

Transition in Chronic Illness

Interacting with Others



BOOKLET 8

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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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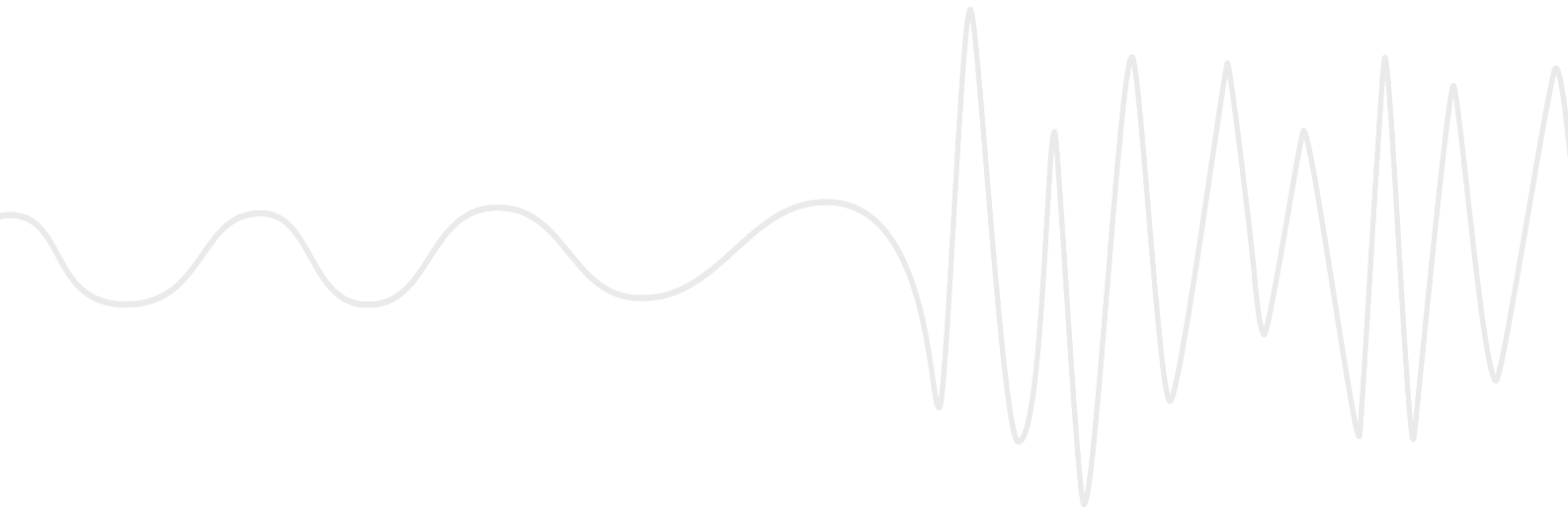
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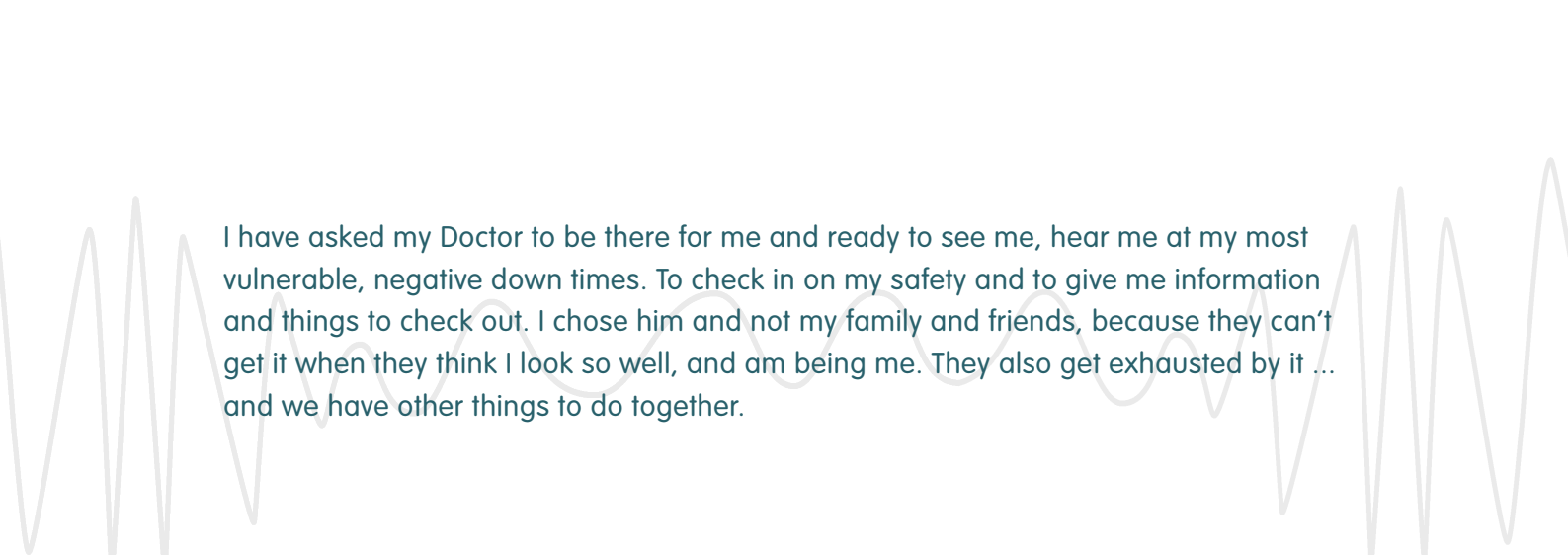
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I have asked my Doctor to be there for me and ready to see me, hear me at my most vulnerable, negative down times. To check in on my safety and to give me information and things to check out. I chose him and not my family and friends, because they can't get it when they think I look so well, and am being me. They also get exhausted by it ... and we have other things to do together.

