Understanding Transition
Title: Understanding Transition

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

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I think there are two choices...to isolate, or to embrace and share.  
– Olympia

What energy I have I use in trying to get my life in order again.  
– Andy

What Is Transition?

In this booklet we describe the process of transition, which is how we move through disruptive or difficult events in our lives so we can learn new ways to live well. Transition encompasses people’s responses during a passage of change. Life and living involve transitional processes. A transitions approach to disruptive life events such as chronic illness creates a focus on what is changing, how we experience those changes and how we can respond. It is not a focus on the illness or disease.

Times of transition can be very difficult periods in people’s lives. We experience transition when one chapter of our life is over and another is beginning. Transition is the way we respond to the changes in our lives... particularly when we experience the change as disruptive. Disruptive change is usually when the change was unwanted and/or unexpected. These sorts of change often jar our inner world.

Whilst I cope most of the time with the pain of multi neuropathy and a few other things, I am still trying to come to terms with the fact that my life in many ways, revolves around how to cope on a daily basis with my pain.  
Denise

When we experience transition, we look for ways to move through the turmoil to create some order in our lives by reorienting ourselves to new situations. Transition may also provide us with the opportunity to review our life, get rid of some old baggage and find new ways of living. It gives us a chance to reflect on past experiences, try some new things, engage new relationships, new thoughts, views and concepts. Transition can involve a lot of trial and error... or discovering new ways of living, doing and being.

It has helped me to recognise and understand things that have happened to me... situations that I haven’t acknowledged.  
Jude

When we go into a period of transition, who we are, what we value, what we want and where we go is often not known until we give it a go and try it out. Transition really is a process of discovery. It is also the fertile soil in which we can plant the seeds of our new future.
When we move further through the transition process, sometimes our old life no longer makes sense and we no longer find satisfaction in the things we once thought were important. During transition, we are forced to look at who we are, what we are doing and where we are going. We often need to let go of our familiar past. This means we are often faced with uncertainty...

People have often said to me that nothing is for certain in anyone’s life and I find this so diminishing of the sharp contrast between the uncertainties that a person with chronic illness faces and the uncertainties of a person living a life without chronic illness. I think to myself ‘they don’t understand and how dare they!’ The uncertainty I live with now is absolutely incomparable to the uncertainty I lived with when I was healthy. Uncertainty then had a totally different meaning to my life.

_Kerry_

It has been very freeing in a way. I have learnt through this group that it is OK that I have a chronic illness, that it’s OK that I need to have a sleep through the day. It has also been confrontational at times to really look inside yourself and face facts. I wouldn’t have missed this opportunity for anything.

I’ve learnt that I can take control of my illness and make suggestions to my specialist and ask questions and disagree if I want to. I’ve learnt that its ok for me to have a day of staying in bed if that’s what I need. I’ve learnt that I’m a lot stronger than I give myself credit for.

_Michelle_

**Experiencing Tough Transitions**

Transition is the way we respond to change. Changes can be chosen or forced. They can bring exciting opportunities, or tragic and irretrievable losses and any state in between. We are always engaged in transition, it is just that many changes in our lives we experience as positive. Examples can be the changes we experience when we find a partner, have children, or land a new job. Throughout our lives we are often engaged in transition. Someone once said ‘isn’t transition just life?’ Yes, transition is life, but sometimes we experience tough transitions where changes are unwelcome and threaten the status quo of our lives. They cause disruption to every aspect of life. There may not be a discreet start or end point in the transition process because all humans on a regular basis face changes.

Life is for living and that is what we all do, according to what is happening to us at the time.

_Judith_
Tough transitions are also inevitable in our lives. Tough transitions may include life changes such as the death of a partner or family member, loss of employment or a chronic illness. If you reflect on your life, you can probably identify a few tough transitions that you may have previously experienced. If you think about the emotion and experience of these tough transitions, you will see that there is a variety in intensity, pain, duration, and effect on your well-being. Some of us have experienced chronic illness as a tough transition, because the experience has disrupted every aspect of our lives. Some of the areas of our lives that illness has affected has been our self-esteem, our confidence, relationships, our capacity to earn income, sexuality, parenting and our ability to be spontaneous. Our vision for our future was shattered because illness had not been a part of our life plans and its presence interfered with the goals we had cherished. It changed the view we have of ourselves and our familiarity with a body that we could rely on. Some of us felt in absolute turmoil.

There seems to be no way to balance my life anymore- even though I have been living with this disease and it’s unpredictability for years, I have yet to find a system that works.
Carol

Even though each of us has lived out a tough transition in our own unique way, we have been able to connect with and relate to the transition experiences of others. This connection has enabled us to feel less alone as we work out ways to live our life with chronic illness.

