

The Need for a Neuromuscular Clinic in Canberra

In the ACT Health system, there is no specific care for the range of neuromuscular conditions like muscular dystrophy. What little is available is disjointed and largely dependent on the patient's ability to develop their own care program.

A neuromuscular clinic is achievable with limited additional resources. It would yield considerable benefits to the ACT Budget and the community through a greater emphasis on preventative care, and a comparative reduction in acute care. It would allow people living with a neuromuscular condition the opportunity to maintain their health and optimise their contribution to the community. While it may be possible to measure the economic benefits, the benefits to those affected by a neuromuscular condition are immeasurable.

The lack of any specific services for neuromuscular conditions is a serious problem which is getting worse. The ACT already has all the services which would be involved in a neuromuscular clinic. It is primarily a case of providing the coordination of their delivery.

A business case for a neuromuscular clinic has been developed by the ACT Health Service and it must be pursued by Government to ensure this situation is addressed and people in the ACT living with neuromuscular conditions are able to access services that are already available to others.

There are a range of similar neuromuscular conditions, such as the muscular dystrophies, which when considered individually seem insignificant but taken together, as they would in a clinic, become a very significant group. A report in the Journal of Neuromuscular Diseases (2/2015) determined their prevalence is at least as common as Parkinson's Disease and almost twice that of Multiple Sclerosis. On the basis of this report, it is estimated there are around 700 people in the Canberra region with a neuromuscular condition without clinical support.

Often nothing is heard of these conditions because groups are small or non-existent due to the difficulties of living with their condition. Without clinical support obtaining a diagnosis is of little practical value. A diagnosis needs to be accompanied with a coordinated and supervised treatment plan. It is possible to develop these services in the ACT, an example of this is the MND Clinic based at Clare Holland House.

The development of a neuromuscular clinic in Canberra would not only make diagnosis, treatment and rehabilitation much easier, it would ensure a better information network, better matching up to research and access to clinical trials through formal networks. It would make everyday life much easier for local constituents living with a neuromuscular condition and

can be achieved within the existing and planned health infrastructure and with little impact on the Budget.

It will encourage preventative treatment programs and reduce the need for acute health care as patients deal with their condition in a more managed and informed manner.

The costs of these conditions are on many fronts:

- untreated or not properly treated disease results in a build up of costs in the acute care health system;
- life with a disability can reduce economic productivity;
- estimates from the research papers show that an average of 13-15 years is lost when living with a neuromuscular condition not properly treated; and
- there is a high economic cost of taking carers out of their normal productive role.

The Difficulty of Living in the ACT with Muscular Dystrophy

If you have a neuromuscular disorder and you live in the ACT region, typically you will need to travel to Sydney to receive a complete diagnosis from a specialist neurologist based at one of the several clinics there.

The range of services you may require include: cardiology; respiratory; genetics; physiotherapy; occupational therapy; pediatrics; psychology; nutrition; and exercise physiology.

Ideally you would receive these services in a coordinated manner under the supervision of the clinic neurologist and associated staff.

However, it can take up to 4 months to gain an appointment at one of the Sydney clinics and then, short of moving to Sydney, you are faced with organizing your own treatment services in the ACT or elsewhere as is possible.

It is difficult to achieve this in any reasonable coordinated manner as a healthy individual, let alone with a debilitating neuromuscular disease. If a clinic existed to support neuromuscular conditions, these services could be provided in a coordinated manner.

CRMD would be happy to discuss any aspect of this submission.

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