What do we know about young onset dementia in Aotearoa?

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Mihimihi | Introduction





Kia ora tātou
Hi everybody

Nō Airangi, nō Koterangi hoki ōku tūpuna
My ancestors are from Ireland and Scotland,

engari i tupu ake au i Ōtepoti
but I grew up in Dunedin

kei Tāmaki Makaurau ahau e noho ana.
and I live in Auckland.

Ko Brigid Ryan ahau
I'm Brigid Ryan,

he kairangahau roro ahau i Waipapa Taumata Rau.
I'm a neuroscientist at the University of Auckland.

Nō reira tēnā koutou katoa!
So, hello to you all!







yodat
Younger Onset Dementia Aotearoa Trust
yodat.org.nz

Outline



What is **young onset dementia (YOD)**?

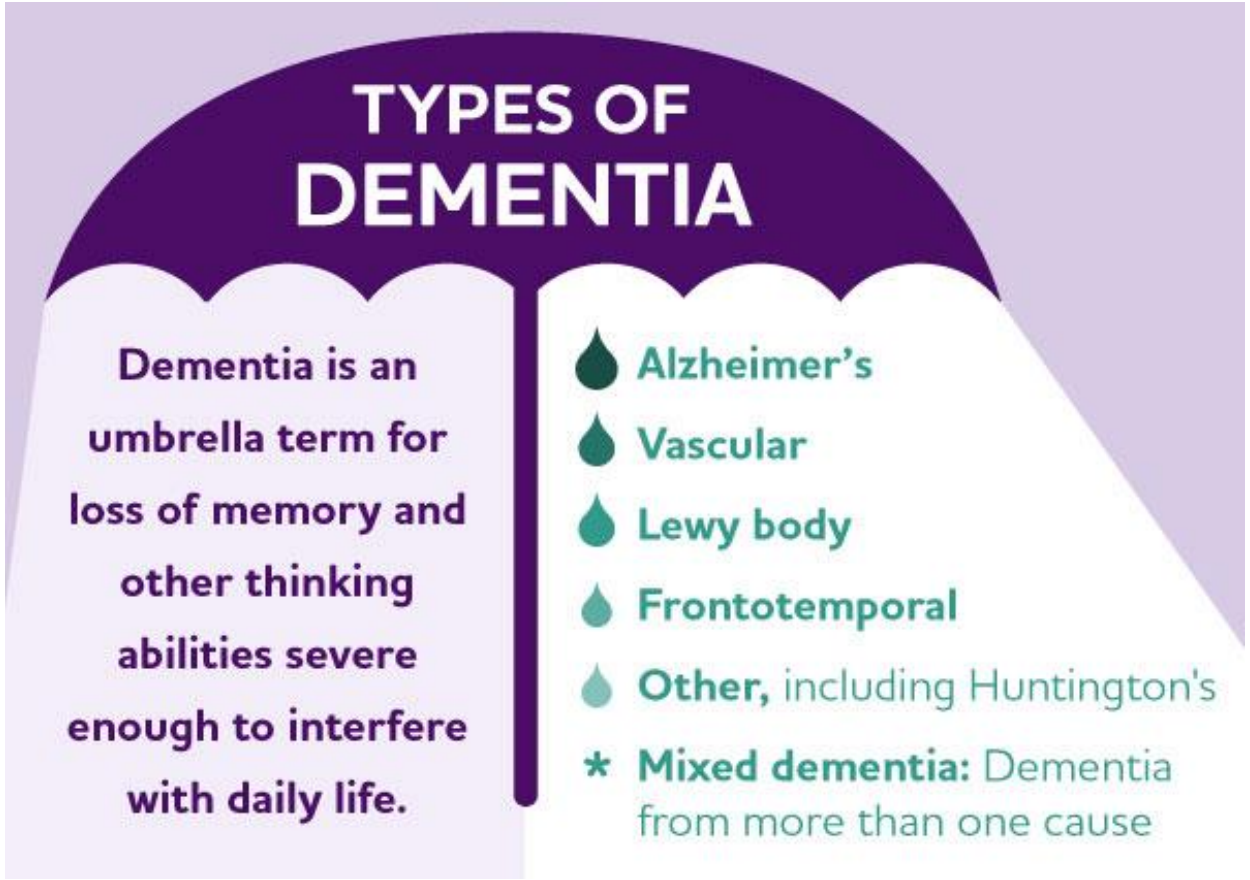


Latest research on YOD in NZ



What **support** is available in NZ?