I so often felt alone and alienated being chronically ill. Knowing there are many others out there who are ill and more importantly being able to communicate with them, has been very supportive. I no longer feel all alone in my struggle.
Chrispy

When we go through times of profound change we may view ourselves harshly because our values have not shifted. We may think that others are judging us to be a success or failure or as coping or not coping with our new situation. If we experience ourselves as struggling or as having difficulty coping we tend to label ourselves as failures. With this label we may withdraw or direct anger towards ourselves and/or others. We feel isolated and alone either way.

Not everyone noticed my disability or commented on it. This was/is in itself disconcerting, because I couldn't pick up clues on how to react. So I was always waiting for them to say something, (nervous tension), then perhaps I
grew more accustomed to them and relaxed my guard. Then they'd ask! and I wouldn't know what to say, or I'd be so furious that they'd noticed after all, I would withdraw. (I wasn't allowed to show my anger as a child, and still have a problem dealing with it.) I also felt the edifice of my self-esteem, so carefully rebuilt, time after time, collapse at the first touch of an intrusive question.

Janice

Signs that transition is occurring include reconnection to, and interaction with, other people. We feel located again and gain a sense of belonging and connection with people. We have found that our illness transitions have provided opportunities to get to know ourselves better and to become more understanding, capable and compassionate people.

I had no concept of illness before this experience and had no way of understanding the impact it has on people’s lives. Now I find that I am looking at people with disabilities and illness differently and wondering how they are coping and how it has changed them. I do not look on in pity anymore but in awe of how they have overcome the obstacles. And in this way I think I have been enriched and have become a better person because of this experience and I think it is up to us to look upon this as a learning experience and to maybe provide insight to others to help allay understandable ignorance.

Gerry

When illness intrudes old ways of living can come to abrupt ends and new ways of living have to be created which cause great internal disturbance and turmoil. People can spend time in an indeterminate space that we termed ‘limbo’, where they could not go back to the familiar and predictable way life was, neither can they work out how to live and be themselves with the changes that had entered their life.

I don't relate much to the person I was because I am so different now ... in the beginning I was constantly comparing, but I think as I have redefined my identity that it has become easier. It has taken me a while to redefine who I am as a woman living with chronic illness. But I think it has been very important. The way I have developed life alongside illness reflects who I am now and I draw from that in knowing what I am about ... If someone asked me how to overcome the desire to make comparisons ... I would say reflect on who you are now and what you like about you ... develop your life and networks around your interests ... be out there in the world interacting meaningfully with others ... make your life something that you want to own.

Kerry
When we learn to reflect on our responses and experiences, we shift some of the ways that we think and behave, we may navigate through tough transitions with more insight, understanding, and a stronger sense of direction. Transition is about embracing the opportunity to move on by finding ways to adapt to new circumstances and situations whilst looking back to learn from past experiences. We may break with old patterns and ways of thinking and behaving and come up with new ways we want to live.

I realised I haven’t fully grieved for many, if any of my problems ... I suppose I was trying to stay happy and positive.

Iolanda

Often during transition we find new ways of thinking, ways of making connections and relationships with others, that we have never experienced before. We all started our transition with illness in a place of uncertainty, newness and unfamiliarity. At some point each of us, at our own pace looked at what our options were, thought about what we could and couldn’t do in a particular situation, and took actions that we considered would help us to move on. This may sound easy, but the reality is that it is two steps forward and one step back. Patience and positive self talk becomes an important part of the transition process. There is little space in the transition process for drawing comparisons with who we were prior to illness.

Hopefully we can go past the pain, which shows in a lot of the anger and body loathing that is being spoken about, we are able to realise the resources that we have gained from what we have been through.

Judith

What has helped me to move on is that I have come to realise that I am embarking on another stage in my life, and to fully enjoy and appreciate it I have to open my senses and mind to new adventures, interests and experiences and not to dwell in the past. What’s done is done and I cannot go back in time and change what has happened.

Julie

We have found it damaging to draw comparisons with who we were prior to illness. We have taken tenuous steps when beginning to navigate transition, we practice, fall back, practice again new ways of thinking and new models of living. Even so, we have found that transitions are creative, dynamic times when we may achieve things we had not thought possible.
Transition As A Process

When we are learning to live with illness we are involved in a process. We have come to understand transition to be a passage that can be convoluted, during which people redefine their sense of self and redevelop the confidence to make decisions about their lives in response to disruptive life events such as illness. When undertaking the work of reclaiming our sense of self and identity, we come to an understanding of what has changed in our lives and how our reality and values have shifted.

