

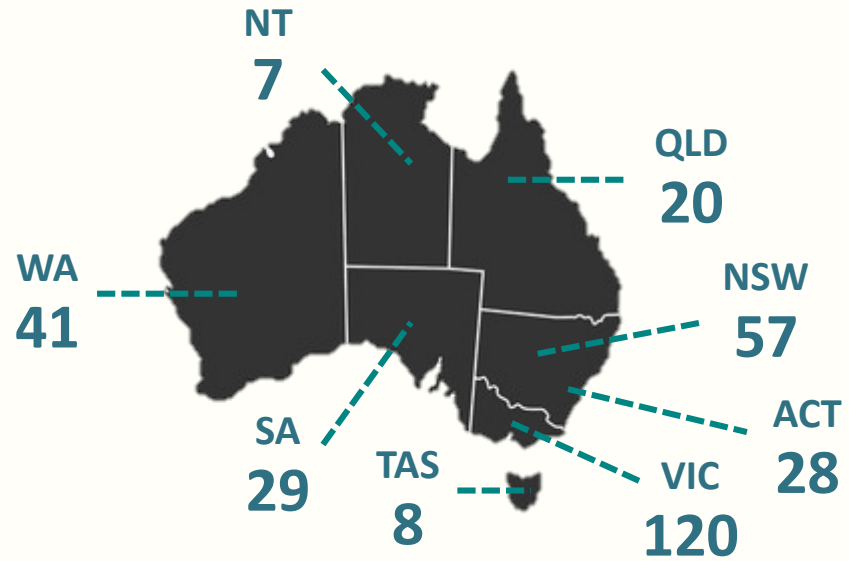
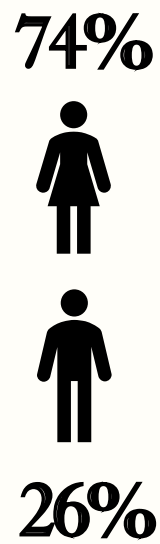


PATHWAY OF CARE: GAPS, BARRIERS, POSITIVES AND OPPORTUNITIES

YOUNG-ONSET DEMENTIA (YOD) IS CHARACTERISED BY SYMPTOM ONSET BEFORE THE AGE OF 65. IN AUSTRALIA, 28,000 PEOPLE ARE LIVING WITH YOD. MANY ARE WORKING, RAISING YOUNG FAMILIES, AND MANAGING MORTGAGES WHEN DIAGNOSED.

313 PARTICIPANTS

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



32%
LIVING IN
NON-METRO
AREAS

>90%
CAUCASIAN

A TIMELY DIAGNOSIS IS CRUCIAL FOR PEOPLE WITH YOD AND THEIR FAMILIES, ENABLING UNDERSTANDING, FUTURE PLANNING, AND ACCESS TO SERVICES.



52% HAD ACCESS TO MEMORY OR YOD CLINICS

55

 WAS THE MEAN AGE WHEN FAMILIES FIRST NOTICED SYMPTOMS

but 48% did not know dementia may occur in people under 65.

YOD IS COMPLEX, AND IT MAY TAKE YEARS TO ACCURATELY DIAGNOSE THE SPECIFIC TYPE

70% were diagnosed within 12 months of presenting to a GP. Most people considered **6-12 months** as the ideal timeframe.

42%

 WERE INITIALLY GIVEN A DIFFERENT DIAGNOSIS

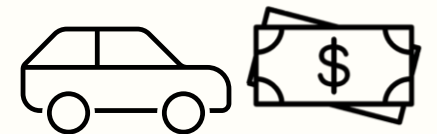
often psychiatric, such as depression



Alzheimer's disease and behavioural-variant frontotemporal dementia were the most frequent types of young-onset dementia in this study



The diagnosis of YOD affects employment, income, finances, driving, mental health, and the wellbeing of partners and children



80%



OF PEOPLE WITH YOD WERE NOT OFFERED COGNITIVE REHABILITATION

65%



OF PEOPLE WITH YOD WERE NOT OFFERED PEER SUPPORT

40%



OF PEOPLE WITH YOD WERE NOT OFFERED ALLIED HEALTH SUPPORT

Respite care, accommodation, and housing options are mostly not age-appropriate



INFORMATION AND SUPPORT MUST BE SUITABLE FOR THE PERSON'S AGE AND STAGE OF LIFE



Community service providers reported an increase in YOD referrals, and 80% wanted more training in YOD



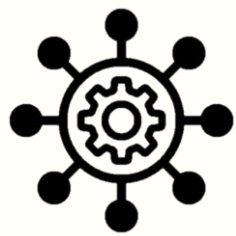
PATHWAY OF CARE: GAPS, BARRIERS, POSITIVES AND OPPORTUNITES RECOMMENDATIONS AND LIMITATIONS FROM A NATIONAL RESEARCH PROJECT INVOLVING 5 SURVEYS AND 10 FOCUS GROUPS WITH PEOPLE WITH YOUNG-ONSET DEMENTIA, CAREGIVERS, GPs, CLINICIANS AND COMMUNITY SERVICE PROVIDERS

8 RECOMMENDATIONS FOR A GOLD-STANDARD PATHWAY OF CARE FOR PEOPLE WITH YOD



1

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



Streamlined services that everyone can access regardless of where they live.

A *hub-and-spoke model* for regional, rural and remote areas.

2

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.



5

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

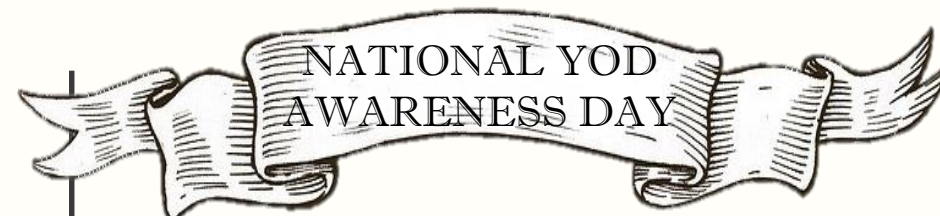


6

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 of this study:

- Unequal representation from States and Territories
- Lack of GP respondents
- Lack of First Nations peoples
- Lack of diversity e.g., CALD, LGBTIQ

BIASES
PEOPLE WITH LIVED EXPERIENCE WERE GENERALLY CAUCASIAN, COMPLETED SECONDARY EDUCATION, AND HAD COMPUTER LITERACY

LIMITATIONS of study:

- Underrepresentation of secondary dementias e.g., Parkinson's disease, MS
- Underrepresentation of people experiencing homelessness, incarceration, or in other institutions