



**Australian
General Practice
Network**

*Delivering local health solutions
through general practice*

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**Australian General Practice Network
submission to the House of
Representatives Standing
Committee on Health and Ageing**

***Inquiry into Dementia: Early
Diagnosis and Intervention***

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Australian General Practice Network

PO Box 4308

MANUKA ACT 2603

Telephone: 02 6228 0800

Facsimile: 02 6228 0899

www.agpn.com.au



The Australian General Practice Network (AGPN) currently represents a network of 106 general practice networks (GPNs) as well as eight state based entities. AGPN and its members are collectively known as the Network. More than ninety per cent of general practitioners (GPs) and an increasing number of Practice Nurses and allied health professionals are members of their local general practice network. The Network is involved in a wide range of activities focused on improving the health of the Australian community including health promotion, early intervention and prevention strategies, health service development, chronic disease management, medical education and workforce support.

The Network is currently in transition, providing the foundation for the establishment of the new national network of Medicare Locals (MLs). MLs are regionally-based primary health care organisations responsible for supporting greater coordination of primary health care services regionally, identifying and addressing local service gaps, driving quality improvement in primary health care and helping to deliver on the goals of the Primary Health Care Strategy including prevention and better self-management of chronic disease.

AGPN will soon establish the Australian Medicare Local Alliance, the national body for the establishing ML network, which will provide leadership to support MLs in driving change management at a regional level, and facilitate high quality performance through MLs.

Australian General Practice Network
PO Box 4308
MANUKA ACT 2603
AUSTRALIA

Telephone: +61 2 6228 0800
Facsimile: +61 2 6228 0899
Email: agpnreception@agpn.com.au
Web: www.agpn.com.au

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Executive Summary

The Australian General Practice Network (AGPN) welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Health and Ageing inquiry into early diagnosis and intervention of dementia.

Current estimates suggest that more than a quarter of a million Australians are living with dementia and that the direct cost associated with providing health and aged care services for people with dementia total over \$6 billion per year.^{1 2} As our population continues to age, the prevalence and societal impact of dementia will increase. It is estimated that by 2050 nearly 1 million Australians will be living with dementia.³

Whilst currently there is no cure for the primary causes of dementia, or treatment that can prevent progression, there are many potential clinical and personal benefits of timely diagnosis and management, and opportunities to enhance the wellbeing of patients and their carers. Further, timely diagnosis and intervention can help reduce the burden posed by dementia on the health and aged care systems.

Despite the well-established benefits associated with timely diagnosis and management, no diagnosis, delayed diagnosis and suboptimal management is common in Australia. It is estimated that the majority of people living with dementia never receive a formal diagnosis and for those who are diagnosed there is an estimated average lag of over 3 years between when symptoms are first noticed by the patient or their carer and when a diagnosis is confirmed.⁴ We can, and must, do better.

AGPN's response to this inquiry focuses on dementia diagnosis and management in primary health care (PHC). Whilst it is acknowledged that diagnosis and management often involves specialists or tertiary care providers, the primary health care setting is the key focus of Network activity and the Network's key area of expertise. PHC is also commonly the first point of contact for patients seeking assistance. Further, PHC providers, particularly General Practitioners (GPs) and Practice Nurses (PNs), often have established relationships with patients, making them well-placed to recognise early symptoms of dementia. For many patients diagnosed with dementia, the primary care system will also provide the majority of their medical care and the GP will assume responsibility for the coordination of their care for much of their journey.

Despite this, there are barriers to timely diagnosis and management of dementia through PHC settings. These barriers are associated with: the skills, knowledge and attitudes of PHC professional; the operation of broader PHC system; and consumer help-seeking behaviours. This submission outlines AGPN's recommendations for addressing these barriers and establishing the conditions necessary to facilitate timely diagnosis and management. Key recommendations include:

¹ Deloitte Access Economics (2011). *Dementia Across Australia, 2011-2050*. Accessed 8/05/2012 via: http://www.fightdementia.org.au/common/files/NAT/20111014_Nat_Access_DemAcrossAust.pdf

² Access Economics (2010). *Caring Places: Planning for Aged Care and Dementia: 2010-2050* Accessed 8/05/2012 via: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

³ Deloitte Access Economics (2011) *op cit*.