Interacting With Others

One of the nicest gifts we can give to others is to pay special attention to what we say and the way we say it. Whoever said 'sticks and stones may break my bones, but words will never hurt me' must have been kidding. Words can do immense harm.

When interacting with others in the social world as someone who lives with chronic illness, we are vulnerable to the assumptions and judgements that others may make about people who may not fit with social norms. These reactions are called expressions of stigma, which come about through lack of understanding, and may target minority groups or people who appear different. For those of us with visible signs of illness we may find that people make judgements about us on the basis of our appearance. Those people who have an illness that is not visible may also be faced with the strain of passing as someone without illness, with making a decision of whether or not to disclose health status (which may also elicit negative judgements). This may be a particularly a decision for people in paid employment.

Expressions of stigma may take different forms, ranging from verbal abuse and/or ignoring the person, to subtle questioning of the authenticity of the illness. Sometimes others are misinformed or ignorant about the cause and nature of the illness and make negative judgements about our lifestyle and about the way we manage illness. This can be both frustrating and hurtful.

It can be difficult for others to 'step into our shoes' and to understand the experience of illness, but reactions from some people can mean that we feel diminished as human beings and this can affect the way we feel about ourself. There is an important choice for all of us to make about the meaning we attach to stigmatising reactions. We may be familiar with the hurtful feelings that can arise from such responses, however, we can also choose to understand them as a lack of understanding, arrogance and insensitivity about chronic illness or disability. When we do this, we distance ourselves from the people who have stigmatising reactions and diminish the impact of them in our lives. If we understand about stigma and why it happens, we gain confidence that it has little to do with us personally. Stigma is often motivated by fear of difference, confusion about those who do not fit the 'norms', and ignorance about people living different lives. We simply do not need to take this on board. There may also be times when we have an opportunity to inform others about the experience of living with illness. We need to judge each opportunity as it arises. The more

we educate and inform others, the more we lessen the impact of the judgements of others upon ourselves. We can choose to respond to others in genuine ways. We talked about and shared our experiences of, and understandings about, other people's reactions toward us.

People with chronic illness and/or disability may be confronted with stigmatising reactions from other people. What have been your experiences of these reactions?

I have no visible signs that other people can see.

Graham

I have had bad experiences with people telling me it was 'all in my head', that I really didn't want to get well, etc. I have found these [reactions] very hurtful, as they have usually been said when I was feeling bad and therefore more vulnerable. I think it is a combination of thoughtlessness, ignorance, and possibly arrogance that makes people say such things. One member of my extended family used to say 'I don't have time to be sick!' She hasn't said it so much after having seen me when I was going through a really bad patch. I think she understands it a little better now. She has certainly been more sympathetic and understanding.

Helen



At different times I've had people - both family and friends - react negatively to my behaviour or my needs. Some are a bit too complicated to go into here, but I've requested some things in the past to help me deal with my memory loss - from letters about what people remember about me to special photos. Most people did what I asked of them but some didn't, and told me in no uncertain terms that they didn't want to do it.

Iolanda

I have a non-visible disability. Since there's a lot 'wrong' with me all the time I could not work without telling people [especially my students]. So I do, up-front and immediately. Doing this is liberating. Sure, over the 40 years of my relationship with my disease and its consequences I've had some quite nasty if enlightening experiences like the professor who said, maliciously (and quite recently) '... you and your mythical disease...'. It was common in the past to get 'go fix your head' and similar but anyone who would say that to me today would get a serve that they would not forget in a hurry.

