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Out of the shadows

A PARLIAMENTARY COMMITTEE IS THROWING LIGHT ON A MEDICAL CONDITION AFFECTING A GROWING NUMBER OF AUSTRALIANS AND THEIR FAMILIES. STORY: MICHELLE MURRAY

It's the ticking time bomb of an ageing population. And as the clock counts down, the affects will be felt by those caught in its grip, their families and the nation as a whole.

For Robert, the first signs emerged at the age of 55. At the time a successful accountant, he started having difficulty dealing with financial matters.

The doctor's advice: it's probably just memory overload.

Four years later, the bomb went off.

"I was travelling from our home to my office, where my accountancy business had been for over 20 years," Robert says. "I became completely disoriented, confused and lost. I rang my partner to ask where I was supposed to be going and how to get there. It took a few minutes of discussion to remind me that I was simply going to work and that I was just two streets away from it."

Robert had become dementia's latest casualty, a condition that affects around 280,000 Australians.

With around 1,600 new cases identified each week, the House of Representatives Health and Ageing Committee has launched a public inquiry into dementia, focusing on how early diagnosis and intervention can play a role in improving quality of life, social and community engagement and future planning for people with dementia and their families.

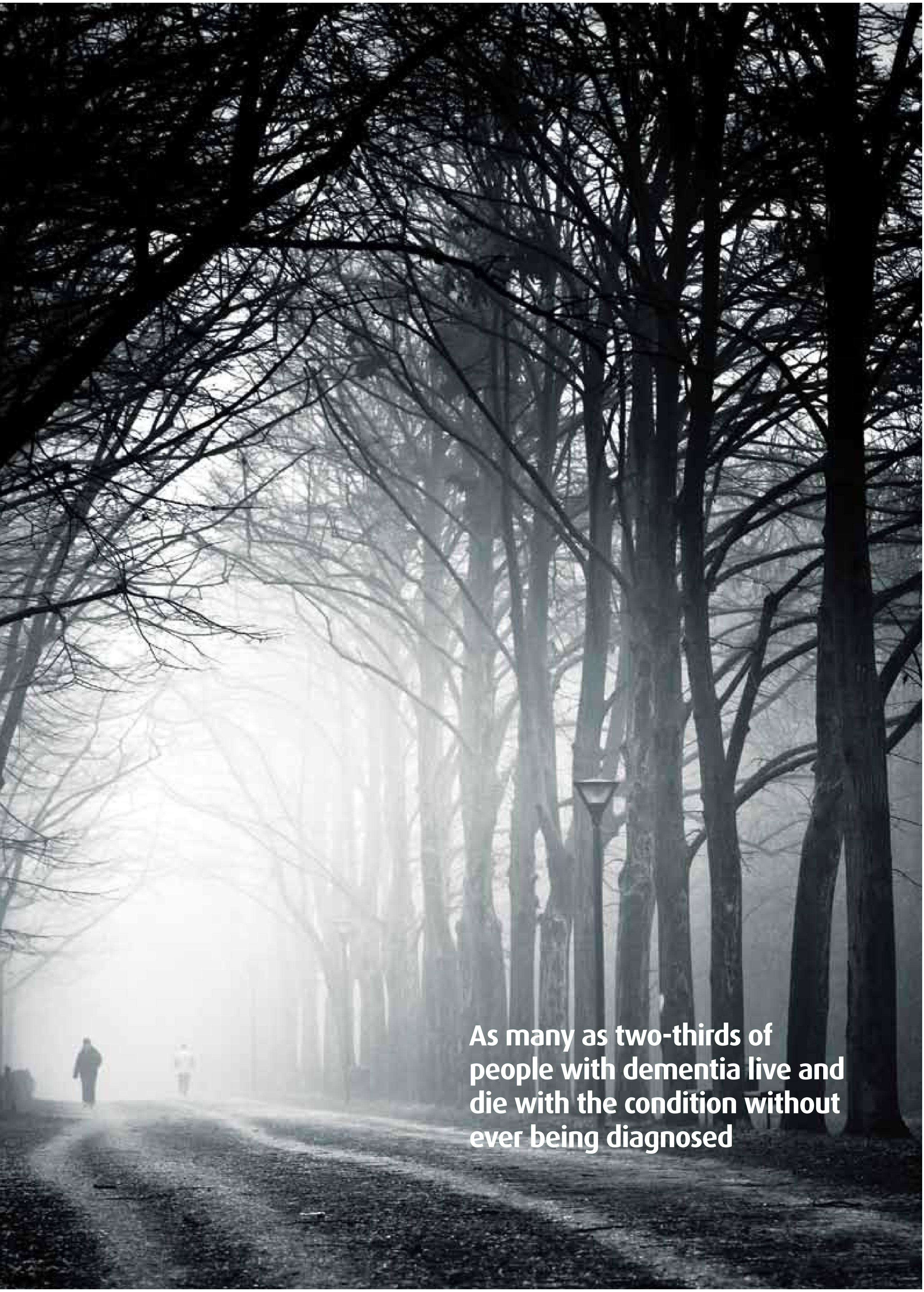
"Dementia is already the single greatest cause of disability for Australians aged over 65 years, and is now acknowledged to be the third leading cause of death among Australians after heart disease and stroke," says committee chair Steve Georganas (Hindmarsh, SA).

