

When we can't fix what is broken

Kath O'Conno

'Our bodies are a temporary arrangement. But at its core the business of medicine struggles against this basic fact. Healing begins when we can't fix what is broken'.¹

This observation comes from a talk by US English professor Phillip Simmons to a group of Harvard medical students and doctors. Simmons was diagnosed at the age of 35 years with amyotrophic lateral sclerosis, a form of motor neurone disease. As outlined by Zoing and Kiernan in their article, Motor neurone disease: caring for the patient in general practice in this issue of Australian Family Physician, the diagnosis of motor neurone disease is a devastating one with a rapid progression of disability and a life expectancy of only 2–3 years from diagnosis.

As general practitioners, we see some joy but also much suffering in the consulting room. The suffering associated with a diagnosis of a chronic neurological condition such as motor neurone disease,² multiple sclerosis³ and frontotemporal dementia⁴ can be particularly challenging as they are associated with an impending loss of nervous system function.

Our nervous system is responsible for so much of our sense of who we are including the sensory world, the functions of our limbs, our ability to think, feel, remember and communicate. It is the 'I' who speaks, walks, reads and contemplates. While each patient's journey will be different, facing a diagnosis of one of these conditions is associated with an inevitable existential crisis as patients grieve current and possible or inevitable future losses. Added to this is the inevitable fear of a loss of independence and the indignities associated with this.

In multiple sclerosis there are disease modifying treatments that can significantly improve outcomes and in all the conditions described in the focus articles this issue there is a great deal that can be done to relieve symptoms.²⁻⁵ Patients may live independently in the community for several years and present to their GP for chronic care and unrelated issues. But patients, their families, and their doctors may at some point need to face the fact that they are powerless to improve their current losses or alter the trajectory of their condition. Powerlessness can be debilitating. As Simmons suggests, the business of medicine is about fixing things.1 What to do when things can't be fixed is a much more difficult proposition.

In the video of his talk, Simmons already shows significant disability: he is in a wheelchair, is unable to use his arms and some of his speech is a little laboured. However, he makes a point of introducing himself 'not as a patient but as a human being.' And he goes on to suggest that his illness has shown him something 'about the situation we all find ourselves in.' In particular, finding a way of living with the knowledge that suffering, loss and death is inevitable, that we are "fastened to a dying animal"⁶.'

At some stage we will all face something we cannot change which brings this knowledge into view. For some people, including some of the patients described in this issue of *AFP*, this may be a chronic neurological condition. For others, it might be cancer, the loss of a loved one or the end of a relationship or career. In these situations the great and seemingly insurmountable challenge is to find a way through the pain to some level of acceptance of things as they are. Because beyond acceptance, Simmons suggests, lies healing.

Of course, as human beings we will continue to strive to find solutions to problems that we

face. As doctors, we will keep looking for and offering evidence based treatments that will help our patients. But when we can't fix what is broken, Simmons argues that there is still something worth offering.

And that something is the knowledge that 'we are all in the same boat', 1 that sooner or later we will all face a problem that cannot be solved, and will need to learn about healing.

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