

Timely diagnosis of dementia: is it happening in Australia?

'AJDC asks' is a column in which we invite a range of contributors to consider topical issues relevant to dementia care



From left: Professor Dimity Pond, Professor Sharon Naismith, Dr Jane Thompson, Professor Graeme Samuel AC, Dr Meredith Gresham

Professor Dimity Pond

Professor of General Practice, University of Newcastle and in active clinical practice for two sessions per week

In my view as a primary care doctor, a lot revolves around the meaning of the word 'timely'. Timely is not the same as early, but it does imply some sense of urgency.

We would not consider the diagnosis timely if the person was very disabled by their dementia and no one had understood this. So I think the question is asking whether we make the diagnosis when the person needs it, to maintain safety and a good quality of life.

There is an element of the person's own openness to the possibility of dementia in this – some people don't want to know whether they have dementia. The NHMRC Clinical Practice Guidelines and Principles of Care for People with Dementia state that people have a right to know and a right not to know their diagnosis

(Recommendation 47). So this needs to be respected. On the other hand, the diagnosis may be needed by family and other carers, so that care can be provided in a safe and realistic manner.

In my view, general public awareness of and acceptance of the condition is improving and reducing the barriers to acceptance of it. Health professionals are also improving in their awareness of the symptoms and signs of dementia, and how to distinguish them from other causes of thinking problems such as medication side effects. Dementia Australia and Dementia Training Australia have made huge contributions to both these factors. Together, they are improving timely diagnosis, but we are not there yet.

Professor Sharon Naismith
Director of the Healthy Brain Ageing Program, Brain and Mind Centre, University of Sydney and Lead, Australian Dementia Network Memory Clinics Initiative

Over a decade ago, it was clear that we are not achieving timely diagnosis of dementia in Australia, which on average takes more than three years from the time of first health professional contact. This figure is unacceptably high and consumers raise this issue as a matter of priority.

There are clear benefits of timely diagnosis including early initiation of treatments, enabling the person with dementia to make choices about their future including financial and legal matters, a longer duration of independent functioning and delays in admission to residential care.

The contributors to untimely diagnosis are multifactorial and may relate to poor awareness of symptoms, stigma and reluctance to seek help, as well as health system and provider barriers including therapeutic nihilism, difficulty recognising dementia and limited access to specialist expertise. At least half of dementia cases in

primary care go undetected. This can reflect time pressures, unsuitability of tools for detecting early dementia and inadequate training. There is often a lack of support for GPs and inaccessible or unclear service pathways.

In a memory clinic setting, multidisciplinary and concurrent assessment usually enables expert diagnoses to be made much quicker – within weeks or a few months, but we need to improve here too! Although international guidelines propose optimal wait times of less than six weeks for first appointment, in Australia only 23.8% of public memory clinics can provide an assessment within two months. The average wait time is almost 12 weeks, compared to, for example, 35 days, 25 days and 33 days in Ireland, Canada and the United Kingdom respectively.

With the expected rise in dementia in coming decades, we need to significantly increase the number of memory clinics (especially in rural/regional areas), ensure

equity of access for all, support private services, and train and assist our GPs in achieving timely diagnoses wherever possible.

Dr Jane Thompson

An advocate for public involvement in dementia research, drawing on her professional background in research as well as her personal experience of caring for her husband Dr Alan Newsome who had Alzheimer's disease and died in 2007. Jane has contributed to numerous dementia research projects, had various advisory roles and was a member of the NHMRC National Institute for Dementia Research Advisory Board (2015-2020) and of the Dementia Australia Research Foundation Scientific Panel (2014-2019). She supports and is a member of Dementia Reframed (www.dementia-reframed.com.au) and Dementia Carers Australia (dementiacarers-aust.com.au)

Observing concerning changes in my husband Alan's behaviour and abilities, I suggested to him that we make an appointment with our GP, with whom he had a long-standing, positive, trusting relationship. He agreed – he had never adopted the heroic "I'll be right mate" attitude.

He made regular appointments with his GP, often booking the last of the day so they could have long chats – no 'long consultation charge' applied! When I raised my concerns, the GP responded immediately, referring Alan to a neurologist. We had an appointment within a month, and the neurologist referred Alan for neuropsychological testing. About three months later, the neurologist told us the testing indicated that Alan, at 69, had Alzheimer's disease. While shocking, Alan's diagnosis was early, efficient and sensitive. A good relationship with a caring GP means timely dementia diagnosis can

ADI on 'Journey to a Diagnosis of Dementia'

In September 2021, during World Alzheimer's Month, Alzheimer's Disease International (ADI) will publish its annual *World Alzheimer Report* – titled *Journey to a Diagnosis of Dementia*.

