bed and in the wardrobe saying, “Okay either I've lost my libido or someone’s stolen it. If you find it anywhere, can you please give it back.” He burst out laughing and that brought the problem out into the open. He’d been worried he was somehow at fault and we discovered this wasn't that big an issue after all. Now we talk openly about any changing sexual needs or limitations. I've found with honesty and mutual respect, between us these problems can be overcome.

*Chrispy*

So far taking it slow, review and evaluation, short term goals, staying connected to activities, people, ideas, objects that stimulate me, that see me and hear me.

*Olympia*

**Our Message To You**

Sometimes when illness intervenes we may place our sexual needs on hold or may loose confidence in our sexuality. Sometimes we may not feel sexual or think that others will not perceive us as sexual beings. Feeling sexy has a lot to do with our feelings that can often be linked to the way we nurture and care for ourselves.

Sex and sexuality is personal and private and, as our conversations have revealed, has different meanings for different people. Our sexual relationships also differ; for some they are long-term partnerships, for others they may be brief or casual relationships. The reality is that people enjoy many types of sexual activities and find many ways of showing love and affection. Remember that sex does not always need a partner. Masturbation can help us to discover what is enjoyable. There are also many sexual aids that may be helpful if you have a disability that affects your sexual pleasure.

Research has shown that very few health workers consult people about issues surrounding sex and sexuality. Some health workers may be reluctant to raise these topics for discussion because they may feel it to be intrusive or insensitive. Others may feel they do not have the expertise to assist with such sensitive issues. If you feel this may be the case with your health worker, then consider asking to be referred someone who specialises in sexual health.
Our Message To Health Workers

It is important for those of us living with illness to feel that our concerns and experiences are affirmed. Discussing issues around sex and sexuality can be difficult, so you may help us by creating time and space for discussion to take place between us. Sexuality is such an integral part of our person and is essential for our sense of health and well being. When illness forces changes to the way we live and experience our lives, this often means that we also experience changes to our sexuality. Physical symptoms may also impact upon the ways we have sex. But this does not mean that our sexuality is not important to us. Research has shown that people who live with chronic illness place considerable emphasis on staying connected to a sense of their sexuality. It is important that health workers do not assume that our sexuality no longer matters to us or that we do not relate to it because of illness or disability. Providing an opportunity for us to talk about sexuality issues not only acknowledges us as sexual beings but also affirms us as a whole person.

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 understandings about what it means to live with long term illness. Maybe you will find some experiences and ideas that are familiar to you or have meaning in the context of your life. We acknowledge that challenges are part of life and fall within the experience of all human beings. Given this, our experiences may also be helpful to 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.