⁴ C. Speechly (2008.) 'The pathway to dementia diagnosis.' *Medical Journal of Australia* 189; 487-9.

- establishing a comprehensive national education and training program for GPs and PNs focused on increasing their knowledge, skills and confidence relating to:
 - recognition of symptoms of dementia
 - effective application of appropriate diagnostic assessments and
 - best practice dementia management
- facilitating the establishment of local networks linking PHC, specialists, aged care, social care and support services, and the development of locally-relevant care pathways
- increased remuneration through the MBS for GP 'house-visits' and services provided in RACFs to more realistically compensate for time associated with providing these services
- introduction of PHC funding models that support health professional consultations with carers of dementia sufferers
- establishment of a program to provide dedicated coordination support from an appropriately qualified health professional to support people with dementia with complex care needs
- a well-crafted and well-targeted awareness campaign to increase consumer awareness of dementia symptoms, encourage consumer help-seeking behaviours and help reduce the stigma associated with dementia
- enhanced investment in community-based information and support services for people with dementia, their families and carers.

About the Australian General Practice Network

AGPN is the national organisation representing 106 general practice networks (GPNs) and eight state-based organisations (SBOs). AGPN and its members are collectively known as the Network. AGPN coordinates and disseminates general practice and other primary health care programs through the Network, including those with a focus on:

- Chronic disease management
- National primary mental health care initiatives
- Indigenous health
- Immunisation
- eHealth and information management
- Prevention and lifestyle modification
- Nursing in general practice
- Quality use of medicines

GPNs represent the community-based infrastructure which enables general practice to provide services to patients in the community and in their homes. GPNs:

- deliver local health solutions through general practice to ensure all Australians have access to high quality primary health care
- increasingly deliver services directly to patients – particularly through allied health and nursing
- are in tune with their local communities. They understand their communities' health needs and socio-demographics as well as how these two interact - which makes them a solid foundation for strengthening Australia's primary health care system
- are involved in a range of activities including
 - health promotion
 - early intervention and prevention strategies
 - health service development and delivery
 - medical education
 - workforce development and support
 - eHealth and other strategies to connect care.

The Network is unmatched in its locally based support services which penetrate the vast array of communities across Australia – it is the only national, state and regional/local infrastructure of its type.

The Network is currently in transition, providing the foundation for the establishment of the new national network of Medicare Locals (MLs.) MLs are regionally-based primary health care organisations, responsible for:

- supporting greater coordination of primary health care services across their region
- identifying and addressing local service gaps and areas of need

- driving quality improvement in primary health care.

The Government has announced that initial focus areas for MLs will include after-hours services, mental health care and care for older Australians. AGPN has also recently argued, through its submission to the Federal Budget, the merits of using the ML network to support more timely diagnosis and management of dementia through education and training for primary health care professionals and enhanced networking and integration of local primary health care, hospital, aged care and social support services.

The first and second of three tranches of MLs have been established, with the full national network of 62 MLs expected to be operational by 1 July 2012.

The Commonwealth Government has made clear its intention that AGPN will evolve to become the national body for the network of MLs (known as the Australian Medicare Local Alliance – AML Alliance) during 2012. The AML Alliance will provide leadership to support MLs in driving change management at a regional level and driving high quality performance through MLs.

Benefits of timely diagnosis and intervention

As acknowledged through the terms of reference for this inquiry, there are multiple potential benefits associated with timely diagnosis of dementia.

Whilst there is currently no known curative treatment for dementia, there are potential **clinical benefits** associated with timely diagnosis and intervention, which, dependent on the clinical circumstances include the opportunity to:

- treat the reversible causes of dementia
- help slow the progression of dementia through pharmaceutical and lifestyle interventions
- support symptom management through pharmaceutical and lifestyle interventions (many of which are likely to be more effective earlier in the course of disease progression) and minimise the impact of symptoms, for example through the establishment of routines that can help patients and families manage declining cognitive function.⁵

It is expected that ongoing developments in dementia research will see the development of additional pharmaceutical and lifestyle interventions that will aid in delaying disease progression and support more effective symptom management.

