

Dementia: What every commissioner needs to know

Guidance on delivering the National Dementia Strategy for England



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Dementia Strategy for England

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1 Introduction

This guide is to help commissioners of health and social care services who need to understand how to effectively commission services for people with dementia and their carers in line with the National Dementia Strategy for England. This booklet summarises:

- the current prevalence of dementia and numbers of people affected nationally and by primary care trust area
- projections on numbers of people with dementia in 2021 nationally and by PCT area
- the estimated financial costs of dementia
- what the draft National Dementia Strategy for England recommends
- how delivering on dementia fits into the broader commissioning agenda
- where to start in commissioning for dementia
- how Alzheimer's Society can support commissioners either through service provision or advice.

There are currently 570,000 people with dementia living in England and as the population ages this number will rise to over 700,000 by 2020.¹

The King's Fund has said that the financial cost of dementia is currently £15 billion per year in England and that by 2018, this cost is likely to rise to over £23 billion per year even if nothing is done to improve the quality and efficiency of services for people living with dementia and their carers.²

Research shows that one in three people over 65 now die with dementia.³

The rise in the number of people living with dementia projected in the next 10–15 years varies significantly by locality. Details of local numbers and projections are included in Appendix 1.

Why a National Dementia Strategy is needed

In 2007, the National Audit Office (NAO) which is responsible for scrutinising the use of public money said that dementia care is as poor as cancer care was in the 1950s.⁴ People often go undiagnosed or are diagnosed too late; there is often little help available for people following diagnosis and people enter long-term care too early. Not

1 Alzheimer's Society, Dementia UK, 2007

2 McCrone, P., Knapp, M. et al. Paying the Price. King's Fund 2008

3 Brayne, C. et al., 2006

4 National Audit Office, Improving services and support for people with dementia, 2007

only did they find that dementia care is leading to poor outcomes for people with dementia and their families, the NAO also found that significant sums of public money are being wasted on bad care. Furthermore, through fieldwork, the NAO found evidence on how a better community service response can shift care out of acute hospitals.

With regard to diagnosis, data from current GP registers of people with dementia shows that only 40% of people with dementia are currently being identified. Set against the expected prevalence rates according to PCT, this figure ranges significantly from 20% to 70%.⁵ Details by PCT area are shown in Appendix 1.

As a result of this evidence, the Department of Health announced in August 2007 that it would work with Alzheimer's Society and a range of stakeholders to develop a National Dementia Strategy for England. At the Public Accounts Committee, the Chief Executive of the NHS and the Director Generals of Commissioning and Social Care told Parliament that dementia was now recognised as a national health and social care priority alongside cancer, heart disease and stroke.

In February 2008 the Department of Health launched Living well with dementia – A National Dementia Strategy and announced £150 million of new funding to support delivery of the Strategy in the first two years of implementation. The policy document sets out a five year transformation plan for dementia under four themes: raising awareness and understanding; early diagnosis and support; living well with dementia and making the change.

Dementia has been included in the NHS Operating Framework for 2009/10 as one of the areas where the Department of Health will expect to see and monitor progress. It states:

The National Dementia Strategy will be a comprehensive framework aimed at driving up standards of health and social care services to improve the quality of life and quality of care for people with dementia and their carers. PCTs will want to work with local authorities to consider how they could improve dementia services.⁶

The Department of Health also said that dementia will be one of only five areas where specific world class commissioning guidance will be produced. This has been issued alongside the Dementia Strategy.

Given the significant numbers of people with dementia using health and social care services, transforming services for people with dementia will be fundamental to achieving world class commissioning, personalisation and the recommendations of the Darzi review⁷.

5 NHS Information Centre, Quality and Outcomes Framework Data, 2007–08

6 Department of Health, The Operating Framework for 2009/10 for the NHS in England, 2008

7 Department of Health, High Quality Care for All, NHS Next Stage Review Final Report, 2008

Alzheimer's Society local area contacts

Alzheimer's Society is the largest and oldest dementia charity in the UK, in contact with more people with dementia than any other organisation. We provide services that are supported nationally with a flexibility to meet local needs. We can help commissioners by providing advice on how local services might be developed to provide better support and care and we can also provide a range of local services that provide choice and put people in control of their lives.

