# Information for media

## About Alzheimers NZ

Alzheimers NZ is the lead organisation at a national level representing people and their whānau living with dementia mate wareware. Alzheimers NZ works to raise awareness of dementia mate wareware, provide information and resources and advocate for high quality services. We also promote research about prevention, treatment, cure and care.

We support local Alzheimers NZ organisations throughout Aotearoa New Zealand, each of which is a member of Alzheimers NZ. Local Alzheimers organisations provide support, education, information and related services directly to members of their communities who are affected by dementia mate wareware, education and risk reduction and awareness raising in communities.

Alzheimers NZ does not have an apostrophe before the 's' but this is a style decision the organisation has undertaken.

## These services may include:

- Information and education to assist with understanding and living with a dementia mate wareware diagnosis
- Support for whanau and friends to enable them to provide support and care for those with dementia mate wareware
- Support groups, day programmes and other individual and group activities for people affected by dementia mate wareware

## Facts about dementia mate wareware

- Dementia mate wareware is an umbrella term used to describe a group of symptoms that affect how our brains work
- Mate wareware is the te reo Māori term for dementia so we try to use both at the same time
- The most common symptoms include changes in memory, thinking, behaviour, personality and emotion
- Anyone can get dementia mate wareware but the likelihood increases as people get older
- Dementia mate wareware is progressive, which means that for most people the changes gradually spread through the brain and lead to the symptoms getting worse

• There is currently no cure for dementia mate wareware. Some treatments can reduce symptoms and improve quality of life in some people, but they do not stop the progress of the disease.

## Statistics about dementia mate wareware in Aotearoa New Zealand

- Almost 70,000 New Zealanders are living with dementia mate wareware today
- Four out of five New Zealanders are affected by dementia mate wareware in some way at some point in their lives
- As our population ages, it is estimated that around 170,000 Kiwis will be living with dementia mate wareware by 2050
- Dementia mate wareware impacts more women than men around 30% higher
- The total cost of dementia mate wareware to Aotearoa New Zealand is now around \$2.5b and will reach around \$5.9b by 2050

#### Attachments:

- <u>10 warning signs of dementia</u>
- Dementia Economic Impact Report 2020
- Reducing the risk of dementia

#### Alzheimers NZ's Mission: 'A Dementia Friendly NZ'

Dementia is one of Aotearoa New Zealand's most significant and growing healthcare challenges. It will have major personal, societal and fiscal impacts in the years ahead, yet there is very little discussion or acknowledgement of its everyday impacts.

Most people with dementia mate wareware live in our communities. They shop, work, eat out, catch the bus, go to the library and do everything else we all enjoy doing. Alzheimers NZ's mission is to create a dementia friendly Aotearoa New Zealand, where people living with dementia mate wareware can exercise their human rights to be included and valued, to contribute and participate, to live independently in the community for as long as is possible for them, and to get the help and support they need.

Find more details about dementia mate wareware and our organisation: <u>www.alzheimers.org.nz</u>

Things to keep in mind when reporting on dementia mate wareware

Here are some key things to keep in mind to ensure you are reporting accurately and compassionately on the condition:

The stigma associated with dementia mate wareware

Unfortunately, there is significant stigma associated with dementia mate wareware. Please refrain from publishing content that reinforces those negative viewpoints and if at all possible look for stories that show people with dementia mate wareware living their best lives possible. For example, try to avoid terms like "dementia sufferers".

### A 'cure' for dementia mate wareware

It is important to be cautious when discussing the possibility of a 'cure'. While this may make an appealing story, inaccurate or exaggerated suggestions in this area can raise expectations for people affected by dementia mate wareware

## Where to go for help

Media can help people affected by dementia mate wareware by encouraging people to get a diagnosis if they have concerns, and by including a point of contact (ie, a local Alzheimers organisation) in their coverage.

People who are concerned that they or someone they know has dementia mate wareware should be directed to their GP or primary health practice in the first instance. For information, support and services they can reach out to their <u>local</u> <u>Alzheimers or dementia organisation</u>.

#### Breaking down the stigma

Telling the stories of people with dementia mate wareware, particularly high profile people who have an experience with the condition, can be helpful in normalising the condition and breaking down the stigma associated with dementia mate wareware.

Interviewing someone with dementia mate wareware

- Interviewing someone with dementia mate wareware may require patience, and in some instances it may be best to include their support person/whānau, and/or someone from the Alzheimers NZ team.
- If you are interviewing someone with dementia mate wareware, allow more time for the interview and repeat any questions as required.
- Ask one clearly phrased question at a time.

- Be aware that because dementia mate wareware is a memory condition, it may be difficult for the person to answer questions which require them to draw on their memory.
- It is common to receive short, concise responses rather than drawn out explanations from people with dementia mate wareware.
- Check with the person's support person/whānau after the interview, or provide a draft of your article for fact checking if possible.

USE	INSTEAD OF
People/person with dementia mate	Dementia patient
wareware	Sufferer
People/person affected by dementia	Victim
mate wareware	Demented
People/person living with dementia	Aged
Person who has dementia mate	Afflicted
wareware	Senile
	Cursed
Condition	Disease
Care partner	Caregiver
Person who cares for/cares	Carer
about/looks after/supports/helps	
Support person	
Primary support person	
Family, friends and whanāu	
Family/whānau/aiga carer(s)	Informal carers
Unpaid care partner	
Older person/people	Aged person/people
	Elderly
Challenging, debilitating	Hopeless, impossible, unbearable
Impact/effect of caring for a person	Carer burden, burden of caring
with dementia mate wareware	

### Terminology