Dear Sir/Madam,

**Striking a balance: what matters most in general practice**

Thank you for the opportunity to comment on the above consultation. General practice is key to ensuring people with dementia and their carers are well supported. With the advent of the coalition government’s White paper and the proposed move to GP commissioning it is vital that general practice understands the needs of people with dementia and their carers.

This response provides background information on dementia and the challenge it presents to health and social care services. It makes some general comments about what general practice must do to address the needs of people with dementia and their carers and then addresses some specific issues raised within the consultation paper.

**Key Points**

- There are 750,000 people in the UK with dementia and it is often described as the health challenge of the 21st century. Therefore it is important that developments in general practice support good care for people living with dementia and carers.
- GPs play an essential role in supporting people with dementia and their carers. They are often the first port of call for people with concerns about their memory and provide access to a range of other support. GPs are valued by people with dementia because they provide continuity of care across the whole disease trajectory.
- The understanding of dementia among some GPs is insufficient. Given the growing numbers of people with dementia and the increasing importance of primary care it is essential that all GPs are equipped to provide high quality care to people with dementia.
- People with dementia and carers may place more weight on continuity of care than speed of access than people of working age. It is important that the voice of individuals living with dementia is heard in the debate.
1. **Alzheimer’s Society**
Alzheimer’s Society is the leading care and research charity for people with Alzheimer’s disease and other forms of dementia, their families and carers. The Society has expertise in providing information and education for people with dementia, carers and professionals. It provides a helpline and support for people with dementia and carers, runs quality day and home care, as well as funding medical and scientific research. It campaigns for improved health and social services and greater public understanding of all aspects of dementia.

2. **Dementia and health and social care services**
- There are 750,000 people with dementia in the UK. This is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051.\(^1\) One in three people over 65 will end their lives with a form of dementia.\(^2\)
- In the 1990s it was estimated that a GP in the UK with a typical list-size could expect a caseload of 10 and an incidence of 1.6 new patients with dementia per year.\(^3\) Given the ageing of the population, the incidence of dementia at the beginning of the 21st century was estimated to be 10 new cases per 1000 people per year.\(^4\)
- Dementia is a complex condition and people living with the condition require a broad package of care from a range of agencies across health and social care. Dementia is progressive, which means people with dementia and carers are coping with a changing pattern of abilities over time. As the disease progresses, people with dementia will need more support. Eventually, they will need help with all their daily activities.
- At least two thirds of people in care homes have dementia.\(^5\)
- Dementia currently costs the United Kingdom £20 billion each year.\(^6\) This is an average of £25,472 per person with late onset dementia. By 2018 dementia will cost the UK £27 billion per annum.\(^7\)

3. **Policy Context**
**National Dementia Strategy England**
The National Dementia Strategy for England (NDSE) published in February 2009 sets out 17 objectives designed to support people to live well with dementia. All have some relevance to general practice, especially:

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6. Alzheimer’s Society (2007) *Dementia UK*, a report to the Alzheimer’s Society by King’s College London and the London School of Economics
Objective 1: Improving public and professional awareness and understanding of dementia.

Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

Objective 2: Good-quality early diagnosis and intervention for all.

All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.\(^8\)

General practice has a major role to play to ensure that these (and other) objectives are delivered to improve the lives of thousands of people with dementia and their carers. The Society believes that it is an essential role of the General Practitioners Committee to respond to recent public policy developments such as the National Dementia Strategy in their planning and ongoing work.

4. General comments on the consultation

4.1 General practitioners awareness and understanding of dementia

GPs play an essential role in supporting people with dementia and their carers. They are often the first port of call for people with concerns about their memory and provide access to a range of other types of support. GPs are highly valued by people with dementia because they provide continuity of care across the whole trajectory of the disease, have established relationships of trust and can act as advocates and problem-solvers. However, there are well-recognised concerns about the lack of awareness and understanding of dementia amongst some GPs. The General Practitioners Committee in their work must take account of areas where GPs are failing to address the needs of people with dementia and their carers:

- Only one-third of people with dementia receive a diagnosis. GPs are partly responsible for this under-diagnosis. For example, GPs often assume that dementia is a natural part of old age, and therefore may dismiss people’s concerns. In addition, GPs can be reluctant to diagnose dementia; concerns relate to their competency in diagnosing dementia and a lack of availability of resources to offer support post diagnosis.\(^9\)

- The NAO report ‘Improving services and support for people with dementia’ (2007) highlights the continuing failure of GPs to improve their understanding and empathy of people with dementia and their carers

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\(^8\) Department of Health (2009) Living well with dementia: A National Dementia Strategy
• Only 31% of GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia, a decrease since the same question was asked in the ‘Forget Me Not’ report in 2000 (NAO 2007).

• Only 47 per cent of GPs surveyed said they had had sufficient training in dementia management, and almost a third were not very confident in diagnosing dementia. There has been no improvement in dementia knowledge over five years.10

• Only 5 per cent of GPs surveyed had discussed the implications of NDSE with their PCT Commissioners.11

4.2 Early intervention

Alzheimer’s Society believes it is vital that the BMA consider how general practice can better support early intervention in dementia. Early intervention offers an excellent opportunity to support the quality of life of both the individual with dementia and their carer. It enables people to make choices about their future care, as well as make any necessary financial and legal arrangements. Getting the right support in place early may mean that individual can continue live in an environment of their choice with independence and dignity. Early diagnosis and intervention in dementia is also cost-effective.12 Offering support such as services in people’s own homes can delay or remove the need for more intensive institutional support, which inevitably comes at a higher price. These are central concerns in the current economic climate.