Before, I seemed to be able to juggle children, work, house and leisure without any problems. It is only since I have had to give up that hectic lifestyle that things seem out of whack, I think... Perhaps it was the fact that I felt useful, organised and ‘in control’ of my life at that time. Since then, I seem to have lost that amazing ability that working mothers have to be super organised, and by not working, I feel less than useful?? I have never really considered that interesting thought though!!

*Carmel*

We have examined the nature of the change and the possibility, or otherwise, of returning to our familiar life. Together we have also explored the significance and difficulty of the changes and the personal familial and social influences that are impacted by, or impacting on, the change. Once identified we can feel and grieve the losses that the changes have incurred. It can be a time of great emotional turmoil, stress and confusion.

It’s not the most blokey thing to do, but yes I cry at times (just don’t tell anybody). Part of the process involves realising that we are undergoing significant changes in our lives and that it is normal to have these feelings.

*Andrew*

This process takes time as we disengage with what was known and familiar and we look toward an altered and uncharted landscape of what lies ahead. At this point it is important to connect with trusted others. A support group, partner, friend or family member who is a good listener becomes an important asset.

“Part of the process involves realising that we are undergoing significant changes in our lives and that it is normal to have these feelings.”
I think disruption to life style, a feeling of abnormality and general dislocation applies to anyone with a chronic condition. People with emotional pain are also able to support people with physical pain and vice versa. Sometimes also people with another condition can see things that you can’t see yourself.

*Helen*

The love and support of my wife and daughter has given me the strength to face the changes in myself. The other helpful thing was to provide some support to (and receive support from) others facing the similar problems to myself.

*Graham*

People can support us by providing a safe space to listen to our story so we can hear our own words and explore new perspectives on that story. We have found corresponding by email useful, because it means that we need to think about what we want to communicate and we have the opportunity to reflect over what we have typed. Through this process we come to better understand our particular experience of illness, how our lives have changed and who we want to be now. While communicating we surface those values that we hold and perspectives of ourselves that we wish to reclaim, and those we want to discard.

I find it difficult to think of myself as having complete control of my future - there is always the need for my ‘medical support team’ who overall have a significant impact on what I should attempt to do. I have had to accept that I can only have limited aspirations. However, I think that I have developed more self-reliance. I am more relaxed about what I think I can achieve so I am less uptight. Thus, overall I think I have become more accepting of my physical and psychological limitations.

*Ted*

Without such examination of the change events, our understanding of what is shifting may be limited. We have examined our perceptions and have considered how this motivates our actions to change over time. The profound life altering effect of chronic illness does not dissipate quickly or easily, however we have come to view illness as a life experience.

I've had health problems all my married life. Many times I struggled thru the day till [my partner] got home from work and then I fell into bed. One of my girls, then aged about four, once said to me, with a sob in her voice, “I don't like it when you are too sick to eat with us. It fells like we don't have a Mummy”. I was of course, shattered, not that I could do any more about it, but I mentioned it to her a couple of years ago and she has ABSOLUTELY NO MEMORY of saying it. So the point of all this is - I think our children cope as ours is the only mothering they know. I think we often lay the guilt trip on ourselves. Most mothers, sick or healthy, do the best they can and our kids usually bounce back despite our shortcomings and mistakes.

*Helen*
We have developed a framework that displays the process of transition. We have seen this process of responding to change as four interrelated phases:

- Familiar life
- The ending
- Limbo
- Becoming Ordinary

Let’s take a closer look at what we mean by each of these phases.

**Familiar Life**

Life is recognisable and predictable. There is certainty in everyday experiences. The ordinary is captured in the daily routines and repetitions of daily living. We know what to expect, even if that is not desirable. In our familiar lives we know our social roles of parent, partner, brother, sister, grandparent etc. Our sense of self is attached to those roles and the status they do, or do not, carry. We feel a sense of order and we feel comfortable. We can rely on our bodies to do as expected. There are parts of our lives that we can take-for-granted. It is familiar and we become acquainted with its ebb and flow.

A familiar life is as much about our lives before illness as it is about our lives when we have incorporated illness into our lives. It is about developing ways for life to be familiar again by learning to live as effectively as possible with the changes that illness has imposed. It is about learning to control and optimise the perceptions we have of ourselves and, to a smaller extent have influence on the ways that others perceive us.
The Ending

Every transition commences with an ending... an ending to our familiar lives. The impact of a long-term illness may cause an ending to our familiar lives, because we need to find new ways of living where illness can have a place. There are new routines, new physical sensations that impact on how we live, treatments and appointments. The comfort and familiarity that we felt about our body and took for granted may not longer be present. When we experience an ending, we may feel as if our lives are shattered and we have little control over our direction. This is often how an ending impacts upon us. Sometimes it takes some time to move from the trauma associated with an ending.

