

Tell Gippsland PHN about dementia 2020 Summary findings from interviews



About dementia

Why did we do this study?

Gippsland Primary Health Network (Gippsland PHN) is a not for profit organisation working to improve the health and wellbeing of people across Gippsland. We use data and information from Gippsland people to learn what is most needed to do that.

In Gippsland, dementia is the second most common cause of death for women and the sixth most common cause of death for males. It is estimated that around 6,000 people are currently living with dementia and that is expected to rise to around 22,000 people by 2050.

In this study, Gippsland PHN worked with Monash University to improve our understanding of what it is like to live with dementia. The information gathered will be used by Gippsland PHN to help us make better decisions about how the health needs of people in Gippsland can be addressed. We work with our partners to improve access to needed services and supports.

What we did

We conducted 26 interviews between August and November 2020, asking people living with dementia, carers / family members and professionals about:

- their experience of dementia and with dementia services and supports; and
- what was needed to make life better and what was most important to them.

What we learnt

We found the health needs of many people living with dementia and their family and carers were not currently met. In some cases, people with dementia and their carers did not access available services. In other cases, the health system did not address their individual needs.

We also heard about very dedicated and capable workers who do their very best.

People living with dementia or worries about their memory or thinking told us:

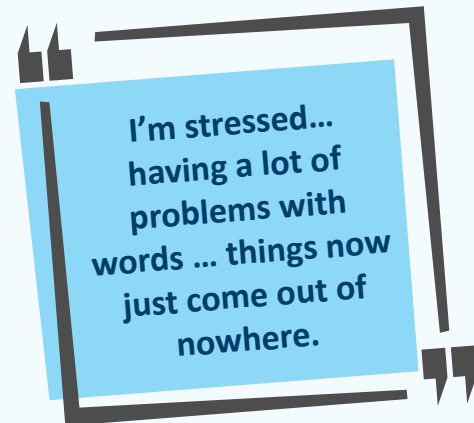
Confusing, frustrating and embarrassing when you can't do simple things any more

Worries about the future and losing independence

Hard to access needed care

Need someone who can provide personal support

Need something meaningful to do and a supportive community



I'm stressed... having a lot of problems with words ... things now just come out of nowhere.

Professionals working with dementia services and supports told us:

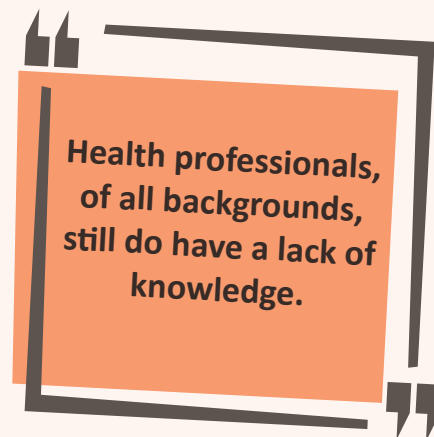
A lack of understanding of dementia in the community

A lack of understanding of dementia among health professionals

Service gaps include access to geriatricians and respite care

Waiting times prevent people from staying in their own home

Model of care makes person centred care difficult



Health professionals, of all backgrounds, still do have a lack of knowledge.

Carers and family members told us:

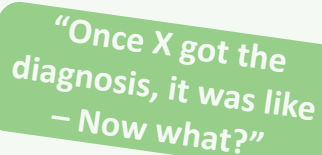
Getting a diagnosis varies a lot from person to person

Support after diagnosis is needed to help carer and person living with dementia adapt

The carer role is essential but can be very demanding

System navigation is challenging

Additional supports are needed to remain in own home



"Once X got the diagnosis, it was like – Now what?"



Some GPs reported as being quite dismissive, more or less saying you know, she's old. For others; GP took us seriously from day one.



I think to have a phone number to ring and just say look, are we on the right track? I felt quite isolated at times."

How can things improve?

Themes from people living with dementia, carers, family and professionals.

Increased community awareness of dementia and available support.

Increased support to get a dementia diagnosis early

Good communication skills among professionals are important

Increased support to navigate the system, especially immediately after diagnosis

Easier access to the right home support services when they are needed

Person-centred care is required in aged care homes

Research needed

Education for health professionals is helpful

More support for, and increased recognition of carers

*"More health professionals aware of dementia to recognise the symptoms and who to refer to as well."
(Professional)*

*"What works for me is when someone will listen to you, respects your parents... you know doctors can be very brusque, very dismissive, or very rude."
(Carer)*

*"I just felt like a completely different person after having respite."
(Carer)*

*"Servicing that better meets the needs of older people without the assumption that they have the internet."
(Carer)*

*"Creating a clear pathway... what happens at diagnosis, what is the next step?"
(Carer)*

*"Tips on how to tell your family. X's children were in total denial that their father had dementia."
(Carer)*

*"What are the early signs of dementia?"
(Person living with dementia).*

*"I don't know if there is currently any treatment like this available to ... stopping the progression."
(Person living with dementia)*

*"Monitoring a person's wellbeing, picking up the little things that are important around their health."
(Carer)*

What happens next?

We are now conducting a survey as a feature of phase 2 of the project. It uses the information from interviews and will allow more people to tell us if the main themes identified are true for them or if other / additional themes may be more important.

[Please access the online survey here.](#)

Phone **03 5175 5444** to be sent a paper copy of the survey.

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Go to www.gphn.org.au for more information