Each year the report provides a comprehensive global update on a specific dementia topic. For the 2021 report, ADI commissioned McGill University Research Centre for Studies in Aging and Faculty of Medicine and Health Sciences in Montreal, Canada to investigate both current and best practice in diagnosis, gaps, barriers and facilitators. The aim was to look at the role of government, healthcare professionals and civil society to identify any gaps, and highlight the experiences of people living with dementia and their families.

Three online surveys were developed for the 2021 report; the first for clinicians and

professionals involved in making a diagnosis of dementia, with over 1000 respondents from over 100 countries. The second survey has, to date, been completed by over 1821 people with dementia and informal carers. The third survey has been sent to 105 Alzheimer and dementia associations globally to better understand if and how governments are measuring dementia diagnosis rates, to determine presence of a diagnosis strategy in national dementia plans, and to highlight the role of associations in information provision.

The *World Alzheimer Report 2022*, also in collaboration with McGill University, will specifically report on post-diagnostic support.

For further information about the *World Alzheimer Report 2021* and *2022*, visit www.alzint.org/

happen in Australia.

However, what comes next is even more critical. The neurologist's response to my question, "So what do we do now?" was unhelpful. We left his surgery in tears, bewildered as to where to turn next.

Diagnosis is important but not enough. Post-diagnostic information must be provided. Neurologists and GPs need to know how to help us find it.

Professor Graeme Samuel AC Chair, Dementia Australia

Dementia is one of the most under-diagnosed of chronic diseases.

Timely diagnosis of dementia is essential to improve care and outcomes for people living with dementia, and to make life better for their carers. Yet the average time between first symptoms and diagnosis is just over three years.

Many people with dementia and their families miss out on early intervention such as targeted medications that can help to maintain cognitive function longer; and time to develop an advance care plan for future medical treatment wishes and powers of attorney.

An integrated and comprehensive approach is needed to educate and inform health professionals across general practice, primary health, acute and aged care, to support timely diagnosis of dementia, including clear referral pathways to specialist dementia services accessible to all individuals regardless of financial situation or geographical location.

A program for community awareness to inform and educate everyone to the early warning signs of dementia and where to find help is also crucial.

These matters were acknowledged in the final report of the Royal Commission into Aged Care Quality and Safety and in the recent Federal Budget by enhanced early support for people living with dementia in the community, their families and carers through an expansion of the National Dementia Support Program, and more support at diagnosis for people to access the services they need. Dementia Australia will be leading and implementing these measures that will have a significant impact in improving timely diagnosis.

We must continue to make this a priority.

Dr Meredith Gresham

Research Fellow, Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney. Meredith coordinates CHeBA's COGNISANCE Project, which aims to improve the dementia diagnostic process and post-diagnostic support (<https://cheba.unsw.edu.au/cognisance>)

Timely diagnosis is receiving a diagnosis early in the course of dementia. Proponents of timely diagnosis champion that it decreases uncertainty, allows time to plan for financial and legal contingencies as well as services that will enable people with dementia to remain living at home.

It may mean that medication can be commenced when the person derives the most benefit. It allows time to access rehabilitation therapies to maintain or improve symptoms and wellbeing. Carers can seek proactive psychological and practical support.

Seeking diagnosis early allows the medical practitioner to assess for potentially treatable conditions with dementia-like

symptoms, such as depression.

Yet we are presented with a conundrum. Those seeking early diagnosis frequently wait and wait. Numerous international studies have found that it takes between one to two years from the seeking to receiving a diagnosis (Helvik *et al* 2018). There are estimates that over half of all people with dementia never receive a formal diagnosis (Pond *et al* 2013).

Delay to diagnosis has contributors on both sides of the diagnostic fence. People with dementia and families may delay seeking diagnosis by not recognising early symptoms, considering them just 'normal ageing'. They may fear a potential dementia diagnosis. For medical practitioners, diagnosis is complex, and the risk of labelling a person too early has significant negative impacts. They may employ a process of 'watchful waiting'. While legitimate, this places many families in a state of 'limbo'. Importantly, lack of a post-diagnostic pathway contributes to an incorrect but pervasive view that there is nothing that can be done for dementia.

Australia must recognise the need for accessible, streamlined and proactive post-diagnostic support. Knowing that something *can* be done will improve patient, family and clinician confidence in seeking and delivering diagnosis in a timely way. ■

References

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