Some of my chronic health problems I have had for 40 years and the worst one for 30 years. As I come from a long-lived family there is every chance that I have another 30 years of this ahead of me. Sometimes that worries me a bit. My faith helps me cope with the idea of the future but sometimes it gets me down.

*Helen*

We may feel disrupted, frightened, anxious or even angry that we have to experience this. We may feel that someone or even ourselves are to blame for us having to go through this very difficult period. We may place blame, we may feel resentful, we feel overwhelmed and ask Why me? Why now? Why this? We feel we are not in control and this is frightening. We may feel that the life we had previously is disintegrating. Or we try to take control, try to look as if we are doing well and don’t need any help.

Illness may cause disruption and disorder to our usual patterns of living and being in the world. The old ways of responding no longer work and a new way to live has to be developed. Our identity is strongly influenced by the socio-cultural interpretations around roles and status and connections within family and community.

There is massive social erosion of the opportunities to gain self-esteem. As chronically ill people we are only too well aware of this. So it’s not just that our self-esteem is eroded by for example, the popular focus on healthy youthfulness but more, it’s that we're not even permitted to gain self-esteem in the first place.

*Frank*

The ending may represent an upheaval and change important connections (changes to relationships, a reduction or change in employment, long periods of hospitalisation causing time away from families, altered appearance and abilities). This affects our sense of self and we may feel uncertain and fearful so we try to keep going back to our familiar ways of living although this causes further turmoil.

I get so frustrated with this wretched body that hurts in so many places and lets me down by not allowing me to do what I want. Sometimes the health problems and this body feel like something apart from the “real me”. Somewhere inside me is a strong, healthy, capable, reliable women who doesn’t get tired so easily and can do what she promises to without letting people down. I wish she’d come out again.

*Helen*
In Limbo

We can move into a state that is neither in the past or the future. During this time, the sense of ‘being different’ can be overwhelming. We may feel victimised, and become hypersensitive to what is happening around us, and powerless about our capacity to live in such a changed environment. We may feel overwhelmed by the losses we have experienced (changed relationships, changed employment and income, changed physical body).

I really feel like I’m living in limbo at the moment. I want to get on with my life now I’ve been forced to retire, but it’s been put on hold and I have no control over the situation. I can’t make any plans for the future, which is a whole different future to what it was a year ago. There are lots of things I’d like to do when I feel up to it but until I can get this other hip surgery done and get through the months of recovery, I can’t get on with living life.

**Chrispy**

When in limbo we may dwell within and can feel very isolated and alone. We may think no-one can understand our experiences and may not even have words to explain our feelings. It is a time of self-absorption because the task of that moment is how to reclaim self in the midst of change. Some of us may withdraw to do some self-examination and may be dismissive of others or reject offers of assistance.

Journaling is an incredible way of finding ourselves in the life we are leading, reading them back, gives us insights into our actions and thoughts, we may remember the confusion of the time and find the stream that brought us out of that place, leaving a trail we may use again if we ever return to on a visit.

**Judyth**

Self-absorption can become self-pity, which is an introspective perspective that turns emotions inward. Self help groups can be useful at this time, to enable us to access processes that facilitate reflection, affirmation and understanding.

Gee this list is nice ...to be able to actually talk and describe how you feel.

**Glenice**

What is familiar is gone and what is to come is not yet clearly visible or achievable. The task in limbo is to commence the sense-making process. To work out the new anchor points that locate one’s self within the changed landscape. This can be a very frustrating and difficult time involving strong emotions.

We needed to let go of the way that things were and the way we perceived how we used to be. Drawing comparisons with how we were before illness was not helpful. We needed to work with the changes that have occurred and find ways to value our lives with illness.
Moving out of limbo can be a very difficult process, because we are letting go of the way of engaging or accomplishing tasks that we thought in the past, had made us worthwhile and useful human beings. We are letting go of our whole world of experience and our identity is shifting. Letting go is important in order to move on but it can be painful and frightening.

**Becoming Ordinary**

Over time the disruption slowly passes and the process of reintegration emerges bringing with it a sense of increased capacities and new perspectives. We have a sense of our lives ‘becoming ordinary’ again. We may feel that there is less need to ‘be in control’. We become more open to learning from life, taking action on issues that confront us and less likely to see the world as working against us.