The majority of dementia care, however, comes late. Diagnosis is often made later and early interventions are not widely offered. The current system does not deliver early intervention for people with dementia and is skewed towards costly crisis interventions. Given their role as a first point of call for people concerned about their memory, GPs have an essential role in supporting early diagnosis and intervention. Given the growing numbers of people with dementia it is important that the General Practice Committee considers how the development of GP services enables the development of early diagnosis and intervention.

4.3 NHS White Paper

Alzheimer’s Society recognises the significant role GPs will have to play in ensuring quality care for people with dementia and their carers, particularly in light of the recent NHS White Paper. Alzheimer’s Society will be working to influence the developing agenda to ensure that the GP commissioning model addresses the needs of people with dementia. Key areas to influence include:

• There are clearly gaps in GPs knowledge and understanding which need to be urgently addressed if the GP commissioning model is to work for people with dementia and their carers.

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11 Ibid
Alzheimer’s Society believes the extent to which a range of clinicians and other professionals are involved in the commissioning process and work to develop a joined up health and social care services will determine whether or not these radical measures will result in improved care and support for people with dementia.

4.4 Intermediate care
General practice can play an important role to ensure that people with dementia have access to services such as intermediate care. They can also work with intermediate care facilities to ensure they are able to support people with dementia and potentially reduce hospital admissions.

For example, Hunter’s Lodge in Leicestershire is a residential home with multiple registration, based in a rural community. Most of the residents have dementia. The home has strong relationships with the local GP practice, community nurses, therapists and social workers. A two-year pilot arrangement with the PCT has enabled the local GP to purchase one bed for the purpose of avoiding hospital admission. The GP provides a physiotherapist who works with the care staff to ensure the exercise regimes are followed. The GP and community nurses maintain continuity of care after people leave.

Local decision-making could transform dementia care but it is important that people with dementia have access to good quality support regardless of where they live. Availability of services should not depend on where one lives.

4.5 Worried about your memory?
Alzheimer’s Society’s ‘worried about your memory?’ campaign encourages people to seek help when appropriate, and help more people receive a diagnosis as early as possible.

The campaign has been running since 2008 and has had a huge impact:
- 42,500 GPs received information about dementia
- 16,000 people requested a campaign booklet
- Thousands of people downloaded information from the Alzheimer’s Society website
- Overall, the campaign reached an estimated 80,000 people

The Society is building on this success by relaunching the campaign. We have mailed leaflets to GP surgeries for display in their waiting areas. People can request a booklet that has further information about dementia and what to do if you have memory problems by filling in a reply form in the leaflet.

5 Specific comments

5.1 Continuity of care
Several questions contained within ‘Striking a balance’ relate to issues around continuity of care. The Society believes it is essential for people with dementia and their carers to receive high quality care from people who they know and trust. People with dementia and carers often report how much they value
continuity of care. Continuity of care enables relationships to build up and also allows the GP to have an understanding of the family circumstances. While at times speed of access may take precedence over seeing the same GP, people with dementia and carers are likely to place more weight on continuity of care than speed of access than people of working age who do not have a long-term condition. It is important that the voices of people with dementia and carers are not overshadowed by larger, more vociferous groups. For this reason, Alzheimer’s Society believes that future health policy must ensure continuity of care is available.

5.2 Telephone and online communication
The Society is aware that increasing numbers of initial assessments are conducted over the telephone in relation to social care. We have raised our concerns about this, as it is inappropriate for many people with dementia. However, telephone and online support may be appropriate for some people with dementia and carers and allow improved access to advice and support. We would therefore support developments in this area, with the caveat that it does not lead to the exclusion of people with dementia (for example the introduction of online only appointment systems).

5.3 Should GPs be responsible for diagnosing dementia?
As noted, GPs have a very important role in supporting people with dementia. However, there has been considerable debate on whether this should include responsibility for diagnosis dementia or whether this should always lie with specialists. Alzheimer’s Society believes it is important all GPs have a good knowledge and understanding of dementia. However, people with dementia and carers were in general agreement that the diagnosis should be made by a specialist or specialist team. Several people raised the point that this does not have to be a consultant, but could also be a specialist dementia nurse or a GP with a special interest in dementia. In general there is a need to give clarity around what is meant by ‘specialist’. 13

A specialist assessment would also allow the type of dementia to be diagnosed, which is vital as the type of dementia can result in different care and support needs. In addition, a specialist diagnosis may also help to mitigate the risk of ‘diagnostic overshadowing’ (in which the main condition prevents detection or treatment of other problems, such as a learning disability or co-morbidity).

5.4 Other professionals within the GP practice
People with dementia and carers can benefit from a range of services that are now often available within GP surgeries, for example counsellors. In addition, staff from local Alzheimer’s Society services have a presence at a number of GP surgeries, facilitating access to the organisation’s support groups and other services.

Access to a range of services within the familiar and local surroundings of a GP surgery is welcomed, although it should not be a barrier to accessing the GP if they are the most appropriate professional. It is also important that there is good communication between the different professionals within a practice, so that a seamless service is provided.

If you would like to discuss any elements of this response, please do not hesitate to contact me.

Yours sincerely,

Ben Cavanagh
Policy Officer
Alzheimer's Society