Young onset dementia (YOD)



Young onset dementia: any type of dementia with **symptom onset** before the age of **65**

Young onset dementia (YOD)

Common diagnoses: **AD** > **FTD** > **vascular dementia** (50-75% combined)

- **Rarer** diagnoses: e.g. Huntington's disease
- More likely to be **genetic**

People living with YOD face **unique challenges**

- Career
- Financial/caring responsibilities
- Active lifestyles
- Services/supports may not be age-appropriate

How are people affected in Aotearoa?



Lived experience:

Rimkeit & McIntosh 2017[1]

- 9 people with YOD using aged care

Leanne Bolton (Masters in Nursing)



- 3 people with YOD

Alzheimers NZ qualitative report 2019[2]

- 11 people with YOD

The activities weren't to his satisfaction…I would like to see somewhere for the people who are a little bit more active…he's still fit enough to have a life…why take it away from him?

Younger people with dementia want services tailored for their age group

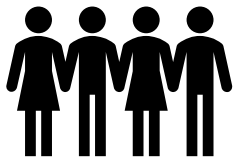
1. Rimkeit et al. 2017 Australasian Psychiatry; 2. Smith et al. 2019 Wellington: Litmus

How are people affected in Aotearoa?

Sociodemographic and Clinical Characteristics of 1350 Patients With Young Onset Dementia

A Comparison With Older Patients

Ryan, Brigid PhD[*,†]; Martinez Ruiz, Adrian MD[†,‡,§]; Rivera-Rodriguez, Claudia PhD[‖]; Curtis, Maurice PhD[*,†]; Cheung, Gary PhD[†,‡]

Young onset dementia <65		Late onset dementia 65+
	vs.	
1,350		45,626

People with YOD were more likely to:

- Exhibit problematic behaviours
- Exhibit neuropsychiatric symptoms
- Experience financial strain

YOD care partners were more likely to:

- Report feelings of distress, anger, or depression
- Report feeling overwhelmed

Ryan et al. 2021 Alzheimer's Dis & Assoc Dis.

Who is affected in Aotearoa?

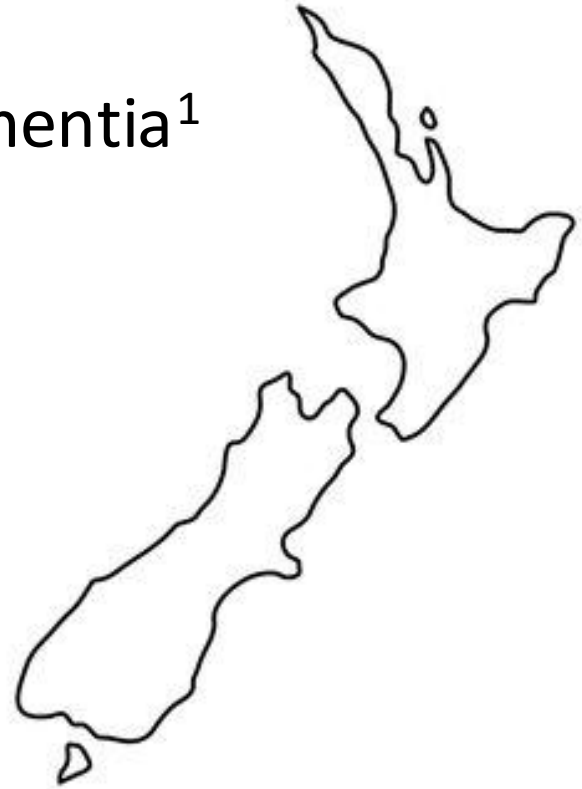
Original research

Prevalence of young-onset dementia: nationwide analysis of routinely collected data