Frank

CHRONIC ILLNESS AND
JUDGEMENT
When I needed this
paraphernalia
It was obvious I was crook
But for those chronic,
invisible symptoms,
It's more a disbelieving look
- Chris

When my arthritis was particularly bad, I needed to use a stick and for some time after surgery, a wheelchair or crutches. As I was obviously in pain and having difficulty in getting around I didn't find reactions, such as stares, upsetting. It's negative reactions to my main invisible condition, which are. Rightly or wrongly I perceive others think I'm making up excuses to get out of doing something, I'm a hypochondriac or just lazy. I realise it's difficult for healthy people to understand what it's like living life as I do, but some people have little desire or the ability to understand. I try to brush off such reactions but being judged unfairly is hurtful.

Chrispy

My experience has varied. Sometimes I feel burdened and transparent in my struggle, sometimes feeling/perceiving compassion and at other times, victimisation from others. The understanding and ambivalent acceptance of being ultimately alone in this journey is amplified when I look around at the way of the world.

I think these reactions have a lot to do with how I'm feeling and my perceptions and strength at the time to ensure a space and place for myself. I feel like I struggle in the contradiction of a collective and individualised approach/belief in life. The meaning I attach to these reactions are sometimes negative, other times positive. A need to find my place in the balancing of these polar opposites.

Olympia

I have found that some people around me can be over protective at times. Being on insulin, physical activity can upset things if one isn't careful - but being active does help overall control. It is good that people want to look out for you, but we are usually in tune with our condition and can judge if and when we are capable of doing things - we NEED to get out and do things as far as our condition allows us to. Ideally, people around us should be helping us to 'push the envelope' of our condition, to help us to live our lives as fully as possible - rather than protecting us from it. Support and encouragement to help us manage ourselves is the key. Also, some people still think that all diabetes is caused by being overweight, diet etc. (they don't cause it, but they are certainly risk factors in the more common form of diabetes). The type I have is actually caused by an immune system problem, but sometimes people think that it is my fault!

The most common experience of reactions to my illness from others usually involves comment about my lifestyle, particularly eating habits eg. 'Did you eat lots of sugar, fat or junk food when you were young?' I feel that some make judgements or suggestions about my diabetes management, e.g. 'Maybe you should try XYZ diet or ABC therapy.' Other comments include diabetes as 'no big deal'. I'm not a fan of any of these reactions, but I understand them to stem from ignorance about diabetes, particularly Type 1 Diabetes. I try to remain separate from ignorant comments regarding my health issues. I tell myself that people who make stupid remarks are just proving their stupidity, or to be less harsh, their ignorance.

Andrew

To Tell Or Not To Tell?

Sooner or later we will be faced with the decision of whether we inform others about illness and, if so, how much we share. When we disclose information about our health status we risk negative and discrediting reactions. Disclosing health status may be accompanied by feelings of loss of control and diminished identity in the eyes of others. Therefore, many people do not share with others that they have a chronic illness, or they are selective about who they tell. Once information is provided it cannot be taken back and the person must live with the consequences of having told. Even when we decide to avoid disclosure, illness activity or progression may expose us at any time. This possibility is always in the back of our mind. These are the dilemmas of the decision to disclose.

When we speak of disclosure the assumption is made that we are referring to people outside our immediate family and close friends. Most of us agree that people who are close to us need to know for reasons of support and understanding. But when it comes to telling others we have a range of different approaches. Some of us have grown tired of the lack of understanding when we have tried to explain illness, and so we prefer not to tell others. Many of us make the decision on a 'need to know' basis. If another person knowing will benefit the situation or the relationship, then we will tell them but be selective about how much information we give. In the case of illnesses where it is important to monitor signs, such as diabetes, some may feel more comfortable having someone else aware. For some, it is helpful if work colleagues understand about the illness we live with. A small number of us are accustomed to telling people out of necessity and, in doing so, are prepared to deal with the consequences, whatever they may be.

Managing information about our health status is an important part of interacting with others. In the main, we have no obligation to tell others about our illness. It is our right to withhold this information. As we learn to live with illness we develop an awareness of when to tell or not to tell others, based on certain considerations. We talked about what we consider when making a decision about disclosure.

How do you make the decision of whether or not to disclose to other people about the illness or condition you live with?

I have almost given up telling people of my health problems. Even those who know me best, outside my immediate family, have no concept of this type of illness. I have gotten tired of the blank looks and unbelieving looks.