I think it is something that we ‘learn’ - or is it adapting to changed circumstances? We need to manage our condition every day. We don’t have days off, and for most of us there is no end in sight. For me, while there is some promising research, there is no end in sight. So I have gained strength from the realisation that I simply don’t have any choice but to be strong and to keep on going - every day. I have learned to listen to my body which tells me when it is time to lie in bed, and when to go somewhere private (or talk to somebody) to deal with the emotional impact.

*Andrew*

We all need to be able to spring back when life takes us for a spin. You have to learn to bend with the winds of illness to cope with the bad times, and then recuperate emotionally in order to be ready for the next bad times.

*Graham*

When we have made sense of our changed circumstances, we learn ways to adapt through trial and error and by valuing our altered roles, status, personhood, or way of life. This requires us to reclaim aspects of who we were in the past with who we are in the present. As we incorporate changes and develop a stronger sense of self, our resilience increases and we build our capacity to overcome adversity.

My poetry is always a reflection of my life experiences as I am living them and on reading your email I realised that I have used poetry to assist me to adjust to my illness and to the ups and downs that come with accepting a chronic illness. I also actively use journaling - writing freely in a journal at the end of a day or when I need to. This allows me to unravel a lot of the confused thoughts I can get when I am feeling anxious about my body and what is happening to it. I use writing to debrief about lots of other things too.

*Dana*

Reflecting and making judgements about what one’s self feels etc. and having experience and knowledge with one’s own illness also is part of ‘becoming resilient’.

*Di*
These successes build confidence which in turn motivate us towards taking increased personal responsibility. We may begin to feel a sense of mastery with our condition and indeed our lives. Success develops perseverance, ignites hope and increases self-agency. Learning to live with chronic illness requires personal effort and constant vigilance over thoughts and responses to the experiences of living with illness. Knowledge about illness and possible symptoms and consequences is important.

... resilience can be developed by knowing my boundaries and working within them, so that if something happens, I know I will be able to bounce back. With severe illness, being out of control and not being able to work with anything new is very difficult and scary. Two years down the track, I know what all of my health issues are, so I have developed some ability to judge what could happen next and how I may adjust life to fit.

*Judyth*

As the newness of this way of life is incorporated we also face choices that we learn to action. When we re-establish continuity in our lives we also promote a sense of confidence and mastery. Decisions and actions become easier. We make errors but instead of punishing ourselves over them we begin to view them as opportunities for learning and growth.

The group has given me the opportunity to explore in more detail and share what are important ways of living with my illness. When you explore something you get some more clarity about what is happening for you. I guess I believe that I am self managing my illness fairly well. One can always learn more though and I still can get caught out with wanting the quick fix solution or become tired and fatigued and lose sight of what choices I have to make things better for myself.

*Donna*

... sharing our lives and histories, we have come to care for each other a lot, it is wonderful now to be also able to share the comedies behind our treatments.

*Judyth*

Eventually we come to a place where feel integrated and more at peace with our situation and ourselves. We feel continuity in our lives and a welcomed sense or ‘ordinary’ and ‘familiar’ again.

Self love can be sexual but it is also connected into lots of other things we have talked about. If you can love your self you can find more choices, tackle doing more new things, be braver, be more confident about yourself and life. So for me the life forces are joined. Self love needs to touch the whole of our beings not always easy because we so often can depend on others to supply what we could just as easily supply ourselves.

*Donna*
The Four Phases Of Transition And The Experiences Engendered By Each Phase

The graph represents the movement that occurs during each phase of the transition process. Disruption changes familiar life patterns and forces the person into a limbo period where they must make sense of the changes so they can relocate new ways to live and be in the world and shift their sense of identity. The red line is an indicator of the change of flow we experience through the transition process.

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<th>LIMBO</th>
<th>BECOMING ORDINARY</th>
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<tr>
<td>Living and being in the world is predictable and situations are taken-for-granted.</td>
<td>The current way of living ends. The change event or experience may be chosen or forced, but life is different.</td>
<td>The changes, chosen or forced, may become disorientating. It can be a time of suffering and disempowerment. Moving through this phase is facilitated by sense-making activities.</td>
<td>Incorporating changing patterns of being and doing into new ways of living and being. Living life in a way that provides coherence.</td>
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In familiar life patterns you experience:
- predictability
- identity
- roles
- status
- location
- situation
- security
- relationships
- connections
- acquaintances
- internalised socio cultural norms
- thoughts feelings attitudes within self
- ordinary life