⁵ For further information regarding pharmaceutical and behavioural interventions to address dementia symptoms see the Royal Australian College of General Practitioners, [The medical care of older persons in residential aged care facilities](#) (the silver book), accessed on 7/05/2012 via: <http://www.racgp.org.au/silverbookonline/2-1.asp>

Conversely, delayed assessment and diagnosis is often associated with poor medical management of patients with dementia, including under-prescribing of potentially beneficial symptomatic medications.^{6,7}

There are also a range of non-clinical **personal and familial benefits** of timely diagnosis and management of dementia for the patient and their family. Timely diagnosis enables patients and their families and carers greater insight into the symptoms the patient is experiencing and greater understanding of disease progression and what the future may hold. This provides greater opportunity for the patient and their family and carers to 'come to grips' with likely future scenarios. It also provides opportunity for patients and their carers to:

- consider preferred care preferences and plan ahead for future care arrangements in a way that can support their realisation. This includes the opportunity to plan to support a 'good death' that, as far as possible, accords with the patients' wishes, including through the establishment of advance care plans and directives.
- make legal and financial arrangements with consideration of the likely future
- make and implement considered choices and changes relating to personal endeavours, relationships, employment and accommodation, without the pressure of a crisis situation and before the patient's dementia progresses to the point where this consideration may not be possible.⁸

In this sense, timely diagnosis can provide an important opportunity for the patient to experience a sense of self determination at a time when it can feel that their self-agency is being eroded.

Timely diagnosis also provides opportunity for patients and their carers to access information and support services, and establish support networks in a timely manner. These resources can help reduce stress and help enable the patient and their family and carers to optimise independence and quality of life, including through support to employ techniques that can help with management of behavioural and psychological symptoms.

These benefits also apply to residents and providers of residential aged care facilities (RACFs). In this context, timely diagnosis provides opportunity for providers to ensure staff awareness of strategies for managing behavioural and psychological symptoms to reduce stress for the resident and their care team and to maximise the resident's wellbeing.

There are also benefits to the **health and aged care systems** of timely diagnosis and management. It is estimated that currently less than 50% of people with dementia receive a formal diagnosis.⁹ Early diagnosis and effective management of these people is likely to lead to a reduction in unnecessary hospitalisations and crisis interventions, as

⁶ A. Bradford et al. (2009.) 'Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors.' *Alzheimer's Disease and Associated Disorders* 23(4); 306-14.

⁷ H. Brodaty (2005.) Six reasons why diagnosis of dementia does not occur and ten reasons why it is important. Accessed 7/05/2012 via: <http://www.dementia-assessment.com.au/resource/TenReasons.pdf>

⁸ *ibid.*

⁹ Deloitte Access Economics, *op cit*

well as delay their entry into residential or hospital-based care.¹⁰ This reduces the burden on the already over-stretched hospital and residential aged care systems, and enables more cost-effective care to be provided in the community. Whilst cost-benefit analyses with specific regard to the Australian context have not been undertaken, international studies indicate significant potential reductions in Government expenditure associated with early-diagnosis and management.¹¹

Barriers to timely diagnosis and effective management

Whilst the benefits of timely diagnosis and management are well established, there are commonly lengthy delays between onset of symptoms and diagnosis. Research indicates that in Australia consumers first notice symptoms of dementia an average of 1.9 years before seeking medical assistance and that diagnosis occurs, on average, 3.1 years after symptoms are first noticed. These statistics highlight ready opportunities to improve the timeliness of diagnosis.¹²

Koch et al., following a rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care, suggest that these barriers can be categorised as health professional factors, health system factors and factors associated with patients and carers.¹³ The following provides an overview of established barriers to timely diagnosis and intervention using this schema.

Practitioner-level barriers

General practice teams, particularly the GP and practice nurse (PN), who often have established relationships with patients and are commonly the first professionals to whom patients present for medical assistance, are well placed to recognise the symptoms and signs of early dementia and to trigger diagnostic evaluations. However, early detection of dementia is difficult to achieve through primary health care. Key barriers to early diagnosis through primary health care include those associated with the knowledge, skill and attitudes of primary health care practitioners, and can be summarised as follows:

- **Knowledge and skill gaps:** Clinical assessment of dementia can be difficult. It requires the GP's clinical judgment, information from the patient and their families, along with the use of screening tests and, in some cases, referrals to specialists. Evidence suggests that many GPs and PNs have difficulty differentiating signs of healthy ageing from early dementia, and lack knowledge of, and confidence in, the application of assessment tools that can assist in making a diagnosis of dementia. Many GPs and PNs also report feeling inadequately equipped to manage patient care post-diagnosis.¹⁴ This is associated with limited education and skills development

¹⁰ T. Koch et al. (2010.) 'Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review.' *BMC Family Practice* 11 (52).