Graham

It depends on whether they need to know. People I see regularly need to know a bit so they understand when I am 'unreliable'. They need to know why I am unable to do things sometimes, despite wanting to. Even these people don't get all the details, I just say something vague like 'I have a couple of health problems'. If people are genuinely interested I will tell them more, but as a rule I go into as little detail as possible. [This group is different] The pitfall of giving too much detail

is that some people always 'know' what you 'should' be doing, because their sister, nephew, son or whoever did this and they got better. The other problem is that things I consider as 'normal', such as fatigue, can make other people uncomfortable. They don't understand that this is a part of my life and there is no point getting upset about it. I just try to accept it and work around it as much as possible. I am constantly amazed at the way people 'cross-examine' me for intimate details of my health problems, often at amazingly inappropriate times. I usually wriggle out of it by saying 'I'd rather not talk about it'. The other issue is that if people know you have health problems that is often all they talk about to you. This can get very tedious and embarrassing.

Helen

This implies telling strangers. I very rarely meet new people so I can't really answer but I'd generally only tell them if it's required.

Iolanda

It is a non-decision; I just let people know - how they react is their problem and I just live with it, clarifying where I have the opportunity, living with the consequences otherwise.

Frank

If there is no need to explain my illness I don't mention it. If there is the need to perhaps explain my limitations, I weigh up how much that person needs to know. If it is an acquaintance I may tell them as little as possible. If it is a trusted friend I'll be more frank.

Chrispy

It really depends on the moment. Sometimes it's not relevant, other times I feel proud to be out there and managing my life so I want to share it. If and when I'm feeling really vulnerable and I think it may support me for others to know, I'll say so. I remember once saying something and I felt so empowered by their response, that it had me reflecting deeper into my life with MS. I can't remember the words, they were few. It was the whole verbal /nonverbal situation. It left me thinking I'm doing the best I can and maybe I could do better without any attachment to ability or disability.

Olympia

I don't keep it from people - but I don't hide it either. I ensure that people I am around regularly know about the condition. It can give you some confidence knowing that there are people around who know enough to be able to keep an eye on you - and lend a hand if necessary. With my condition, diet is very important - so if I am offered something I shouldn't have, I tell them that I can't have it because I'm diabetic - rather than offend them.

Andrew

I generally don't disclose my diabetes unless my health needs/limitations have some consequential impact on the relationship. Having said that, I don't actively hide my diabetes either. It doesn't bother me if people see me taking injections or blood tests, and if anyone asks about my diabetes I'm open to discuss it. To me, that's educating others about living with diabetes.

Mari



GETTING THE BALANCE RIGHT

Everything I eat is weighed because I need to work out how much carbohydrate I am having so that I can take an appropriate amount of insulin. EVERY time I eat or have a drink with carbohydrate (even fruit juice), I have an injection with it. The injections don't really bother me; the real battle is trying to balance the insulin dose with what I eat and any physical activity.

– Andrew

Preservation Of Self

Sometimes, in the face of negative reactions, we have learnt ways to protect ourselves. Evident in our responses is that we hold to certain principles in maintaining self-worth. Most often, we choose to treat others with respect, no matter what their attitude. It is important to realise that these reactions are about the other person's feelings of fear, confusion or lack of understanding. Mostly, we resist the temptation to lash out at them. This approach leaves us feeling good about ourselves and less vulnerable to their reactions. Another principle is to hold true to oneself, accept and be proud of our strengths. Each of us travels a difficult journey that requires much of us. We have reason to be proud, to have faith in ourselves and to hold our head up high. Lastly, we have learned to be resilient and to move on from negative attitudes. The ups and downs of life with illness have taught us to be hardy and, even if we feel hurt, to recover and refocus on what we have learned to be important.

Remember that many people do not fit with social norms for one reason or another, e.g. sexual preference, race, culture, religion, lifestyle choices etc. Other people also experience stigmatising reactions. We are not alone. There are many people who believe diversity makes our community rich and interesting. We contribute to that diversity. Let us accept and celebrate our place in the community. The key to maintaining our sense of worth lies in our mindset about who we are, being aware of our rights, and our value as members of our community.

How do you protect your sense of self and identity (stay feeling good about self) in social situations?

I keep to myself.

Graham

Hasn't really happened to me.

Helen

I would just try to be civil because it's not really worth any other reaction.

Iolanda

One gets over the degradations, demeaning behaviours etc. Eventually - have faith.

It's a 3-part thing:

1. pretence [at "normality"] ie. hiding one's condition
2. anger ie. forcing others to recognise one's condition/state
3. being your condition [it comes if you work on it & let it]

Frank

I try to be positive. If I am positive and act with self-respect, it is more likely others will react in a positive way. In explaining my limitations I may say something like:

- "Oh I'd love to come along, but unfortunately I can no longer cope in hot, humid venues." Or,
- "It's so nice catching up with you again, but would you mind if we sit over there in the shade." Or,
- "I'm not very well today, but I should be okay if I just sit quietly over here." Or,
- "I'd love to meet up again. How about lunch at such and such a place." (Making sure I pick an air-conditioned venue and also avoid cooking myself, if I feel the need to do so)

Chrispy

In my experience so far, few people or situations can make me feel not good about myself. My concern is when I'm not feeling good about myself for whatever reason and then I don't venture out. This could lead to isolation and hopelessness. I work hard like you all to keep myself well and buoyant. I want to focus on the maintenance of that ability/motivation, hope, purpose, energy, and love.