Brigid Ryan ,[1] Edith To,[2] Etuini Ma'u,[3] Amy Hai Yan Chan,[4]
Claudia Rivera-Rodriguez,[2] Maurice A Curtis,[1] Sarah Cullum ,[3] Gary Cheung[3]

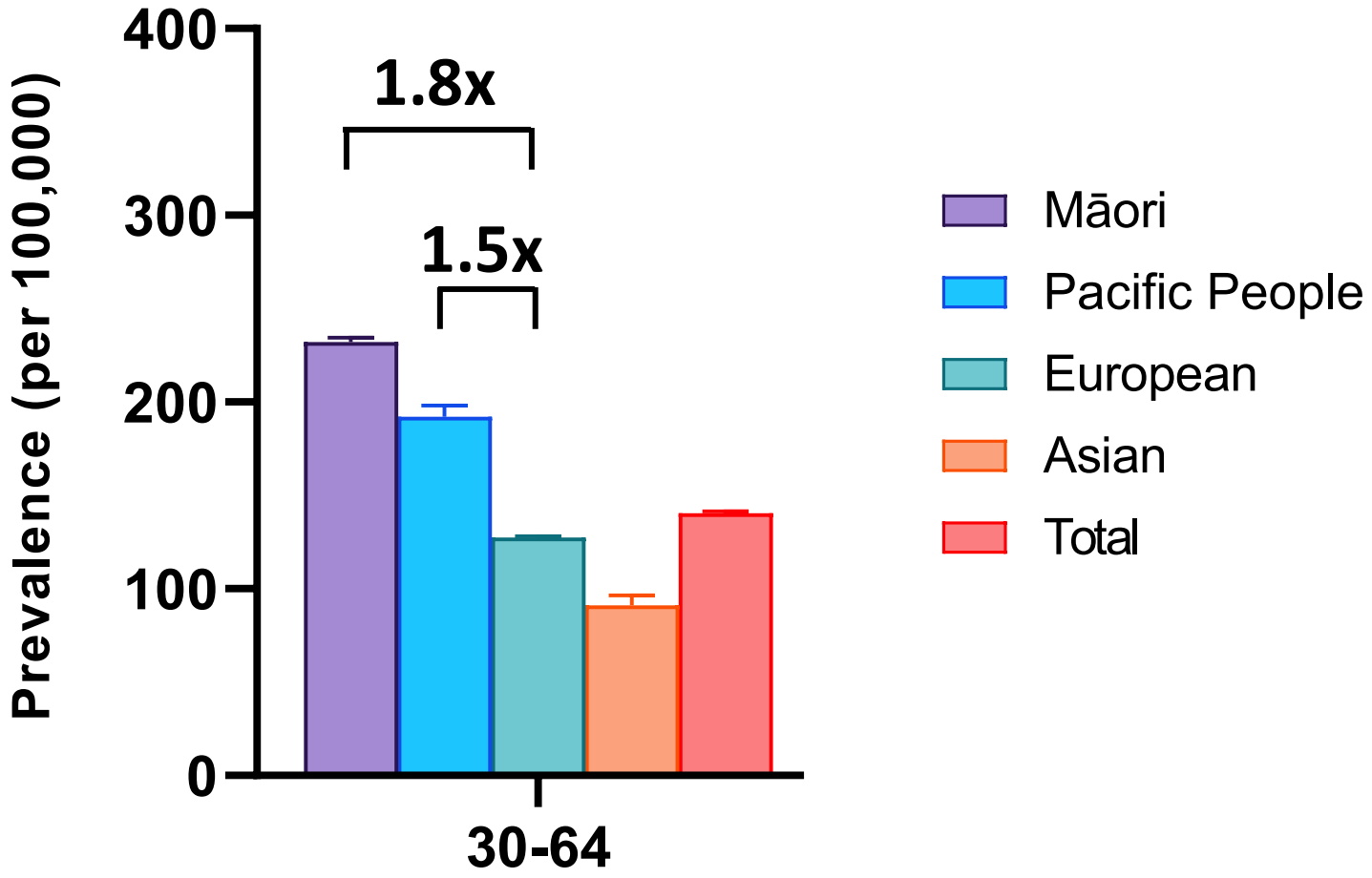
Who is affected in Aotearoa?