¹¹ J. Gaugler et al. (2011) 'Early community-based utilisation and its effects on institutionalisation in dementia caregiving.' *The Gerontologist* 45 (2); 177-85.

¹² J. Phillips et al. (2011) [Timely Diagnosis of Dementia: Can we do better?](http://www.fightdementia.org.au/common/files/NAT/Timely_Diagnosis_Can_we_do_better.pdf) Accessed on 7/05/2012 via: http://www.fightdementia.org.au/common/files/NAT/Timely_Diagnosis_Can_we_do_better.pdf

¹³ T. Koch et al. *op cit*.

¹⁴ J. Phillips et al. *op cit*.

opportunities for general practice teams relevant to the diagnosis and management of dementia, but may also be linked to the relatively low caseload of patients with dementia in many practices.

- Poor recognition of the value of timely diagnosis: There is some evidence that some GPs and PNs are not aware of the many potential benefits associated with timely diagnosis, including the opportunity to delay the progression of, and to manage, symptoms, and subsequently do not value timely diagnosis.¹⁵ Poor recognition of the value of early diagnosis and intervention may also be associated with stigma around the disease and a belief that diagnosis may harm rather than assist patients and families, and/or negatively impact the health professional's relationship with the patient.¹⁶
- Low confidence in making diagnosis early in disease progression: There are no available assessment tools that provide for definitive diagnosis of dementia. Research suggests that PHC professionals in Australia and internationally can delay or avoid diagnostic evaluation processes as a result of low confidence in effectively applying diagnostic procedures and fear of false diagnosis. This is particularly true during the early stages of manifestation when symptoms may not be as pronounced and the distinction between 'normal ageing' and cognitive impairment can be hard to define.¹⁷
- Failure to disclose diagnosis: International research suggests that most PHC professionals experience difficulties in providing a diagnosis and that it is not uncommon for PHC professionals to fail to disclose the diagnosis to the patient and their carers or to inform only the family or carers of the diagnosis.¹⁸ It is reasonable to assume that issues related to disclosure of diagnosis may also be experienced by practitioners in the Australian context.

The capacity of primary care teams to support patients and their families in managing dementia effectively post-diagnosis is also inconsistent and, too commonly, limited. There are not always clearly established referral pathways relevant to the local context, and practice teams are often not aware of appropriate care pathways and the availability of local support services.

System-level barriers

Alongside barriers to timely diagnosis and intervention associated with the knowledge, skills and attitudes of PHC professionals there are also barriers associated with the primary health care system. Key system-level barriers may be categorised as those associated with:

- Consultation times: The insidious and inconsistent nature of early stage dementia poses particular challenges for diagnosis in brief primary care consultations where the

¹⁵ *ibid*

¹⁶ T. Koch et al. *op cit.*

¹⁷ *ibid*

¹⁸ *ibid*

GP or other health professional may not observe symptoms. Assessment processes for dementia, and often provision of the comprehensive dementia management support required, cannot effectively be undertaken within the time period associated with the shorter consultation that can be claimed through the Medicare Benefits Schedule (MBS) item. Whilst there are avenues to claim longer consultations under the MBS, for both patient flow and business viability reasons, many practice systems are structured around shorter consultations. Some practices are also not aware of how to effectively use available MBS items to support longer consultations for people with dementia.

