**10th May 2019**

**News release:**

**New research shines light on dementia**

New research commissioned by Alzheimers NZ gives a rich insight into what it’s like to live with dementia.

***This is our story*** features the lived experiences of 49 New Zealanders who either have dementia or are the care partner for someone living with the condition.

Because of the stigma and discrimination associated with dementia, it’s very difficult for people to talk about their ‘dementia journey’, making this research very special, says Alzheimers NZ chief executive, Catherine Hall.

“This is one of the first times we have been privileged to be given a first hand account of what it’s like to live with dementia in 21st century New Zealand,” Ms Hall said.

“This research is extremely valuable. It’s in equal parts edifying and inspiring … and sad.”

Ms Hall said the research findings shine a much-needed light on what people living with dementia need to live well, both from friends and family, and from the health sector, which often lets them down badly.

“These are real people talking about their day-to-day struggles with a health sector that provides woefully inadequate services and support. Hopefully this research will be heard and listened to at The Beehive.”

**New Dementia Declaration issued**

Linked to the research, Alzheimers NZ has also issued a **Dementia Declaration** that has been written by New Zealanders living with dementia.

They have prepared the Declaration to outline what they need from society to live well.

Alzheimers NZ board member, Alister Robertson, who has dementia, issued the Declaration when the *This is our story* research was launched.

The Declaration is a first for the New Zealand dementia community, he said.

“We wrote the Declaration as a vehicle for change. For too long people living with dementia have been marginalised and stigmatised, both by society and by the health sector.

“Our lives do matter. We want to be treated with respect and acceptance, just like anyone else.

“Our Declaration outlines what we need to live well.”

Mr Robertson listed the problems facing people with dementia, including the lack of adequate and appropriate support and care services and the difficulties navigating the health system.

“Add to that the social isolation, stigma and discrimination, the lack of control over, and involvement in, decisions that affect us and being marginalised as if our lives are over and of no consequence the moment the diagnosis is made.

“We hope the Declaration will help to change things for the better.”

For more information contact Daniel Paul (021) 400-993.

Editor’s note: The report *This is our story* and the Dementia Declaration can both be found at **www.alzheimers.org.nz.**