- 3400 people with a diagnosis of young onset dementia[1]
- 14/10,000 30-64 (US: 12; Europe; 16[2])
- 7% of all dementia
- One third 60+; 70% 45+



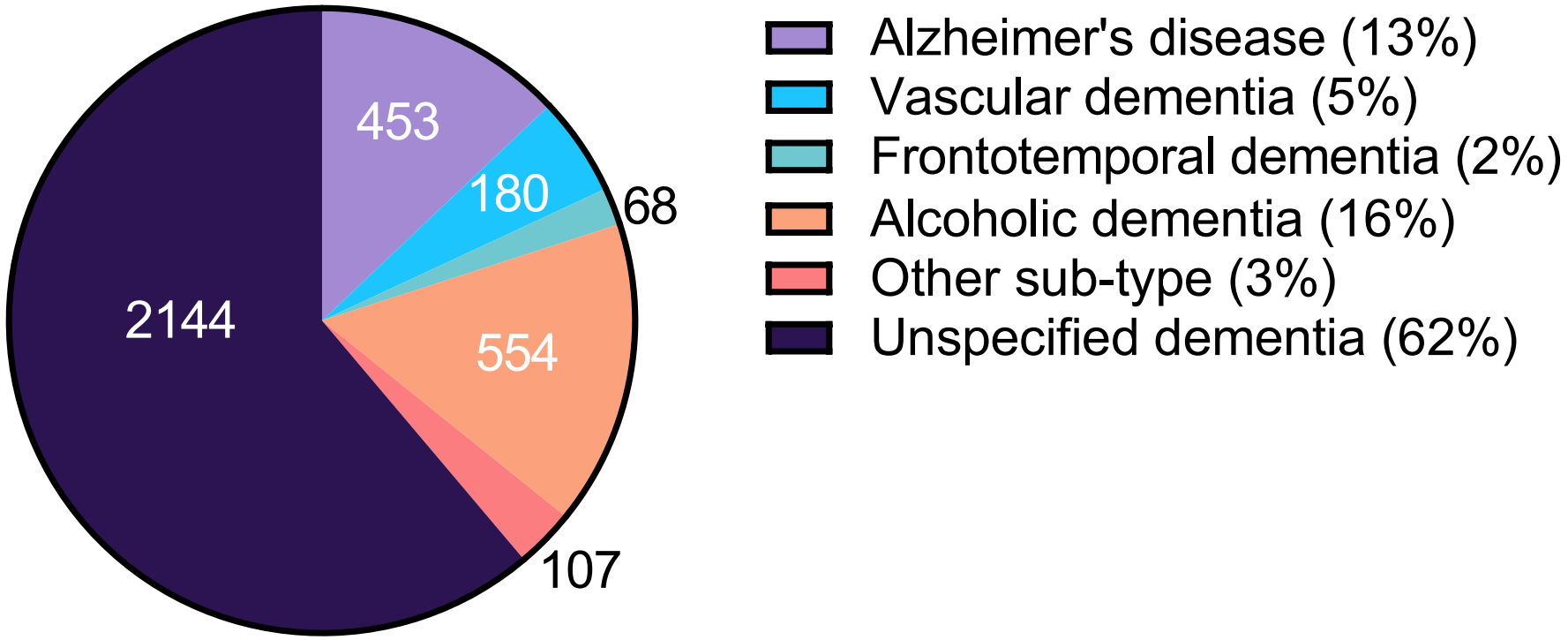
1. Ryan et al. 2022, JNNP; 2. Hendriks et al. 2021 JAMA Neurol

Who is affected in Aotearoa?



