Australian Parliamentary Update

Enquiry Reference: Transitional arrangements for the NDIS
Submissions close 10 August 2017

What has happened to Lifetime Continuous Multiple Sclerosis Care?

Concurrent with the introduction of the NDIS there have been many changes in homecare arrangements. Collectively these changes should, inter alia, complement and enhance the capacity of all Australians living with Multiple Sclerosis to continue to live in their own home where that is their choice

This is not necessarily happening, particularly in the case of many at a more advanced stage of MS - especially when evaluated against benchmarks for managing the outcomes of advanced MS conditions. One universally acknowledged benchmark relates to access to 'Lifetime Continuous Care delivered by multidisciplinary teams'

These recent and significant changes have brought with them mixed messages, at times, inconsistent with the holistic aspirations associated with Lifetime Continuous Care.

What is needed?

Following is a synopsis of a recent submission on this topic to the Australian Productivity Commission by the Multiple Sclerosis Network of Care Australia.

In a recent survey by the MS Network of Care frustrations flowing these imbalances were summed up as follows

> 'I am 66 and already receive home care support. While my needs have increased and more support is urgently needed I am too scared to ask for additional help because of what it may now cost me.'

Hurdles and Roadblocks

The principles of consumer directed are well suited to the MS environment. What is not well suited is the introduction of hurdles and roadblocks that can significantly frustrate/fragment/delay the achievement of this holistic model. A single framework that acknowledges and enhances the holistic model would be far more cost effective with better patient outcomes. GPs have an important role in this process

A good starting point in matching service delivery expectations with outcomes is for services to be delivered in ways that are consistent with the Guiding Principles for the Provision of Services to people with MS as included in the (2003) publication 'A Charter for MS Services: the voice of people affected by MS'

The Charter Observes

> In many instances it is not the MS itself that is restricting a person's life, but the expectations and actions of others.

Services need to be flexible enough to adjust to their changing circumstances and expectations. People affected by MS must be in a position to participate fully and make decisions about their support and care, with information and advice to help them make such decisions.

References

1. Productivity Commission Submission
http://www.msnetwork.org/future/ndis-senior-australians.htm
2. About lifetime continuous care
http://www.msnetwork.org/bookmarks/lifetime-care.htm
3. Charter of Individual Rights
http://www.msnetwork.org/roadmap/issues.htm#provision