

# Dementia

Dementia is a group of conditions characterised by the gradual impairment of brain function (including memory and thinking), the most common is Alzheimer's disease affecting about 70% of people with dementia. One person can have more than one type of dementia.

### **Dementia data for Gippsland**



An estimated **7,488** people in Gippsland with dementia (2021); expected to increase to **13,783** by 2058

An estimated **438** people with younger onset dementia (under 65 years)

Second cause of death among females and the sixth cause of death among males



An average of **171** deaths per year attributed to dementia (2015 and 2019)

**35.3** deaths per 100,000 people, compared to

**41.5** across Australia (age-standardised rates)

**40%** of aged care residents have a dementia diagnosis

### **General practice data**

**0.5%** of all general practice patients had an active dementia diagnosis, increasing by age to **3.1%** of patients 75 years or older.

New dementia related diagnoses increased from **424** in 2017-18 to **456** in 2019-20; **80%** were for people aged 75 years or older

"...we need more home care packages. ...it would be more effective money wise to keep people at home...with the right support to the carers." [Professional]

### People with lived experience

Gippsland PHN research in 2020 found the health needs of many people living with dementia and their family and carers were not currently met. We also heard about dedicated and capable workers who do their very best.

> "... people have been fantastic." [Carer]

"Diagnosis helped to find supportive services at home." [Carer]

#### Key themes for people living with dementia or worries about their memory or thinking

Important to stay fit, well and connected

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

Worries about the future, losing independence and being a burden

Barriers to accessing care

Need someone who can provide personal support

# Key themes for carers and family members of people living with dementia

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

"I don't have a regular GP that I am comfortable with at this point. The last GP I saw ... she told me everyone has memory problems." [Person worried about their memory]

Indicator	Bass Coast	South Gippsland	Baw Baw	Latrobe	East Gippsland	Wellington	Gippsland
Dementia prevalence estimate 2021	1,149	805	1,257	1,713	1,499	1,065	7,488



#### **Professional stakeholder perspective**

Lack of understanding that dementia is a terminal disease Many health professionals do not know of available services and supports

High demand for services suitable for dementia patients, both in residential aged care and support in the community setting

Service gaps have been identified related to dementia assessment services, allied health services and dementia beds in Residential Aged Care Facilities

Younger onset dementia is increasing and there continues to be a need for appropriate accommodation as an alternative to aged care

# COVID-19 restrictions had an impact on people living with dementia and their carers

**32%** of carers indicated they had experienced poorer mental health or loneliness

**30%** of people living with dementia and **34%** of carers indicated their physical wellbeing had declined

**43%** of people living with dementia and **38%** of carers postponed health or medical visits

## Key themes about how things can improve from people living with dementia, carers, family and professionals in Gippsland (2020 project)

Timely access to services to prevent ill-health

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

Education for health professionals is helpful

More support and increased recognition of carers

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

Person-centred care is required in aged care homes Research needed

### **Gippsland services and supports**

Results from Gippsland PHN research in 2020 informed a community facing summary of service and support options for people worried about their own or someone else's memory. It is available here.

Local services that people have found most helpful include Dementia Access and Support Worker, CDAMS (Cognitive Dementia and Memory Service), day respite, dementia counsellors and social workers assisting with discharge planning.

**Dementia Help Line 1800 100 500** – a free telephone service for anyone seeking information, advice or support about dementia. Online resources: https://www.dementia.org.au/

**General practitioners** (GPs)–Major changes to memory or thinking are not normal at any age.

Dementia Access and Support Workers can help find the right support services, including specialist dementia clinicians.

Specialised dementia services are available via:

West Gippsland Healthcare Group

Latrobe Regional Hospital

**Gippsland Lakes Complete Health** 

Latrobe Community Health Service (LCHS)

<u>Dementia Support Australia</u> is a free service for carers of people living with dementia where behaviours are impacting on care. Phone **1800 699 799** 

<u>My Aged Care</u> for help at home, respite or aged care for everyone 65 years or older. Phone **1800 200 422** 

Local governments have an important role in providing a healthy community for people diagnosed with dementia, including support to live at home. Several of the six local government areas in Gippsland have a Positive Ageing Strategy and all deliver support services.

<u>Gippsland HealthPathways</u> includes a suite of clinical pathways and supportive local public and private referral options to dementia services and supports.

"There never seems to be sufficient time to be able to learn the history and life story of each person which is what would lead to improved care."

"Increased understanding by family as well as those caring for the patient [would make the most difference to improve care]".