- Remuneration for consultations outside the clinic: whilst the current MBS system subsidises GP service provision to patients in their own home and in RACFs, remuneration for these services is inadequate. As a result many GPs/general practices do not routinely offer home visits. Yet home visits are acknowledged as an important means to support early detection, particularly for patients with limited mobility and for those who have not yet acknowledged the symptoms they are experiencing. Similarly, regular and timely access to a GP or PN for residents in RACFs is important to enable observation of behavior changes and other symptoms and timely assessment. Further disincentives to GPs for the provision of services outside their practice rooms is provided by the additional time required to provide these services. This reduces the practitioner's ability to provide services for their presenting practice population, a demand which many practices are already unable to meet.
- Barriers to consultation with carers: Family and carers often observe and acknowledge symptoms when the patient themselves is unwilling or unable to do so. This takes its toll but the wellbeing of the patient and their carers post-diagnosis can often be enhanced through supporting carers to employ techniques to manage behavioural and psychological symptoms and to promote their own health. Currently, however, there is no remuneration available for PHC teams for consults with carers unless the carer is seeking personal medical assistance. There are also (real and perceived) barriers to open communication between PHC professionals and carers regarding a patient's health and wellbeing.
- A lack of clear guidelines, locally-relevant care pathways and local care 'networks': Evidence suggests that many GPs are not aware of diagnostic guidelines for dementia and that in many cases there are not clearly established care pathways relevant to the local context. Associated with this is often poor integration of general practice with other relevant primary health care and specialist services and limited awareness amongst GPs and PNs of locally-available support services and resources. This can mean that care provided does not follow best practice care pathways and may be poorly coordinated, with patients and their carers missing out on needed or potentially beneficial care and support.

Limited education and training for health professionals: Education and training for GPs and PNs related to dementia diagnosis and management is limited during pre-vocational training and there are limited opportunities to undertake professional development

focused on dementia care for practitioners in practice. This includes limited opportunities to enhance skills through consultation with relevant specialists.¹⁹

Patient and carer factors

It is estimated that in Australia, delays in consumers seeking medical assistance with regards to dementia symptoms are common, and average over 18 months amongst those who do receive a diagnosis.²⁰ A range of factors may contribute to delayed help seeking behaviour by consumers, including:

- lack of knowledge and understanding of dementia, and belief that symptoms are a normal part of the ageing process
- denial of symptoms or of what they may signify by the patients or their carers, or failure to acknowledge symptoms (the latter can itself be symptomatic of dementia)
- concern from either the patient or their carers about how the diagnosis will impact on their life, including concerns relating to stigma and the perception of others
- uncertainty about where to seek help. Uncertainty may be on behalf of either the patient or carer, and is complicated in cases where one party endorses help-seeking and the other does not acknowledge a need for assistance.

Improving timely diagnosis and intervention

Supporting timely diagnosis and management of dementia demands comprehensive targeted action to address and overcome barriers in all three of the categories highlighted above, and to establish systems, processes and contexts that facilitate timely diagnosis and effective management.

Primary health care practitioners

To overcome barriers to early diagnosis and effective management of dementia associated with knowledge, skill and attitudes of primary care practitioners, we need to increase the confidence and capacity of general practitioners and primary health care teams to diagnose dementia early in its progression and to provide best practice care for patients with dementia.

AGPN recommends the introduction of a comprehensive national education and training program for GPs and PNs focused on increasing their knowledge, skills and confidence relating to recognising the symptoms of dementia, effective application of appropriate diagnostic assessments and best practice dementia management.

The Federal Government has recently announced its intention to provide education and training for PHC professionals to support early diagnosis and management of dementia as part of its Living Longer, Living Better, aged care reform package. Details of what this entails are not yet available. AGPN advises that education and training initiatives will be

¹⁹ J. Phillips et al. *op cit.*

²⁰ C. Speechly, *op cit.*

most beneficial if they are supported by targeted efforts to establish or strengthen linkages between primary care, aged care, social care and specialist care services at a local level. This will enable the establishment of care pathways relevant to the local context. It will also enable PHC teams to apply learning about best practice in the real life context, and support primary health care teams to extend their knowledge, skills and confidence through consultation with specialists in relation to complex cases. AGPN, in partnership with Alzheimer's Australia has previously detailed a proposal to the Department of Health and Ageing to deliver a comprehensive package to enhance the capacity of PHC teams to provide timely diagnosis and management of dementia that includes a nationally-standardised education component and support for the establishment of local networks and locally-relevant care pathways delivered at a local-level through MLs.