Ryan et al. 2022. JNNP.

Who is affected in Aotearoa?



Ryan et al. 2022. JNNP.

Who is affected in Aotearoa?

Journal of Alzheimer's Disease 90 (2022) 1321–1327
DOI 10.3233/JAD-220802
IOS Press

Incidence of Young Onset Dementia in Waikato, New Zealand: A Population-Based Study

Lochanie Fonseka[a], David Wang[b], Brigid Ryan[c,d], Gary Cheung[e] and Etuini Ma'u[e,*]

- 64 new diagnoses in a 3-year period
- Suggests **220 new diagnoses** in Aotearoa each year
- Higher incidence in Māori compared to non-Māori (1.7x)

Diagnosis in Aotearoa



Shruti Sharma

- **Timely** and **kindly** diagnosis is critical to patient and care partner **well-being**
- **Is this happening in Aotearoa?**

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Do you or a loved one have dementia?

Phone conversation, then consent in person/over Zoom → Questionnaires: Patient Care partner + Medical records

Diagnosis in Aotearoa

- On average, it takes **3.6 years** to get a diagnosis in Aotearoa
- 40% of care partners think this is **too long**: “The journey has been long and frustrating”
- **92%** of patients present to their GP first
- **50% of GPs** referred to specialist within 3 months (25%: >1 year)
- All patients were diagnosed by a specialist (75% neurology)

Sharma et al. 2024, Under Review

Diagnosis in Aotearoa

Neurological Foundation
A pathway to hope

- Follow-up: **in-depth interviews** to understand experience
- 13 interviews: 1-2.5 hours long
- Care partners, patients, clinicians



Ashleigh O'Mara Baker

Pre-diagnosis

- Delayed presentation to GP
- Multiple clinicians before correct referral
- Private vs public discrepancies
- EPOA etc hard to navigate

Post-diagnosis

- Services/resources hard to find
- Day services extremely limited
- Rigid and opaque funding systems
- Respite and long-term care limited

O'Mara Baker et al. 2024, unpublished

Key **recommendations** for clinical practice

7% of people living with dementia in NZ are under 65

1. GPs see these patients first: **detection** of **suspected** dementia is critical
   → See regional health pathways; listen to patients and loved ones
2. All suspected cases of young onset dementia should be referred for **specialist diagnosis**
3. GPs have an important role to play in **post-diagnostic support**
4. People with young onset dementia want and need **age-appropriate services**
   → Contact your local dementia organisation, or yodat.org.nz

What **support** is available in NZ?

- **YODAT**
  - Charity, established in 2015 to improve wellbeing for NZers with young-onset dementia
  - Provides services, and works with other providers

- **Age-appropriate** services and support are available in NZ
  - Respite care/day services/activity groups
  - Support groups: in-person and online
  - Help to navigate the health system and identify financial support
  - Contact your local dementia organisation or yodat.org.nz

    - Do you know of other supports/services? Let YODAT know at yodat.org.nz

What support is **needed?**

- **Clear, easy-to-find information**
  - Health system navigation
  - Available services, support
  - Financial support

- **Timely and kindly diagnosis**
  - Prompt referral from GP to specialist
  - Dedicated young-onset dementia clinics
  - Plan for post-diagnostic support

- **Tailored, age-appropriate** services and support available **across NZ**
  - Respite care/day services, including Cognitive Stimulation Therapy
  - Support groups: in-person and online
  - Residential care

Thank you!

Collaborators:
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Neurological Foundation
A pathway to hope

Brain Research NEW ZEALAND
Rangahau Roro Aotearoa

Auckland Medical Research Foundation
est. 1955

ALZHEIMERS NEW ZEALAND

The Kelliher Charitable Trust

hrc Health Research Council of New Zealand