

Chronic illness – a view from the other side

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Physiotherapists regularly interact with patients who have a range of illnesses and conditions and thus are, arguably, more aware than the general population of both the preciousness and fragility of good health. However, personal experience of illness can reveal the shallowness of that knowledge. We, the authors of this Editorial, are physiotherapists from disparate areas of practice, with chronic, non-life threatening illnesses (chronic fatigue syndrome and seronegative spondyloarthropathy respectively) that have had life changing effects. We are at quite different stages of our illnesses – one of us has been ill for over 16 years and has experienced periods of improvement after a variety of interventions, followed by prolonged plateaus, while the other is at a comparatively early stage with a less clear clinical pattern. We met as a result of these illnesses and, while we do not claim to have had unique or special experiences, or to be experts in chronic illness, our experiences and reactions to them have been very similar and we share some common symptoms, including fatigue and musculoskeletal pain, that fluctuate from day to day. This Editorial provides some personal insights into the impact of chronic illness and how we have learnt to cope with our conditions. These insights may be relevant to the way you interact with patients in your professional practice, or they may resonate with you personally now or in the future. Remember, you too could end up viewing chronic illness from the other side.

In our experience, the development of an illness is accompanied initially by a period of physical and emotional chaos. We have found that learning to cope with and accept chaos is important as we have often revisited this period of crisis during recurrent or unexpected relapses. Once the initial turmoil had passed and our illnesses had taken on an element of chronicity, learning to manage the condition effectively became an ongoing, challenging, and essential process. We needed to develop and continue to look for strategies to cope both with flare ups and our baseline levels of impairment.

To assist in the development of our coping strategies we used personal resources, medical and other health practitioners, and family and friends. We found, particularly in the early stages of illness, that the need for consultation with various medical professionals contributed to our feelings of bewilderment, especially if differing and conflicting diagnoses and treatment options were given. A supportive general practitioner who was able to provide some consistency and orchestrate referrals and management was very important. Although such conflicts did not happen frequently, we found it particularly frustrating when health practitioners dismissed or ignored signs or symptoms because they did not fit the usual pattern of presentation, at times seeming almost to 'blame' us for this. We certainly preferred it when those we consulted were open-minded, non-judgemental, and curious, acknowledging the limitations of medical knowledge and understanding. Not

all health practitioners were able to provide help in all areas, nor was any one intervention likely to be a total solution for our conditions – instead, we learnt to accept the help and knowledge that could be gleaned from each person and sought assistance from others if required. Books, articles, Internet websites, and conversations with others provided additional valuable sources of information; they increased our knowledge of our illnesses and how others had coped in similar situations, and provided solace during difficult times. Three books that we found particularly helpful are listed at the end of this Editorial.

Learning the physical strategies to cope has been a painstaking process – particularly difficult if the underlying condition is inherently unstable, irritable, or has a latent reaction to increased activity. The strategies that we have used with some effect have included task avoidance, task modification, pacing, and trade off (ie choosing to do activities that are important, even though ill effects may result). Both of us have found the gentle and mindful approach to movement of the Feldenkrais Method invaluable. Learning to cope physically has required an acceptance of our conditions, an intimate knowledge and recognition of the activities that increase and decrease our physical symptoms, and a willingness to be inquisitive, to take calculated risks, and to experiment with these activities. In some respects, being physiotherapists was helpful in this process, in that it gave us a head start in knowing how to interpret and react to physical symptoms and signs. However, our exposure as physiotherapists to patients with much more serious and at times life threatening conditions had both positive and negative sequelae, in that while we were always aware that there were others much worse off than we were, it also meant that we sometimes questioned and even belittled our physical problems.

We have found that coping with the emotional impact of illness is equally, if not more, complex. The emotions that we have experienced as a result of illness, which are similar to those experienced with loss of any kind, have included denial, grief, anger, frustration, isolation, fear, sadness, and acceptance. They impacted not only on us but also, to varying degrees, on family, friends, and co-workers. For both of us, this range of emotions did not occur in an orderly or systematic manner, nor did it gradually subside to bring us to a settled emotional state. Instead, they have been tumultuous and cyclical, often triggered by apparently trivial events such as situations that emphasise lost abilities. For one author, an ex-fitness fanatic, an insignificant event such as being passed by runners (no matter how slow and ungainly they may be) while walking can induce an intense pang of grief. For the other author, the opportunity to do something as simple as give her young children a 'whizzee', or go for walks with them, has been lost forever. Many physiotherapists will identify with the self-image of being an independent, busy, full time professional who helps other

people; the need, by virtue of illness, to reduce or cease work and accept help from others is difficult to accommodate, to say the least. With the shift to chronic illness, we have experienced repeated episodes of grief for what has already been lost, for additional activities that we can no longer do, and for what we may potentially lose in the future. While these losses hurt, and can dramatically alter self-image and self-esteem, it is important to recognise that what has been lost is only a part of oneself, and the real 'you' is still there.

While the emotional aspects of chronic illness can seem overwhelming at times, we have learnt to anticipate, expect, and acknowledge these emotions, rather than resenting and fighting them. With experience we found that we were able to recognise the emotions at an earlier stage, allowing choice in our reactions to them and thus avoiding the trap of reliving memories of other times we have encountered that emotion. Neither of us copes well at all times and we have learnt to accept this and to seek help from others if required. Even if the underlying physical condition does not change, the ability to cope better from an emotional perspective is in itself a significant achievement that should be acknowledged. While we don't expect that all people we consult in relation to our illness will address its emotional impact, even a simple question such as 'How are you managing?' at least acknowledges the emotional impact of illness, shows compassion and empathy, and may allow a more holistic approach to management. We have deeply appreciated those health professionals we have encountered who have been willing to address both the physical and emotional impact of our illnesses. Our experiences as patients and the resultant increased awareness of the emotional impact of illness has altered the way we interact with patients as physiotherapists, and our expectations of them.

With time, a long time, we have become at least partially reconciled to our new situations, and with an increased level of knowledge and self-awareness we have become our own expert managers. This has been very empowering in a

situation that can otherwise be characterised by a feeling of intense vulnerability and powerlessness. Chronic illness may mean that your life has changed irrevocably, and it makes the future uncertain; however, in reality, the future is always unknown and what have really changed are your expectations. Indeed, the fact that the future is unknown has been a source of hope for both of us, as we have learnt that our conditions and our ability to cope with them will change with time. Chronic illness, or any type of loss, need not be a completely negative experience. Chronic illness has provided both of us with the opportunity for new discoveries and deeper insights into our own strengths and weaknesses, and made us reappraise our lives in general by forcing us to take time out to sort out what and who is important to us. To do this, as Stephanie Dowrick says, you need to create time and space in your life, and care for yourself tenderly and kindly. Although each person's illness is different, the impact of and reaction to illness or suffering is universally similar. Chronic illness has been described as a journey, and while it is not a journey either of us would have chosen to undertake, by necessity we have both looked for and continue to look for the positive effects that can result. Illness can make you grow as a person, in part balancing losses that have occurred, by extending your boundaries of courage, resilience, patience, tolerance, compassion, and empathy.

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