Olympia

There is more to me than my medical condition. Before I had the condition I went through a period of depression, and in order to get back up went through a period of having a good look at who I am. Medical condition or not, a person needs to be able to look in the mirror, look at the whole package and accept what is there.

Andrew

Given diabetes is 'invisible' I can keep quiet about it if I feel threatened by negative reaction. If I still choose to disclose my health issues despite this, I usually maintain my sense of self by realising that no one else can ever walk in my shoes; what someone says is a reflection about him or her more than a reflection about me.

Mari

“There is more to me than my medical condition.”

Protecting Our Rights

Part of learning to live with chronic illness is to acknowledge that we have the same rights as all human beings. When we interact with the systems, such as welfare or healthcare, we expect that we will be treated with respect. Health workers are part of our support network, hence it is important that we do not accept anything less from them. Addressing the behaviour of a health worker is not easy, especially when their role is to assist and provide support. Health workers have a lot of power invested in their role, and we might not feel assertive enough to let them know we are not happy with an aspect of their behaviour. Being aware of the power that they have may silence us. When this happens we do not feel valued as a person. It is important to try to find a way to let them know that you are not satisfied. Depending on available energy and comfort levels, there are a few ways we may do this. We may decide not to see them again, hoping they will get the message that we were not satisfied, or we might write a letter outlining the aspects of dissatisfaction with their service. If feeling strong, we might tell them that we are not satisfied and outline the offending behaviour and what we would prefer. If these options do not have an effect we can also choose to lodge a formal complaint. It is your right to do this.

When we assert ourselves with a health worker we are teaching them that we will not accept lack of respect. We are teaching them that we have a strong sense of self and are confident in exercising our rights. It is also giving the health worker an opportunity to recognise their failure to provide appropriate service and to address it. That can pave the way for a more respectful relationship for the future.

As a person with illness, what do you perceive are your rights?

My rights as a person are to be respected just for being a person, as I try to respect others. More than 50% of health workers give me the same look as the normal population.

Graham

My rights are to be treated fairly, with sympathy and compassion, and also humour. I have experienced a couple of health workers who did not respect me. One was a GP [not my usual one] who was so rude to me that I left the surgery in tears, sat in the gutter and cried. Left my husband to pay the bill. Wrote the doctor a letter [when I had calmed down] stating the problems I had with his treatment of me. Never had any reply but at least I got to tell him. Refused to see him again after that. Also had a bad experience with my former prosthodontist. He asked me how I was and when I told him he complained that I was always saying I was sick! As I was consulting him because I was in severe pain I thought this was fairly unreasonable. He is another one I no longer go to. I now have a lovely prosthodontist who cares whether I feel well or not. Wish I had found him years ago. I think it is very important that we are treated with dignity and respect. If we do not have health workers who respect us it is hard to respect or trust them. Health workers who make you feel worse are to be avoided if at all possible. Having chronic health problems can make you feel emotionally vulnerable at times, particularly in a bad patch, and a thoughtless or heartless health worker can easily make you feel even worse.

Helen

My rights are to be treated fairly, with sympathy and compassion, and also humour.

I don't do anything because I don't want to get them offside. I might answer back once, but then I leave it and then complain, rant and rave when I get out. I've known one doctor like this but thankfully I don't see him anymore.

Iolanda

Address it directly with the person. Be sensitive to their rights as a [perhaps naive] person though, and join the health consumers' movement [e.g. chronic illness alliance], and work on publicising these general problems - don't bother with the specific disease organisations, they do not address these general issues.

Frank

I believe I have the right to be listened to and treated with respect. I try to be assertive but not aggressive, even if I am being treated with disrespect. If I feel my concerns are being trivialised or brushed aside, I may mention that I have to live like this every day of my life, that I want to be as well as I can as quickly as I can, and for as long as I can, and need their help to do so. This approach is sometimes easier said than done with some health care professionals. If they are being too arrogant, I'll no longer deal with them and seek help elsewhere. After all I'm paying for their services.

