



## **Access to palliative care for people with motor neurone disease in New Zealand: a patient's perspective**

McKenna and MacLeod highlight an important issue in their article *Access to palliative care for people with motor neurone disease in New Zealand*.<sup>1</sup> However they do not go far enough in their suggestions to provide effective palliative care services for people with motor neurone disease (MND).

As a New Zealand health professional who has been living and working in Sydney for the past two years, I have first-hand experience of the services offered to people with MND “across the ditch”. Having had the misfortune to be diagnosed with MND one year ago, I attend one of the four multidisciplinary MND clinics in NSW that are partially funded by the MND Association NSW. At the clinic I am seen by several health professionals including a neurologist and the palliative care doctor from the local hospice.

Although I will probably return to New Zealand when I have a need for palliative care services, I have been able to build up a good relationship here with the palliative care doctor. She has visited me in my home for a baseline assessment and I can contact her by phone or email if I need to.

Another important issue in the Trans Tasman disparity of services and treatment for people with MND is access to the only drug that has been found to slow the progression of this dreadful incurable disease.<sup>2,3</sup> At the time of my diagnosis, I was immediately commenced on the Pharmaceutical Benefits Scheme (PBS)-funded, special authority drug, Riluzole. Riluzole is standard treatment for MND in countries including Australia, Canada, USA, United Kingdom, and many European countries. Riluzole is not registered in New Zealand.

If, as McKenna and MacLeod estimate, there are 250–300 people with MND in New Zealand the annual cost of providing Riluzole for those who meet the criteria would be no more than 3 million dollars. A cost which would be offset by people with MND remaining in the workforce longer and paying taxes rather than being a drain on the taxpayer.

Is it ethical to deny MND sufferers access to medication that is standard in countries with similar living standards? Furthermore, is it ethical to deny them (and their families) access to adequate palliative care when their need is greatest?

The progress of MND can be aggressive, particularly in the absence of Riluzole therapy, thus to monitor progress and intervene at the first sign of deterioration referral to palliative care services needs to start soon after diagnosis.

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## References:

1. McKenna C, MacLeod R. Access to palliative care for people with motor neurone disease in New Zealand. N Z Med J. 2005;118(1222). URL: <http://www.nzma.org.nz/journal/118-1222/1667>
2. Bensimon G, Lacomblez L, Meininger V, et al. A controlled trial of Riluzole in amyotrophic lateral sclerosis. N Engl J Med. 1994;330:585–91.
3. Lacomblez L, Bensimon G, Leigh PN, et al. A dose ranging study of Riluzole in amyotrophic lateral sclerosis. Lancet. 1996;347:1425–31.