> "My biggest fear was that doctors were going to tell me that nothing was wrong"

The alarming statistics have spurred calls for greater action to overcome the barriers to early diagnosis and intervention for dementia.

But expert groups admit that even with the best intentions, improving diagnosis of dementia is often easier said than done.

The Australian Psychological Society says one of the main challenges is that patients often present with symptoms that could be applied to a number of conditions, making misdiagnosis common. For example, depression and dementia present with similar symptoms, including poor concentration, low mood and irritability.



As many as two-thirds of people with dementia live and die with the condition without ever being diagnosed

A family GP is often the first point of contact for sufferers, with the final diagnosis being made by specialists who rely heavily on clinical tests, such as brain imaging scans, in conjunction with the patient's medical history.

However the psychological society says these clinical tests can often miss the subtle changes that signal the early stages of dementia.

They are calling for greater focus on psychological testing in early diagnosis and intervention, regarding it as an essential component often overlooked by medical practitioners.

"These tests of brain function provide an accurate characterisation of current functioning," the Australian Psychological Society says in its submission to the inquiry.

"Furthermore, cognitive assessment can differentiate between cognitive decline due to normal ageing or mood disorders compared with decline due to dementia related issues."

In a personal submission, Leo, a member of Alzheimer's Australia Consumer Dementia Research Network, says one of the main reasons he was able to get an early diagnosis and treatment was access to a psychological assessment.

"The neuropsychological testing was very extensive and detailed; it gave me lots of information about how dementia was affecting my memory," Leo says.

However these tests can be expensive and difficult to access. Leo paid $800 for the testing which is not covered by Medicare or private health insurance. Eventually he had to travel to his nearest capital city for the test after waiting months for an appointment at his local memory clinic.

Alzheimer's Australia says limited access to specialists is a key issue, especially in regional and rural areas. In their submission to the committee they recommend the federal government work with the states to improve access to publicly funded specialists and memory clinics in all regions of Australia.

The Australian Psychological Society wants a greater use of psychological testing to help overcome these access issues, as specialised psychologists are more easily deployed in remote areas where expensive specialist medical equipment may not be available.

While improvement of early diagnosis rates is complicated, a number of dementia patients have told the committee it is crucial not just for improving treatment but also to let them understand their symptoms and move on with their lives.

"As hard as it may seem to believe, receiving the diagnosis was a relief to me," Leo says.

"My biggest fear was that doctors were going to tell me that nothing was wrong with me when I knew something was seriously wrong; I would have thought I was going crazy … at least I know what I'm dealing with."

Fellow patient Robert had to push for a diagnosis after initially having his symptoms dismissed by doctors. His persistence paid off as he was diagnosed at a relatively early stage, enabling him to have a say about lifestyle decisions and plan for his future.

But Robert believes he would have benefited even more from an earlier diagnosis and better access to support services.

"Had the diagnosis been in 2006 when I first became aware of the changes I would have had a much greater capacity to make decisions and therefore more choices from which to make them," Robert says.