Chrispy

I have rights and responsibilities, and my understandings are evolving all the time. I've had a long history with the health care system, on a personal level and through others. This has resourced me in so many ways. I have a relationship with orthodox and alternative health care practices. Mostly I feel fortunate. I consider I have a healthy scepticism. What bothers me is the reality that once in the system [there are frustrations] - the time, money, energy, the going back and forth, the juggling, the waiting, the grey harshness of the environment, the lack of information, the unknowing, the grasping for answers, being thrust out of one system and into another, often without any relationship between the two, the temporary loss of identity and then the search for another [identity] alone.

Olympia

I have the right to be treated as a person with a medical condition, rather than a medical condition. While part of me is broken, I am still a valuable person, and should be treated as one. This is my medical condition and I know how it affects me more than anybody else - so while guidance and information does help, the final decisions on how to manage my condition must be mine. To maintain my sense of being 'in control', I must be in charge - but with the guidance and assistance of people (including my medical team) around me.

Andrew

Respect is a two-way street. If I don't receive respect than it's hard for me to reciprocate it. Appropriate communication is a large part of it. Sometimes I've written letters regarding my dissatisfaction with treatment. Sometimes I vote with my feet and never go back. Sometimes I find I become aggressive and 'mirror' their tone in my communication with them; perhaps not the most mature approach, but if an ego presents itself, I'll fight back with mine. If I'm in the right frame of mind, I prefer to be assertive and say 'I don't appreciate the way you are speaking to me.' It's quite powerful, and I find it helpful to address issues that way. Equally, I've also told some of my doctors what I haven't appreciated in other ones.

Mari

'Pearls Of Wisdom'

Some things stand out to us as being important when interacting with others. Some of these are things we have learnt in order to maintain a valued identity and sense of worth, along with participation in social world. A strong message is to involve yourself in life and to live each moment as fully as possible. In doing this, it is suggested that we find ways to refocus on aspects of life other than our symptoms and illness. We acknowledge that people do not want to hear about our symptoms and pain each time we talk with them. This has led some of us to prefer not to discuss illness issues when we are with other people. We are more than the illness we live with and, even though it may be difficult, we want to present other aspects of ourself to people we spend time with. So, keeping abreast of current affairs and what's happening in other people's lives and having other interests is also essential to conversation.

To maximise the success of social interaction we find that we need to prepare for it; to plan ahead for our needs to be met with a minimum of fuss. This might mean finding out where the toilets are or where wheelchair access is to avoid disturbing the time together. We can settle and enjoy ourselves if such things are worked out beforehand. It is important for us affirm to ourselves that we are valued in the world and that we matter to others. Although the experience of living with chronic illness can be fraught with difficulties, the journey opens us up to new understandings and insights about life that we may not have otherwise found. So our perspective on life can be quite different to that of other people. That can make us interesting to be around. We have much to contribute to other people and perhaps the most important principle is to believe in ourselves. Here we impart our 'pearls of wisdom' about interacting socially that have been learnt from our experience.

I have the right to be treated as a person with a medical condition, rather than a medical condition.

What do you consider to be the most important things to keep in mind when interacting with others?

People are not interested in your problems, especially health problems unless they can out do you with something worse that is afflicting them. What is most important... to keep my mouth shut!

Graham

Not to focus too much on my problems or I become just a condition to them. I need to assert myself as a person and force myself to interact socially as much as I am able. This is easier said than done. Since fatigue is an integral part of my day it would be easy to just stay home all the time. Especially as the outside world can be a 'minefield' for me, with so many migraine triggers and allergens out there.

Helen

I suppose a few things [are important] like to not expect too much from others and I won't be disappointed. Having said that, I don't do it - I still get disappointed if I'm ignored or not treated like I think I should be. It's got the potential to make me feel less of a person. To avoid problems I need to plan ahead in all areas. For example, to maintain energy, look for the location of toilets, look up notes I've made on friends (including social and phone call logs) so I don't say something incorrect because I've forgotten things [as a result of memory impairment]. And when I'm with others I need to make an effort not to compare myself and my life to what I see in them - it's got the potential to be upsetting.

Iolanda

[It's important] to keep on keeping on as publicly and as generally as you can. I assure you that the media are interested - you just have to pitch your story so that they can make something of it and, that's really not so difficult. Also try reading Arthur Frank's books: 'The Wounded Storyteller' and 'The Renewal of Generosity'.

Frank

Although my body is weak and I can't do what I once could, it does not mean I'm a lesser person. I am still strong spiritually and I hold dear that belief. I try to remember I matter just as much as anyone else. If I want the respect of others, I must first respect myself.