We are well placed to help commissioners deliver the National Dementia Strategy through:

- public awareness campaigns
- workforce development
- dementia advisers
- information
- peer support networks.

Please contact your area team with questions or to discuss in more detail what support Alzheimer's Society can offer you. Please find below contact telephone numbers for Alzheimer's Society area managers.

Central West Area. Berkshire, Buckinghamshire, Hampshire, Oxfordshire and Wiltshire. Telephone Bob Moore, Area Manager on 0118 959 6482

East Anglia and Central Area. Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk. Telephone Paul Dunnery, Area Manager on 01284 753886

East Midlands Area. Derbyshire, Leicestershire, Lincolnshire, Nottinghamshire and Northamptonshire. Telephone Ian Howarth, Area Manager on 01636 642804

London Area. Greater London boroughs. Telephone Maggie Owolade, Area Manager on 020 7264 5980

North East Area. Cleveland, County Durham, Northumberland and Tyne and Wear. Telephone Caroline Burden, Area Manager on 0191 217 3810

North West Area. Cheshire, Isle of Man, Cumbria, Lancashire, Merseyside, Greater Manchester and the Lancaster and Morecambe. Telephone Helen Foster, Area Manager on 01925 572239

Northern Ireland, North and East Area. Telephone Thelma Abernethy, Area Manager on 028 9038 7784

Northern Ireland, South and West Area. Telephone Danny McQuillan, Area Manager on 028 9038 7785

South East Area. Kent, Surrey, East Sussex and West Sussex. Telephone Chris Wyatt, Area Manager on 01403 276649

South West Area. Bristol, Channel Islands, Cornwall and Isles of Scilly, Devon, Dorset, Gloucestershire and Somerset. Telephone Debbie Donnison, Area Manager on 0117 967 2975

Wales, North Area. Telephone Carol Jones, Area Manager on 01248 677137

Wales, South Area. Telephone Sue Phelps, Area Manager on 029 2048 0593

West Midlands Area. Herefordshire, West Midlands, Shropshire, Staffordshire, Warwickshire and Worcestershire. Telephone Elaine Ivis, Area Manager on 01543 255955

Yorkshire Area. East Yorkshire, North Yorkshire, South Yorkshire, West Yorkshire. Telephone Nicki Dyson, Area Manager on 01904 633804

If you have general queries about dementia please visit Alzheimer's Society website alzheimers.org.uk

2 What is dementia?

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease.

Dementia can affect people of any age, but is most common in older people. One in six people over 80 has a form of dementia and one in 14 people over 65 has a form of dementia⁸. Estimates suggest that at least 15,000 people under 65 years of age have dementia, but this number is likely to be a significant underestimate. Dementia is a progressive condition. This means that the symptoms become more severe over time. Understanding how this progression happens can be useful in helping someone with dementia anticipate and plan for change.

Researchers are still working to find out more about the different types of dementia, and whether any have a genetic link. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia. There are very many underlying causes. The main risk factor for most forms of dementia is advanced age, with prevalence roughly doubling every five years over the age of 65. Onset before this age is known as young or early onset dementia. It is very unusual and, in the case of Alzheimer's disease, often suggests a genetic cause.