Following and ending you may experience:
- disruption
- difference
- fractured identity
- brokenness
- over burdened
- displacement
- separation
- disconnection
- uncertainty
- hesitation
- insecurity
- ambiguity
- vulnerability
- inadequacy
- violation
- victimisation

During limbo you may experience:
- confusion
- turmoil
- uncertainty
- confrontation
- alienation
- isolation
- loneliness
- self absorption
- self pity
- incongruence
- unanchored to life
- betrayal
- powerlessness
- grief & loss
- insecurity
- disenfranchisement
- extraordinariness
- suffering

In becoming ordinary you may experience:
- new beginning
- transformation
- growth
- progress
- continuity
- return to ordinary life
- coexisting
- feel ‘normal’
- realignment with self
- reconstructing
- revising
- revaluing
- reconnecting
- reclaiming
- refining
- reconciling
- returning to familiarity
- relocation
- renewal
- mastery
- healing
- resilience
- ‘I’m OK!’
Helping Others By Facilitating Transition

Given our point of view that illness is a part of life, our intention is to seek and facilitate understanding and tolerance for people living with illness and to connect with others. We can share the process we have engaged with that enabled our transition experiences to unfold.

Connecting with others is important. It is through conversations with others, either in person or on-line that we have come to realise that we have common experiences even though our conditions are vastly different. Our experiences are affirmed by listening to the stories of others. It seems a positive gained from the illness experience may be the connections made with others that I may not have otherwise met. I have met so many valuable friends because of my changes in health and lifestyle that resulted from these changes. It is amazing how as our lives change and how if we don’t fight it we change too, it is a case of going with the flow.

Judyth

The support and kindness from this group and the knowledge that we all have similar symptoms despite different illnesses kept me going when I joined just over a year ago. I was feeling extremely ill at the time and felt anxious about it all, and grappling with how to deal with it and who to tell about it, and how to tell them. A forum helps us develop the confidence to know we are right, that we really do feel ill that it is not imagination or exaggeration, it is real and therefore resilience springs from this understanding of ourselves.

Di

When helping people with chronic illness through a period of transition, patience is important. Most people want to take initiative in managing the symptoms of their illness and where possible, and have some control about how illness impacts on their lives. The way people manage and their capacity for managing however is very individual and fluctuates throughout the illness and life. We have often said how each day is different. Sometimes people need time to become ‘ready’ before they move on.

“...resilience can be developed by knowing my boundaries and working within them, so that if something happens, I know I will be able to bounce back.”
The way people manage and their capacity for managing is very individual. We are all different as to how we try to manage our illnesses and our ability to do so varies depending on how we are feeling.

I know of a man who has the same condition I have but through a different cause. He copes by refusing to talk about it or discuss his symptoms and his concerns, even with his wife. His wife tried to encourage him firstly to search for information on the Internet and later to join a support group. He refused to do either. She finds he has almost completely changed personality since becoming ill, mainly due to the fact he can't and won't accept his life is different to what it once was, nor the frustration of not being able to do all the work and activities he could before. His attitude is putting a strain on their relationship, but she is unable to break through the barrier he has built around himself. I know another young woman with chronic illness who prefers to manage by never complaining on bad days nor will she ask for help. She is learning to accept offers of help when offered however.

Chrispy

Transition for people learning to live with chronic illness can be facilitated by the ‘Look, Think, Act’ process. When looking, we begin to acknowledge that things are different. Just allowing a person to tell his/her story in an uninterrupted manner will commence this process. Sometimes it is useful to ask questions that enable the person to identify what has changed and what feelings, thoughts and emotions the changes are triggering within them. Sometimes our thinking may become distorted by low self-esteem. To correct such thinking, we have found it important to discuss or unpack what we perceive as ‘normal.’ When thinking this through, we discovered that ‘normal’ is only in our perception. Irrational beliefs may need to be sensitively dispelled through gentle questioning. We are not ‘damaged goods’, rather we are people learning to live with illness, just as a large number of people are doing. What a force we would be if we connected!

I have often described my bad patches as “character-building”. To me resilience means that when I am having a bad patch, realising that I will have good days again and not getting too despairing while I have the bad days. It is also remembering that even at my very lowest I eventually bounced back. It is being thankful for the things I do have, rather than sorrowing about the things I don't have...without resilience depression could be a constant companion.

Helen

The way people manage and their capacity for managing is very individual.
Action As The Catalyst In Transition

Action is important in the transition process. The significant movement in transition comes with the 'Act' phase of the 'Look, Think, Act' process. It is considered and thoughtful action that moves us forward rapidly. If we only look and think, we will make slow progress. We need to action our choices to make movement. Movement is directly correlated to our thought-through and planned action. We don't mean knee-jerk action, but considered responses. If we action without looking and thinking, just because it is expected of us or it seems like the right thing to do, it is unlikely that we will be able to sustain our efforts. Action has risks and it can be easy to choose the safe option and do nothing. We found taking action was a difficult hurdle, particularly when we are not feeling well.