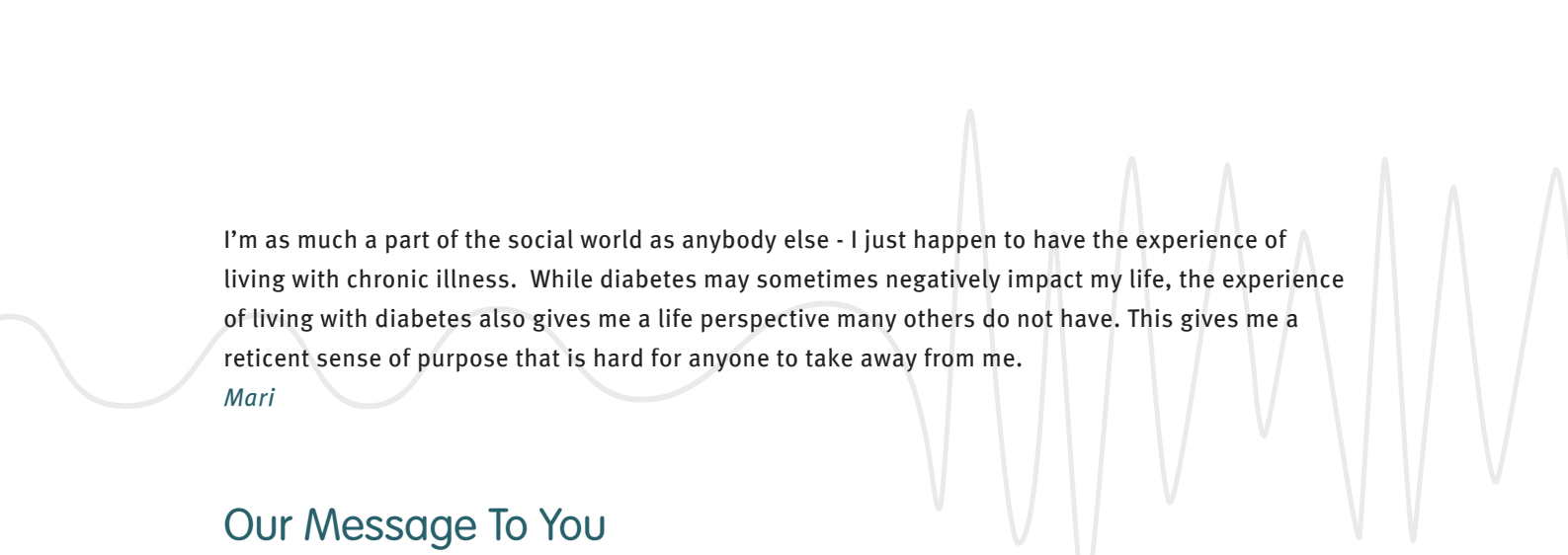
Chrispy

Be active in living your presence in the present.

Olympia

Do it. You are a person, not a medical condition. Stretch things, live your life to the limit. 'Life is not a chronic illness'

Andrew



I'm as much a part of the social world as anybody else - I just happen to have the experience of living with chronic illness. While diabetes may sometimes negatively impact my life, the experience of living with diabetes also gives me a life perspective many others do not have. This gives me a reticent sense of purpose that is hard for anyone to take away from me.

Mari

Our Message To You

What we project to the world often reveals very little about the personal challenges we contend with on a daily basis. Try to avoid letting your illness change the perception of who you are, who you were, and who you will become. You are much more than your illness and your physical body. You are not a 'patient', but rather someone who is learning to live with a condition.

Some people may scrutinise our appearance and express doubt about our conditions, particularly when we seem to have good and bad days. We may also appear to be well and project an energetic demeanour. There may be nothing in our appearance that easily reveals the symptoms and challenges that we are learning to live with. Chronic illness is a part of the lives of many people... we are not different. Illness and/or disability is a part of life. If our illness and/or disability is hidden to others, then there must be countless others who live the same way. Perhaps those who live with diabetes, chronic fatigue syndrome, lupus, arthritis, and many other chronic conditions, look just fine on the outside, yet they may be contending with pain, discomfort and other ongoing symptoms.

You may be concerned about how other people will react when you tell them about your condition. You may lose your self-confidence or become depressed and anxious about the future. Although it shouldn't be the case, coping with certain conditions and illnesses is even more complicated because of the associated social stigma. Some questions that you may ask yourself before you disclose to others are:

- Do you trust the person you are confiding in?
- Are you ready to take on the emotional issues that may be a consequence of disclosing to others?
- Will disclosing to this person help you or bring you more problems?
- Do you have enough information and facts to alleviate the concerns and fears of others?

A support group may be an ideal environment to share your experiences of illness. It is your personal choice whether or not to disclose your illness with anyone. Discuss with a sympathetic health worker about how and what to tell people. Most people will appreciate your honesty, and you will help them understand how to respond to your fluctuations in energy, mood and behaviour.