"I would not have found it necessary to sell my accounting practice. Even now I am still able to perform some accountancy functions and it could have been reorganised to allow my continuing but in a different capacity."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"Early diagnosis helps families to negotiate amongst themselves the distribution of care"

A common theme in many submissions to the parliamentary inquiry is that early intervention allows for greater financial independence, enabling dementia patients to stay in paid employment longer and reducing the cost impact on families and ultimately the community.

With dementia estimated to cost the health system more than $6 billion per year, helping patients stay in the workforce and out of care has become a priority for governments.

As part of its 'Living longer, living better' aged care reform package, the federal government has allocated additional funding to support early diagnosis and other dementia services aimed at reducing the need for residential care.

For each year a dementia patient is able to live independently of residential care, the health system saves an estimated $100,000.

But as a strategy, ageing at home depends on the availability of carers. With carers often facing financial disadvantage, poorer physical and mental health and less social contact, it can be difficult for people to persist with the responsibilities of caring.

Carers Australia, the national peak body representing Australia's 2.6 million carers, says carers for people with dementia face a particularly difficult struggle as they cope with both the physical and mental decline of the person in their care.

"The strains on dementia carers seem especially acute, especially in later stages of the disease when increased

supervision, personal care and often physical exertion are required and when behavioural and cognitive changes caused by the disease can be a source of great distress within the family," Carers Australia says in its submission to the committee.

The 'Living longer, living better' package acknowledges this strain and includes support to carers in the form of more funding for respite care and counselling support.

While recognising the government program will streamline and expand carer services, Carers Australia says much more needs to be done to support carers in the future.

"In particular 'Living longer, living better' has little to say about helping people to combine caring with paid employment. For what many people will be seeking is not just support to help them in their caring, with an occasional break in the form of a few days respite each month, but arrangements which allow them to genuinely combine caring with paid work, even to the point of not sacrificing a career.

"It is likely that if such caring and work combinations are not possible many people will be discouraged from caring."

As well as assisting carers cope with the strain, Carers Australia says the government should be giving families the skills to assist with the early diagnosis of dementia.

"They are often the first to notice cognitive decline, changes in mood and behaviour and changes in the person's care needs associated with the onset of the disease," Carers Australia says.

"However, they can only play this role if they are aware that the changes they notice are changes which are commonly experienced by people with dementia rather than, for example, being assumed to be a consequence of ageing. Unfortunately many people are not aware of the early symptoms of dementia."

The benefits from helping families improve the rate of early diagnosis are likely to extend beyond better treatment outcomes for the dementia patient themselves.

"Early diagnosis helps families to negotiate amongst themselves the distribution of care and other responsibilities and to plan for the future, including about life's priorities – caring, career and other goals. There is a much better chance that life will be manageable."

LIVING BETTER:
An enjoyable life is still possible for dementia sufferers

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Alzheimer's Australia reports that as many as two-thirds of people with dementia live and die with the condition without ever being diagnosed.

They say the false beliefs that all memory problems are a normal part of ageing and that nothing can be done to treat dementia often leads to symptoms being ignored, and prevents a proper care plan from being implemented.

Alzheimer's Australia is calling on the federal government to fund a comprehensive dementia awareness campaign to address this fundamental lack of understanding in the community.

Dementia patient Robert echoes this call in his submission, saying he feels there is a basic lack of familiarity and discomfort with the disease.

"My wife and I have personally addressed several local groups about my journey with Alzheimer's in order to help people in the community understand that the disease is individual in the way it progresses in the long term, but a very enjoyable life is possible for those who work within the parameters of how the disease affects them and who have the chance to plan their lives around the gradual impingements and limitations," he explains.

Robert hopes the inquiry leads to action that reduces the stigma and misunderstanding that cloaks the condition, lifting dementia out of the shadows and slowing the countdown towards an otherwise imminent health epidemic. •

** Some surnames have been omitted to protect privacy.*

FOR MORE INFORMATION on the House of Representatives Health and Ageing Committee's inquiry into early diagnosis and intervention for dementia visit **www.aph.gov.au/haa** or email **haa.reps@aph.gov.au** or phone **(02) 6277 4145**.