Dementia is one of the main causes of disability in later life. In a wide consensus consultation for the World Health Organization's Global Burden of Disease report, disability from dementia was accorded a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer. Of course, older people are particularly likely to have multiple health conditions – chronic physical diseases affecting different organ systems, co-existing with mental and cognitive disorders. Dementia, however, has a disproportionate impact on capacity for independent living and its global public health significance continues to be under-appreciated and misunderstood. According to the 2003 World Health Report Global Burden of Disease estimates, dementia contributed 11.2% of all years lived with disability among people aged 60 and over; more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of cancer (2.4%).⁹

The way each person experiences dementia, and the rate of their decline, will depend on many factors – not just on which type of dementia they have, but also on their physical make-up, their emotional resilience and the support that is available to them. Typically, symptoms will include:

8 Alzheimer's Society, Dementia UK, 2008

9 Lopez, Alan D. et al., Global Burden of Disease and Risk Factors, 2006

Looking at a brain with Alzheimer's

SPECT scans can reveal decreases in glucose and oxygen uptake in the areas of the brain specifically affected by Alzheimer's disease and the darker colours in the bottom pictures show these areas.

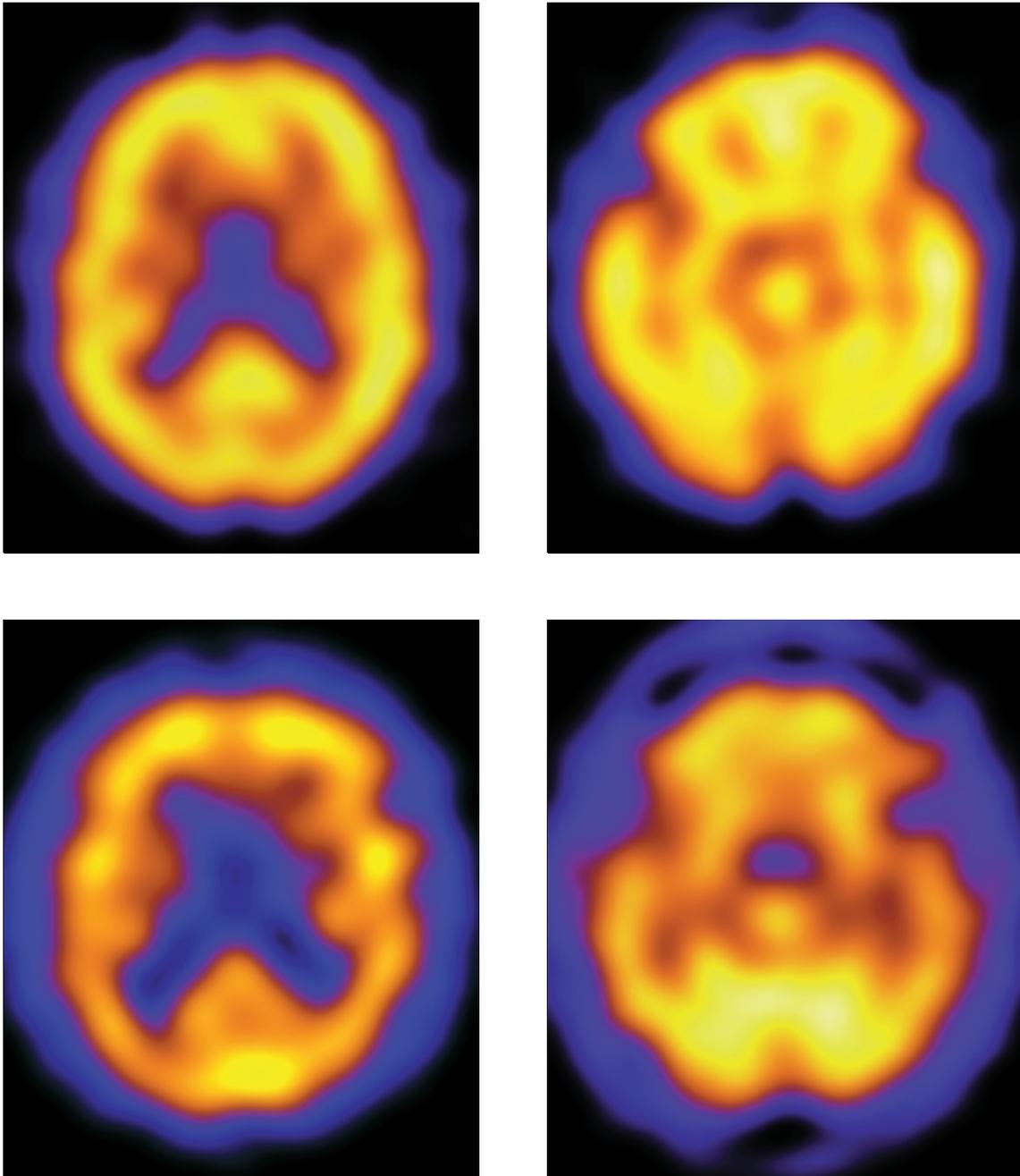


Figure 2.1 Four SPECT scans are illustrated above. The two to the left are from the same area relatively near the top of the brain and show a normal brain (top) and a brain with signs of Alzheimer's disease (bottom). The two SPECT scans to the right are from an area deeper in the brain and also shows a normal brain (top) compared to a brain with signs of Alzheimer's disease (below).

The scans are not to the same scale. (Images courtesy of Prof J O'Brien)

- a gradual and increasing loss of memory – this may start with simple things like forgetting the way home from the shops, or being unable to remember names and places
- mood changes – this happens particularly when the parts of the brain which control emotion are affected by disease. People with dementia may feel sad, angry or frightened as a result
- communication problems – a decline in the ability to talk, read and write.

Types of Dementia

There are different types of dementia caused by different diseases of the brain. Because these diseases affect the brain in different ways, they produce different symptoms. Some of the most common forms of dementia are listed below.