Words can heal, and sharing can transform pain. Having a network of people who are supportive is very important, as they can help when needed and can share the burden. It assists us to feel connected and helps us to cope with the ups and downs. Life with illness is complex. If people find it hard to understand when you talk to them about living with illness, you may seek to obtain information and educative materials which explain the illness and the issues you are experiencing. Be patient and supportive while they learn.

Our Message To Health Workers

People with chronic illness need and value your expertise. As a health worker, you may know what is best for managing a wound, diabetes, asthma or congestive heart failure, but that does not mean you necessarily know how people can best manage that illness in their day to day lives. Even in close relationships, you won't always know the details of a person's life: what is most important to them, what their other priorities are, what motivates them, what their financial situation is, and so on. Each person is the expert in his or her own life.

The old models of health care, in which people play passive roles, do not work well for people who are learning to incorporate chronic illness into the rest of their lives. Effective chronic illness care requires a team of active participants, with us as the most important member of that team. Most chronic illness care is not provided by nurses, doctors or other health workers but by the person who has the illness. We as people with chronic illness must learn to manage the daily symptoms and consequences within the context of our wider lives.

You may be the expert in clinical matters, but we are the experts in our own lives. We see that your role is to provide clinical expertise, to collaborate with us to find solutions, and to offer support. Some things to remember when working with a person with chronic illness are:

- We are usually hungry for clinical information about our condition/s. We understand that our daily decisions may have a major impact on our health and wellbeing and so we want to be informed
- When learning to live with a chronic illness, we need support to make significant and lifelong behavioural changes. One way this may be achieved is by working with us to set and review goals.
- To help us set goals, work with us to explore the issues we're dealing with and to identify the real issues confronting us. If the issue is outside your knowledge or expertise, show respect for our concerns by helping us to find resources or answers.
- Before offering what you think are the solutions to our issues, work with us to do some problem-solving of our own.

It's always more meaningful when we find the "ah ha!" on our own, so give us that chance. Encourage us to come up with ideas first, then offer your own suggestions or additional information that we may need. You can say "this works for some people" or "have you tried this?" or "here's why I don't think that's a good idea." The important thing is to give us the opportunity to say "no" and to make the final decision on what goal to try.

Be there for us, because we need you. You are an important person in our network.

About Us

We are men and women who live with chronic illness. Our ages, sexuality, backgrounds and economic situations are diverse and these all impact on the way we experience illness. We are participants in an Australian research project that connects people living with long term illness through the Internet. Talking with each other on the Internet facilitates an opportunity to discuss issues related to our experience. We came together through being involved in a research project. Over time, we have got to know each other through our email conversations. We feel strongly connected to a network of caring and support that carries us through the hard times and enables us to celebrate each other's good times. Knowing that we can always tap into the understanding and support of others who live with chronic conditions is important in our approach to making sense of, and managing, illness.

There has been a lot of discussion about chronic illness self-management promoted by health care professionals. Yet it has been estimated that between 95 percent and 99 percent of chronic illness care is given by the person who has the illness. In other words, we look after ourselves. On a day-to-day basis we are in charge of our own health, and the daily decisions we make impact upon our quality of life.

We all have something in common: we live with a chronic illness. A chronic illness is one that persists over time without an easily definable beginning, middle and end. While the symptoms that accompany a chronic illness can usually be alleviated to some extent, the illness itself is not curable. What we share is that illness was an unexpected intrusion into our lives.

Living with chronic illness brings many life issues to the fore. One of the primary experiences for us has been the realisation that our lives have changed, often permanently. Illness has disrupted our future plans. It has troubled our partners, family and friends when they realise the way in which illness has intruded on our collective lives. However, we are learning to deal with the many changes that the illness has brought to our lives.

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

About The Booklets

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

The booklets are set out in question and answer format and are intended to connect you with our voices about our experience of living with long term illness. There are no right or wrong answers to these questions. Our answers reflect our current thinking and understanding about what it means to live with long term illness. Maybe you will find some experiences and ideas that are familiar to you or have meaning in the context of your life. We acknowledge that challenges are part of life and fall within the experience of all human beings. Given this, our experiences may also be helpful to people living without illness.

About The Research Inquiry

A three year research grant (2003-2006) from the Australian Research Council (ARC) was awarded to our research team. This was a collaborative project between The University of South Australia and the Research Unit, Royal District Nursing Service. The investigators are Professor Tina Koch, Dr Debbie Kralik and Dr Kay Price. Project Management Members are Kerry Telford, Professor Jim Warren, Gino Pignone and Natalie Howard.

What Are We Researching?

The main thrust of the research program has been to understand the ways that people make transitions or learn to live well with chronic illness. We are interested in ways that people can learn to incorporate the consequences of chronic illness into their lives and move on. How people learn to move on or make transitions is important to understand, and so this project aims to describe this transition.