I have come to believe that I am a 'survivor' (in my limited environment). I am more optimistic than before and feel blessed with undeserved good fortune so far. I have come to realise that I have loving, caring, and accepting friends and relations. I am becoming to see that it is me that is ultimately responsible for my actions and well-being.

Ted

The purpose of action is to put together practical solutions that facilitate the reshaping of our future. Creating action plans is difficult but actually enacting those plans is by far and away the most arduous aspect of this process. It will help if you can begin by focusing on something small. We are encouraged by the achievements we make and we encourage each other.

None of us give up - we are not going to give up because we can still do things and keep adapting and transitioning - so we give heart and strength to each other and therefore, resilience. This group is a close group because we have developed a sense of trust.

Julie

Resilience is something we all have to foster living with long term illness. We feel really bad and often feel down with it and then we gradually bounce back again, until it all happens again. We have to acquire resilience I suppose otherwise we'd just give up. Can we learn resilience? Practice makes perfect!

Chrispy

We began by creating some specific goals which were seemingly small. We have asked ourselves, 'What is important right now?' What is achievable for me at this time? Sometimes we have needed the help of members in our discussion group to clarify our priorities and support with defining the tasks that we needed to action so we could move towards our desired outcomes.

It seems to me that my level of acceptance is increased if I can just explore what choices I might have in any given situation. There are always choices it is just that when I am fatigued, in pain or anxious I cannot find as many choices to choose from. When I have choices in front of me I feel in control of what is going
on for me at that time. I guess I would equate acceptance with a loss of anxiety and giving myself permission to live each day as it comes. I sometimes write down what choices I have and then others I had not thought about will come to me. Chris you said that acceptance comes from knowledge and control well the knowledge is not only about your illness but about the choices you have and how you can decide which one to choose that is best for you at that time and place.

Donna

When we first begin to see our actions come to fruition our motivation grows and our confidence to try new things develops. Many of us were unaware of what strength we had.

Look, Think And Act

The ‘Look, Think, Act’ process is one that many of us may be doing in our lives without being conscious of it. When we feel particularly challenged by a situation, it can be useful to become aware of the process and engage it. Look, think and act can be a process that may assist us to work out what is going on our lives and bring clarity during times when we feel uncertain. It is a process that facilitates action and provides step by step guidance towards regaining a sense of order and continuity in our lives.

‘Look, Think, Act’ focuses on creating awareness, promoting reflection, helping to name the emotions that inform our thinking process so we choose self-caring responses. Often it is useful to follow this process with others, such as members of a group, so together we can bolster our strengths and coping strategies by gently challenging thinking and opening each other to new possibilities.

‘Look, Think and Act’ processes can bring awareness to our uniqueness, strengths and life priorities and provides a guiding framework for us to restructure our goals and take action on those aspects of our lives that are important following the intrusion of illness. It can pave the path towards continuity.

Looking

During this phase we build a picture based on information available about what the issue is. We find the issues that we want to work on so that we can move forward. We encourage you to take some time to:

- **Describe**: What is going on? The circumstances.
  What do you feel inside? How do you respond to these feelings? (anger, being withdrawn).

- **Gather information to build a picture**:
  Who: are the people involved;
  Where: is the place; and
  When: does it happen?

- **Record the information from your experiences**:
  Try to get other people’s views.
• Describe the context of what is happening:
  What are your thoughts?
  How long have you been mulling over this?

Thinking

When thinking, we aim to clarify meaning and increase our understanding of the why, when, what, where, how... of our experiences. Describe the issues and think about what we need to do with/about them. We can ask ourselves questions like:

• What's the main issue?
• Why is this happening?
• What was the trigger or cause?
• What are the consequences?
• How have you been behaving? (eg is it usual for you to respond in anger in this situation?)
• Which area/s can you act upon?
• How might the action look?
• When should you begin- what order...?
• How should you do it?
• What are your strengths?

Try writing down the answers to these questions. This may bring clarity for you and give you some responses that you can consider over time.

Actioning

Thinking about change does not effect change. We can spend a lot of time thinking about what we would like to change but never take a step toward making change happen. Actioning requires that we become involved with our current situation and choose actions that take us toward our chosen goals. Often there is little choice about the need to change, and so our choice is about how we will change. A good place to start is to think about what could/should be done differently to get the desired outcome. Then we can begin to action the smallest and most easily managed act that would have the most benefit to our wellbeing.