Alzheimer's disease is the most common type of dementia. It changes the chemistry and structure of the brain, causing brain cells to die. In the early stages of Alzheimer's, the person's behaviours may change in very small ways. For example, they may start forgetting things or repeating themselves more often than usual. At first, people often attribute these symptoms to factors such as ageing, stress or bereavement.

In the middle stages of Alzheimer's, the person may need reminders to carry out activities of daily living such as eating, dressing or using the toilet. The person's memory will get worse, and they may have difficulty recognising familiar people or places. Over time, the person will become increasingly dependent on others for help. They are likely



to experience severe memory loss and become increasingly frail. They may have difficulty with eating, swallowing, continence and experience loss of communication skills such as speech.

Vascular dementia is caused by strokes or small vessel disease, both of which affect the supply of oxygen to the brain. Vascular dementia affects people in different ways. It can cause communication problems, stroke-like symptoms and acute confusion. The symptoms that a person experiences as a result of a stroke depend on which part of the brain has been damaged. For example, if the damaged area is responsible for movement of a limb, paralysis may occur. If the part of the brain damaged is responsible for speech, the person may have problems communicating.

When vascular dementia is caused by a single stroke, it is called single-infarct dementia. Vascular dementia is more commonly caused by a series of small strokes. These can be so tiny that the person may not notice any symptoms or the symptoms may be only temporary. This is called multi-infarct dementia.

Vascular dementia progresses in a similar way to Alzheimer's disease, but progression is often 'stepped' rather than gradual, declining suddenly as the person has a new stroke. Progression of vascular dementia may be slowed through the control of underlying risk factors such as blood pressure.

Fronto-temporal dementia is a rare form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change.

In the early stages of fronto-temporal dementia, the person is less likely to become forgetful than in Alzheimer's disease. Instead, their behaviour can change quite dramatically. For example, they may seem more selfish or unfeeling than usual or sexually uninhibited. The later stages are very similar to Alzheimer's disease.

Dementia with Lewy bodies is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills.

This type of dementia has symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement. The person may also experience hallucinations. The progression of this condition can be confusing for carers, as the person's abilities may fluctuate.

