



Neurological Alliance
C/O Private Bag 110022
Auckland City Hospital
Auckland 1148
8 June 2020

CARER AND RESPITE SUPPORT

Kia ora NZ Carers Alliance,

The Neurological Alliance (Alliance) ¹ is writing to you to raise awareness of our concerns with the support for Carer's and the levels of respite care available to those supporting people impacted by neurological conditions within New Zealand. Across our organisations we represent 1 in 5 New Zealanders impacted by a neurological condition or supporting a family member who does.

People with neurological conditions regularly experience dismissive attitudes, and lack of understanding, as well as more widely experienced challenges within our current health and social system. The understandings of their needs and those that care for them is very low within the majority of New Zealanders. We are seeking your support in addressing issues for our sector, through your role lobbying with the appropriate parts of the New Zealand Government and the broader health sector. The April 2020 meeting of the Alliance members agreed the need for a collaborative approach to address these issues, bringing improved levels of support for Carer's and a significant uplift in their access to respite care.

Firstly, we are looking to support the work you are leading with the Ministries of Health and of Social Development by adding our collective voices on a call for change. We have nominated Catherine Hall, CEO at Alzheimers New Zealand, to represent our collective voice in your work.

Secondly, we have captured the key areas for improvements within the care community in New Zealand, based on feedback from those relying on our organisations. These areas include, but are not limited to:

- Visibility of the needs for carers of those with neurological conditions
- Regular and consistent access to carer / carer respite services to offset issues of significant burn out
- Consistency of access to support services and care across New Zealand and its District Health Boards (DHB's) as the experiences vary significantly across different neurological conditions and across different regions
- Challenges with admitting members to rest homes when short or medium term care is needed
- Addressing issues of isolation for carers and those they care for with opportunities for connection



- Appropriate funding for carers to offset lost income from normal employment and support to access flexible learning and employment options where possible
- Neurological awareness training plan for support workers to ensure competent workforce
- Recognition through funding for the work we do to support carers

The organisations in the Alliance will continue to push forward individually for specific needs of their membership, continuing to provide day to day support where they can. They continue to work tirelessly to collaborate with teams in the Ministries and DHB's to connect with the appropriate professional or supportive service.

We look forward to working together with you to deliver a better set of outcomes for carers and those impacted by a neurological condition in New Zealand. We sincerely hope that in the development of ongoing support for our communities, from the financial through to the psychological, that the neurological disorders community will be included.

Ngā mihi,

A handwritten signature in blue ink, appearing to read "Rich Easton", with a long horizontal line extending to the left.

Rich Easton

Secretary, Neurological Alliance &

CEO of the Neurological Foundation of New Zealand

Note¹ the Neurological Alliance is made up of the following organisations (listed alphabetically):

Alzheimers New Zealand

Cerebral Palsy Society

Epilepsy New Zealand

Huntington's Disease Association New Zealand

Motor Neuron Disease New Zealand

Multiple Sclerosis New Zealand

Muscular Dystrophy New Zealand

Neurological Foundation of New Zealand

Parkinson's New Zealand

Rare Disorders NZ

Stroke Foundation New Zealand