• What area/s do you want to act on first?
• What is most important to you right now?
• What is most achievable thing you can act on right now?
• What's the likely outcome of the action?
• What will help you to achieve the goal?
• Which people can help?
• Where can you find support if needed?
### The Look, Think, Act Process Can Facilitate Transition

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<thead>
<tr>
<th>Look</th>
<th>Think</th>
<th>Act</th>
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<tbody>
<tr>
<td>• What’s going on?</td>
<td>• How am I feeling about it?</td>
<td>• What do I want/need to do right now?</td>
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<tr>
<td>• What’s happening?</td>
<td></td>
<td>• Who can help? Where?</td>
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<td></td>
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<td>When? How?</td>
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You build a picture based on information available to you about the issues you are dealing with. From here you locate the areas you want/need to work on to move forward.

**Describe:**
- What is going on?
- What are the circumstances?
- What thoughts are in your head?
- What emotions are being triggered?
- What are your responses?

**Gather information, build a picture:**
- Who is involved?
- Where is this change occurring?
- When is it happening?

**Describe the context:**
- Try to get other people’s views on the situation
- How much are you mulling over the event/experience afterward?

Try to get a better understanding and meaning of the issue so that you can work out what you need/want to do about it.
- What is the issue?
- Why is this happening?
- What do you think is the trigger or cause? (Eg. attitudes, beliefs, past experiences)
- What are the consequences?
- How are you behaving (Eg. Are your responses appropriate? Are they reactions that are grounded in the past?)
- In which area/s can you move forward?
- How might this moving forward look?
- When and How should you begin?
- Who can help you?
- Is such a plan possible, given the changes that have occurred?
- What might the anticipated consequences and outcomes be?
- What are your strengths?

Focus on what is possible in the situation.

Adversity provides little choice about the need to change; you can only choose how you will change. Thinking about change does not effect change. Doing nothing is a choice!

Set your personal action goals and then plan how you will make them happen. Become involved with your situation and choose the actions that will take you toward your chosen goals.
- Focus on the opportunities change can bring
- Draw on your past strengths
- Have support people who can reinforce your new patterns of living
- Take specific steps toward your desired outcome
- Do what is most important now
- Start with the smallest thing that is likely to have the most positive impact on your wellbeing with the least work

**NOW TAKE ACTION!**

These phases of transition start with life as familiar in an understood world. Then a change event/experience may cause disruption and a limbo phase develops. In that phase we are no longer living the predictable life we knew, nor have we had time or been able to incorporate the changes into new ways of living. When the changes are integrated into our lives, we locate a sense of self with which we are content. This is the experience we term, becoming ordinary.
Our Message To You

Learning to live with chronic illness is an ongoing complex personal process. Sometimes the waters are smooth sailing and at other times it can seem like never ending disruption. Sometimes the waters are murky and it is difficult to see our way forward, and at other times the waters are clear and we feel like we have control of our journey. The experience of illness is constantly shifting. Be gentle with yourself and allow for the ups and downs. Remember that it will not always be this way. Eventually we transition to a sense of order once more. Even when disruptions continue to occur, the impact is minimised because we have developed resilience and the skills we need to work through difficult times and bounce back. Negotiating the initial transition is no small feat. It is a life changing process, which requires personal resources, balance and courage. Our understanding of the process that people go through after chronic illness strikes is based on the stories and experiences of many people living with chronic illness. It is useful to understand your experience as a process of personal transition and one which despite being chaotic at times will lead to you reclaiming a sense of living an ordinary life.

Our Message To Health Workers

We need support to transition through times of disruption and you are ideally placed to assist us. Help us to share our difficult times by walking with us through the 'look, think and act process'. During this process we need you to be with us rather than judging us. Bring a willingness to sit beside us and listen, try to understand our experience, and to find places where your understandings can enhance our well being and our 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 incorporating change into our lives takes time.

The process of setting "self care" goals with those of us who are learning to live with chronic illness can involve three steps.

1. Look... Explore and define 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, use open ended questions to explore those issues with us. Ask, “Can you think of any other reasons why you might be feeling this way? Are there other things that might be happening which may be contributing to this issue? When does this happen? How do you react to the issue when it happens? How do other significant people react?”
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. It also stimulates the type of dialogue whereby people can articulate their experience and emotions openly. The opportunity to do this is not usually forthcoming in daily life and it is profoundly helpful. Engaging in this process will help 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. We can also learn the skills to independently work through situations as they arise in the future.

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.