3 Prevalence and projections

In 2007, Alzheimer’s Society commissioned the Institute of Psychiatry at King’s College London to evaluate the current evidence base on population prevalence – numbers of people with dementia and projections. Their findings, published in the Dementia UK report, were that prevalence of dementia rises with age. Whereas one in 14 people over 65 has a form of dementia, this number rises to one in six over the age of 80.¹⁰ Further work looking at research data shows that in total, one in every three people over 65 will develop dementia before they die.¹¹

By applying the agreed prevalence data to census data from the Office of National Statistics, it is possible to estimate how many people are currently living with dementia and how many there are likely to be in the future. There are currently at least 570,000 people with dementia in England. This will rise significantly to over 700,000 by 2021. Figure 3.1 shows further projections for the UK as a whole, showing an increase of 156% in the number of people with late onset dementia between 2005 and 2051.

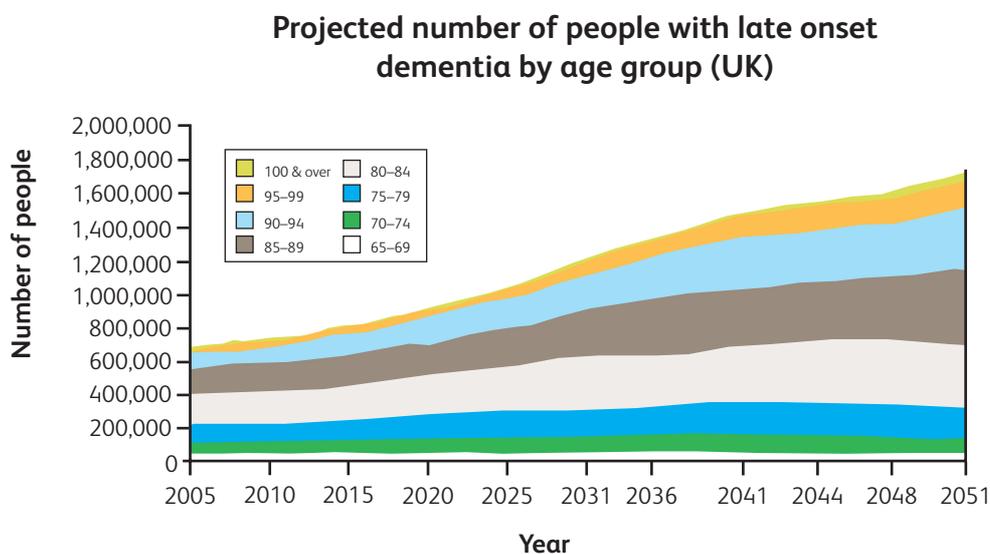


Figure 3.1

The Dementia UK report also estimated numbers of people with dementia by locality. The numbers of people with dementia in the population vary significantly according to locality depending on the age profile of the local population. The older the profile of the local population, the more people with dementia there are likely to be. To see

10 Alzheimer’s Society, Dementia UK, 2007

11 Brayne, C. et al., 2006

estimates of the numbers of people with dementia by locality please see Appendix 1 or visit alzheimers.org.uk/dementiauk

Given the ageing of the population, the number of people living with dementia is going to grow although increases will vary significantly across the country. There are areas where significantly larger increases are predicted and projections for increases to 2021 are as high as 64% in Milton Keynes and 63% in Lincolnshire. Urban areas with younger populations by contrast, will tend to see lower increases. It is important to note that this data is based on prevalence data which does not take into account how changing lifestyles may impact on changes in numbers of people with dementia in future. We know that obesity and sedentary lifestyles can lead to increased risk of dementia. This means that projections are likely to be conservative estimates.

Figure 3.2 shows the residential status of people with dementia. Two thirds are living at home in the community, with one third of people with dementia living in care homes. In care homes, two thirds of people have a form of dementia.

