



# Tell Gippsland PHN about dementia

phn  
GIPPSLAND

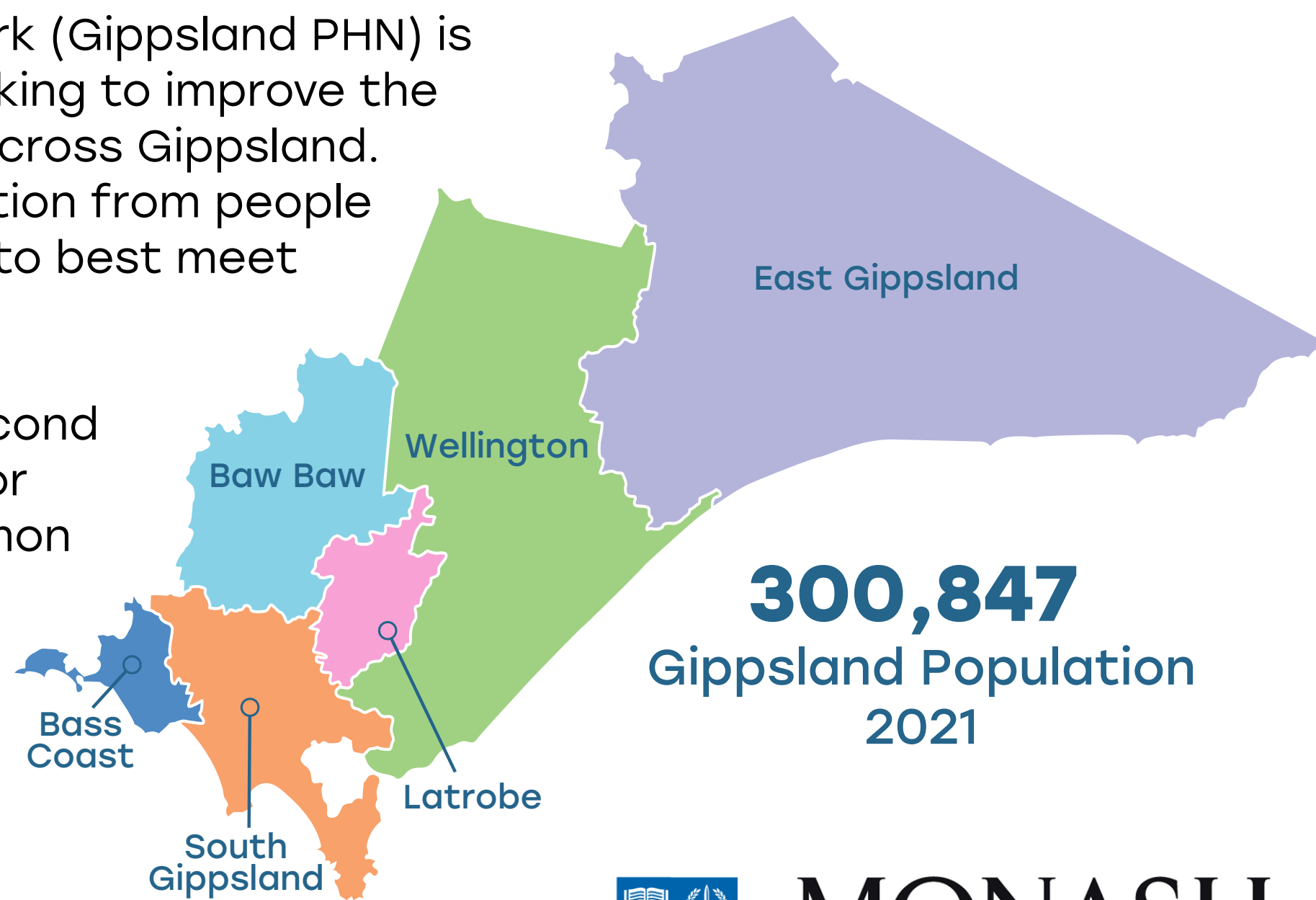
An Australian Government Initiative

**Authors:** Denise Azar<sup>1,2</sup>, Maria Garrett<sup>1,2</sup>, Dianne Goeman<sup>1,2,3</sup>, Liz Craig<sup>1,2</sup> and Mishael Thomas<sup>1</sup>  
**Affiliations:** <sup>1</sup> Gippsland PHN, Victoria, <sup>2</sup> Faculty of Medicine, Nursing and Health Sciences, Monash University, <sup>3</sup> School of Medicine and Public Health, The University of Newcastle

## 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 health data and information from people in Gippsland to understand how to best meet their needs.

In Gippsland, dementia is the second most common cause of death for women and the sixth most common cause of death for men. 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 living with dementia 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 dementia services and support.
- what was needed to make life better.
- what was most important to them.

Interviews were recorded, transcribed verbatim and analysed using NVivo.

Ethics approval was provided by Monash University HREC.

## 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 and services 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:

It's confusing, frustrating and embarrassing when you can't do simple things any more

They experienced worries about the future and losing independence

It's hard to access needed care

They need someone who can provide personal support

They 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:

There's a lack of understanding of dementia in the community

There's a lack of understanding of dementia among health professionals

That service gaps include access to geriatricians and respite care

That waiting times prevent people from staying in their own home

The 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 their own home



**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 is 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**



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

**- Carer**



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

**- 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**



## Key Message

Findings reveal that within this sample, the needs of people living with dementia and their carers are not currently being met. In particular, poor education and awareness about dementia and dementia services, structural barriers accessing appropriate and quality healthcare, and the shortage of trained professionals are areas that need addressing.