



Joint Solutions Project Results

Associate Professor Samantha Loi

Dr Priscilla Tjokrowijoto

Dr Clare Beard



*Understanding the gaps,
barriers, and positives in the
young-onset dementia care
pathway*

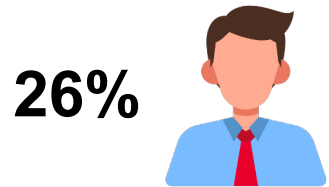
Mixed Methods



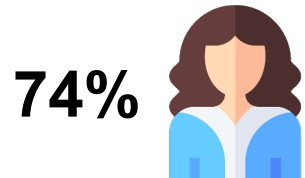
Demographics

313 Participants

- 33 People living with YOD
- 105 Caregivers
- 93 Clinicians and GPs
- 82 Community Service Providers



>90%
Caucasian



32%
Living in
non-metro
areas





Highlights from the project findings...

Obtaining a Diagnosis



- Specialist diagnostic services
 - Comprehensive investigations
 - Confident and able clinicians
- Many are being diagnosed within 12 months of presenting to GP with symptoms



- It is challenging for GPs to recognise that a YOD process may be occurring
- Issues with availability, timeliness, cost, perceived invasiveness
- Low public awareness that dementia can affect younger people

Obtaining a Diagnosis

Mean age when families first noticed symptoms: **56**

Mean age at diagnosis: **58**

Need to balance early diagnosis with accuracy



- **43%** were given other diagnoses prior to receiving a YOD diagnosis - **mental health / other neurological**
- Follow-up appointments to review diagnosis
- Acknowledge that this may be frustrating for the person

Diagnostic experience contingent on:

- ✓ Amount of information
- ✓ Clarity
- ✓ Sensitiveness and supportiveness of clinician(s)

“

We received the diagnosis... In the same meeting, husband was told he must give up work and driving, and as we left, we were handed a pamphlet about brain donation.

I was simply told I had FTD and had 3-6 years to live, bugger off and come back next year!

”

Genetic testing

- Case-by-case: age of onset, family history, patient preference
- Need a guide for when/how to make referrals



Diagnosis and After



- Modification of risk factors routinely discussed
- Informed about essential services – e.g., Dementia Australia, Forward with Dementia, Carer Gateway
- Lack of follow-up appointments
- People unsure where to go; clinicians unsure where to refer
- Fragmented care

Post-diagnostic Care



- Where available and utilised, services are considered useful, relevant, and timely
- Support workers are highly engaged and eager to improve YOD expertise
- Dementia Support Australia helpful for behaviour support
- Geographical inequity
- Limited availability of services (e.g., psychological support for carer and family, allied health trained in YOD)
- Services not suitable to age or life stage



“

I am a highly educated person, a former public servant and a teacher with many years of admin experience. The plethora of forms required, and inflexible online applications, have beaten me.

”

Psychosocial Implications

- Family and friends advocate and support **better access to services**
 carer burden

“ We’re educating carers to say you need a break, please look after yourself so you can continue to care, and there’s just nothing apart from perhaps someone coming into the home for three or four days. ”

- Peer support groups: **connecting with others “in the same boat”**
confronting



- Most of our lived experience respondents had children, and **52%** lived with them at some point. **Only 12%** received support for children.

Advance Care & Future Planning



- Most agree the topic should be raised early, while the person still has capacity to make life decisions
- Process for driving notification depends on legislation and clinician preference
- While a minority, some good housing/respite models exist – well-staffed, social engagement
- Some people may not be emotionally ready to discuss this immediately post-diagnosis
- Many clinicians consider providing financial advice out of scope of practice
- Lack of alternative transportation
- Limited options for age-appropriate accommodation

Recommendations

for a gold-standard pathway of care

1

A **key person** to support, inform, and help navigate services from the point of diagnosis.



2

Streamlined services that everyone can access regardless of where they live. A **hub-and-spoke model** for regional, rural, and remote areas.



3

A **dedicated YOD website** as a centralised system or hub.

4

Improve communication and collaboration. Set up a **confidential portal** for families and professionals to access care notes and letters.

Recommendations for a gold-standard pathway of care

5

More **individualised** support; assistance with accessing the NDIS and other supports to meet physical, psychological, and social needs.



6

Improve access to **day programs, respite care, and age-appropriate accommodations** with YOD-trained staff.

7

Improve access to diagnostic and post-diagnostic services for **diverse groups**.

8

Increase **public awareness** of YOD and tackle **stigma**.



Limitations

- Representativeness
 - Unequal representation across States and Territories
 - Underrepresentation of secondary dementias (e.g., MS, HIV, Intellectual Disability, Down Syndrome)
 - Hard-to-reach groups: people experiencing homelessness, people who are incarcerated in prison/forensic institutions
- Limited diversity
 - First Nation Peoples
 - Culturally and linguistically diverse communities and other ethnic minorities
 - LGBTIQ+ community
- Small sample of GP respondents
- Small sample of caregivers whose loved one is in the advanced stages or has died





Young Onset Dementia Project

Thank you!