Primary health care system

To provide the system context to facilitate timely diagnosis and management of dementia, and address existing barriers to these outcomes, AGPN recommends:

- a review of remuneration provided through the MBS to support GP 'house-visits' including adjustments to make these financially viable for general practice
- increases in remuneration for GP services provided in RACFs to more realistically compensate for lost clinic time (which equates to lost income in a fee for service environment) associated with travel, service provision and follow-up paper work. Remuneration increases should be accompanied by measures tailored to overcome locally-specific barriers to GP service provision in RACFs, including relationships between RACF clinical staff and attending GPs, and the efficiency of communication systems between GPs, RACFS, community pharmacies and hospital services. Overcoming many of these barriers can be realised by imbuing MLs with both the responsibility and resources to broker GP services for RACFs in their region.
- introduction of funding models to support consultations with carers regarding the health and management of the person they care for, and guidance for practitioners relating to how to provide support for carers in accordance with privacy legislation
- targeted promotion to general practices about how to effectively employ existing MBS items to support comprehensive assessments relating to the diagnosis of dementia and how to use the longer consults required to support effective management of dementia. This should be done in coordination with education and training for primary health care professionals.
- investment to facilitate greater integration and networking of local primary and specialist health services, and social care and support services, to help ensure people living with dementia and their families can access comprehensive and well-coordinated care that optimises the potential benefit of local services. As noted above, AGPN believes that facilitation to establish and strengthen local networks should be provided in conjunction with education and training for PHC professionals, and that MLs, who are charged with regional primary health care coordination, are well-placed to undertake this role.

- establishment of a dedicated coordination support program for those with dementia from an appropriately qualified health professional. The program would:
 - provide support to dementia sufferers with complex care needs who are struggling to manage their condition
 - with oversight the implementation of a care plan
 - assist in self-management strategies and
 - coordinate and monitor various aspects of care, including facilitating access to care where there are practical and financial access barriers.

Lack of service coordination and fragmentation of care can have a detrimental effect on health outcomes and lead to reduced wellbeing and preventable hospitalisation. Conversely, well-coordinated care can promote health and wellbeing; there is good evidence that a dedicated coordination role has a positive impact on patient outcomes and leads to lower service utilisation.

- Consideration be given to the potential benefits of introducing and incentivising advanced dementia training for GPs, including the potential for additionally qualified GPs to prescribe specialist medications

Consumers and carers

Although the research suggests that carer and consumer factors play a significant role in delays around diagnosis there has been little effort to address these barriers in a systematic way. To support more timely diagnosis we need to increase consumer awareness of potential symptoms of dementia, and of the benefits of consulting a GP about these symptoms. We also need to decrease the social stigma associated with dementia and its negative impact on help-seeking behaviours. AGPN believes that effort to address these barriers should include a well-crafted and well-targeted awareness campaign. Consideration should be given to the need to further develop the evidence base in Australia around the factors that cause people to delay seeking help for symptoms of dementia so that an effectively targeted, evidence based campaign regarding dementia can be developed and implemented.

Facilitating timely diagnosis and post-diagnosis management that enhances wellbeing and quality of life for patients and their carers, also requires continued and enhanced investments in effective community-based information and support services for consumers and carers. AGPN recommends enhanced investment in community-based support services provided through the National Dementia Support Program and in respite programs tailored to addressing the needs of clients with dementia.

Carers often play a vital role in providing the level of care and support necessary to assist people with dementia to stay living in the community as their disease progresses. It is often, understandably, the fatigue of carers that can lead to institutionalisation of a person with dementia. Evidence attests to an inextricable relationship between the wellbeing of carers and that of patients²¹. Carers too often have limited access to support

²¹ L. Higginson et al. (1990). 'Palliative care: views of patients and their families.' *BMJ* Vol 301; 277-81.

them to continue their caring role and, at the same time, to care for themselves. Critical to supporting carers maintain their caring role is access to sufficient and timely in-home care for the patient as required. To better support carers, there must also be systems in place to:

- provide ready access to information and education regarding dementia disease progression, symptom management approaches and future planning, including planning for future care scenarios
- provide ready and regular access to flexible respite arrangements that are tailored to meet the needs of patients with dementia
- develop and implement tools to assess carers' health and wellbeing needs, and approaches to address these needs
- ensure carers are involved as much as possible, and with the consent of the patient, in care discussions and decisions
- provide sufficient financial support to enable the carer to perform their caring role.