

# Dementia and primary health care

- ⇒ Dementia care is becoming increasingly relevant in Australia as our population ages, presenting challenges for an already stretched health system.
- ⇒ GPs are the first port of call in dementia identification and care, and are the coordinators of dementia identification and management. There is increasing involvement of practice nurses in these processes.
- ⇒ Carers and many health professionals believe early diagnosis is critical, though GPs report diagnosing only for functional necessity such as to prescribe medication.
- ⇒ Referrals for carers to information and support services are often delayed until carers reach 'breaking point', highlighting the need for anticipatory referral processes.
- ⇒ Carers are often called the 'hidden patients' as they suffer from higher physical and mental illness resulting from caregiver burden.

Dementia describes a syndrome associated with a large group of diseases which cause the progressive degeneration in an individual's capacity for intellectual, social, memory and rational functioning.<sup>1,2,3</sup> In 2006, it was estimated there were 181 000 individuals in Australia with dementia, though this is expected to increase two and a half fold to 452 600 in 2031 due to the ageing population.<sup>4</sup> Indigenous Australians have a significantly higher prevalence than all other studied populations.<sup>5</sup> There is no cure for dementia, and drug treatment can only offer mild symptom relief.

For those involved in primary health care (PHC), dementia care presents evolving challenges. As dementia diseases progress, individuals require significantly more support from health and community services. Patients in regional, rural and remote areas face increased barriers compared to those in metropolitan areas, as they have limited access to a medical workforce with skills in dementia management and inadequate local support services.<sup>6</sup> To address this growing challenge, the management of dementia in PHC requires the most effective use of time, financial and workforce solutions.

## The role of the GP and practice nurse in dementia care

GPs are usually the first health professionals consulted when dementia is suspected by patients and families.<sup>7</sup> As such, they generally coordinate the identification and diagnosis of dementia, are responsible for the ongoing management of the illness, referral to other health specialists and providing support and health promotion advice to both the patient and the carer.<sup>8,9,10</sup>

Practice nurses (PNs) are increasingly involved in the identification and management of dementia. In many cases they assist in assessment processes, medication and behavioural management, support for patients and carers and networking with community services.<sup>11,12</sup> However, recent research suggests some PNs are unsure of their prescribed roles and responsibilities in the diagnosis and management of dementia and desire best practice guidelines which include their profession. PNs identify barriers to optimal care as time, lack of GP

acknowledgement, patient resistance to the diagnosis and its consequences, and lack of knowledge of patient functioning outside the general practice environment.<sup>11</sup>

## Early GP diagnosis is critical to providing quality care

Identification of dementia generally occurs via informal means rather than by formal testing. GPs and PNs consider family or spousal identification of behavioural or cognitive changes in patients as a trigger to initiate assessment.<sup>7,11,13,14</sup> Incidents such as missing appointments, poor self care, and social withdrawal are also warning signs.<sup>1,9</sup>

Case studies indicate that initial investments of time in formal diagnosis and the development of management plans pay off in the long-term through better care outcomes for the patient and their carer.<sup>10</sup> However, in Australia and internationally, time and money constraints continue to routinely be identified as barriers to the identification, screening and diagnosis of dementia.<sup>1,8,11</sup>

Research in Australia has indicated GPs' reluctance to make a formal diagnosis of dementia diseases, unless necessary for referral, or access to medication through the Pharmaceutical Benefits Scheme (PBS).<sup>1,8,11,14,15</sup> In this context, GP reluctance has been attributed to patient factors including the stigma attached to the diagnosis, the damage or loss of patient relationships<sup>11,15</sup> and concern about the patient's emotional reaction to the diagnosis.<sup>15</sup> These same issues have been noted by practitioners in the US and Canada.<sup>13,16</sup>

Perhaps as a consequence, the use of screening tools tends to be sporadic. There is agreement that the most popular tool, the Mini Mental State Examination (MMSE)<sup>17</sup> is of limited

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use in the PHC context beyond its role in accessing medication in the PBS, due to a perceived lack of sensitivity in detecting early cases of the dementia. Therefore, GPs often use clinical judgement to identify cases before the patient falls in the MMSE dementia-affected range.<sup>11,14,15</sup>

A recently developed screening tool, the General Practitioner Assessment of Cognition (GPCOG),<sup>18</sup> takes less time to administer than the MMSE<sup>18</sup> but provides only marginally better success rates in diagnosis<sup>19</sup> without the advantage of assisting in the prescription of medication. A promising feature of new tools such as the Rowland Universal Dementia Assessment Scale<sup>20</sup> and Kimberly Indigenous Cognitive Assessment<sup>21</sup> is their appropriateness for use with those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds.<sup>5,19</sup>

## The importance of referral

Aged Care Community Assessment Teams (ACAT), Alzheimer's Australia, day centres and other community services can provide or access valuable support and services for those with dementia and their carers.<sup>8,11</sup> However, carers often expressed a desire for more information or faster referral to services, reporting they felt these aspects were often ignored by health professionals.<sup>1,14</sup> Referral to services to assist in the care of the patient was hindered by a delayed diagnosis process.<sup>1,7,14,15</sup> Carers of people with dementia tend not to request referral-relevant assistance until they reach 'boiling point'.<sup>11</sup> However the long waiting list for the community services mean this is often too late. This highlights the need for anticipatory action by the GP with the carer early in the diagnostic process.

## A focus on carers enables quality long-term care

The carer's role is critical in the management of patient care, though they are called the 'hidden patients' suffering as a consequence of their highly stressful and sometimes unrewarding role.<sup>13</sup>

Prevalent themes in the stories of carers are concerns about the future, a lack of time for themselves away from caring, high stress levels, and a lack of control over their lives.<sup>8</sup> The importance of maintaining the health and wellbeing of carers is now recognised by health professionals.<sup>1,4,10,11,13</sup> Many carers have the same GP as the person with dementia<sup>8</sup> which provides GPs with greater opportunities to monitor the wellbeing of both individuals. Carers recognise the caring role as having a direct impact on their health, and suffer from higher rates of illness than the general population.<sup>4</sup>

Carers identify the need for more information about dementia and its management, swifter diagnoses, and earlier access to support services which enable them to care for their family member. Both Australian and international guidelines stress the importance of anticipatory action regarding support for carers,<sup>9,13</sup> however this rarely occurs.<sup>1,7,14,15</sup> A focus on cohesive management plans, including swift identification and referral will relieve the burden for the carer, and improve care for the patient.

## Organisations and research centres to watch

- ⇒ Alzheimer's Australia: <http://www.alzheimers.org.au/>
- ⇒ Dementia Collaborative Research Centres: <http://www.dementia.unsw.edu.au/>
- ⇒ Department of Health and Aging dementia resource guide: <http://www.health.gov.au/internet/main/publishing.nsf/>

[Content/ageing-dementia-resource-guide.htm](http://www.health.gov.au/content/ageing-dementia-resource-guide.htm)

⇒ National Health and Medical Research Councils dementia-related research funding: <http://www.nhmrc.gov.au/grants/dataset/priorities/alzheimers.php>

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