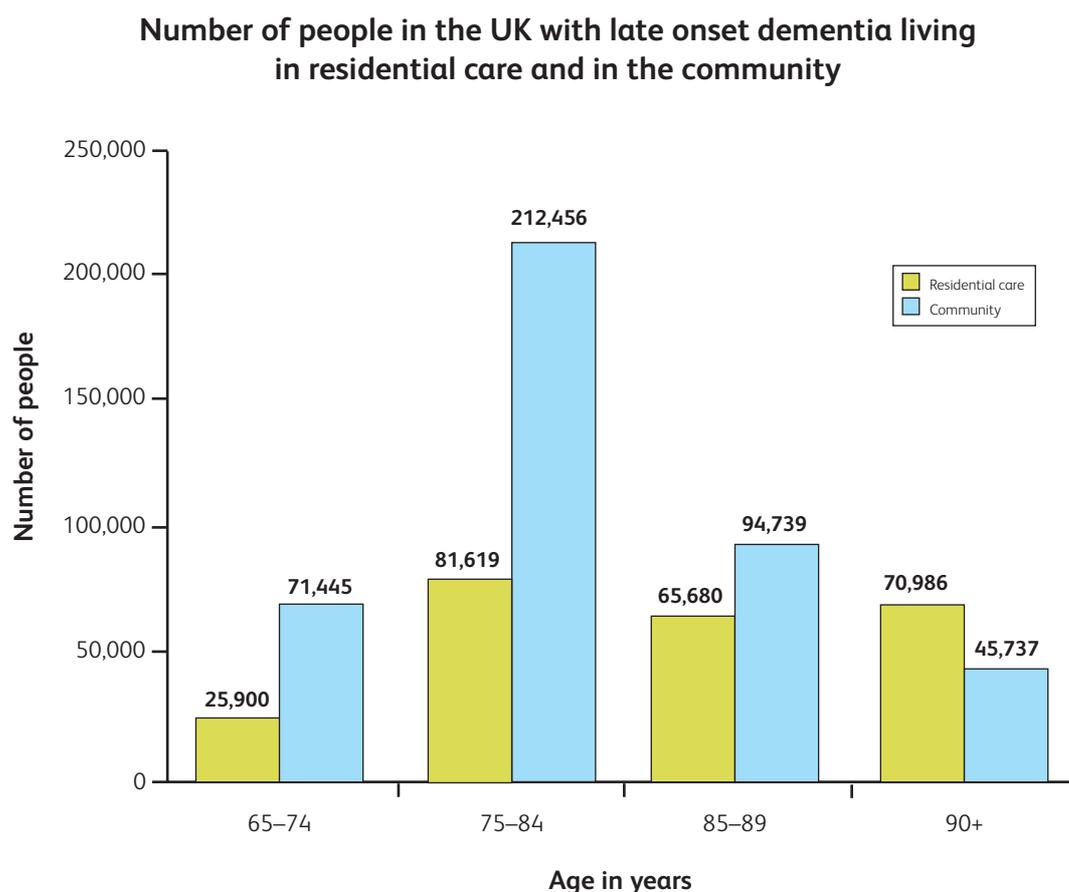


Figure 3.2

4 Costs and quality of dementia care

The financial costs of dementia are significant to the NHS, social care, families and society. In 2007, the London School of Economics estimated that the annual cost of dementia in England is £15 billion per year (more than cancer, heart disease and stroke combined). This amounts to an average of £25,000 per person with dementia per year.¹²

In 2008, in a follow-up report, the King's Fund estimated that this cost will rise to £23 billion by 2018 unless work is done to improve the cost effectiveness of dementia services, reducing hospitalisation and use of residential care.¹³

In October 2008, Alzheimer's Society published *Dementia: Out of the shadows*, a report following detailed research into the experience of people with dementia and their carers in relation to getting a diagnosis of dementia, their subsequent experience and social stigma. The report found that many people with dementia experience significant delay before getting a diagnosis and that when they do get a diagnosis, this is often communicated poorly with little information or support provided. It also found that over 50% of the general public think that there is a social stigma attached to dementia, a higher number than for cancer or heart disease.¹⁴

The National Audit Office published a report in 2007 in which it argued that the current health and social care response to dementia is similar to the poor state of cancer care in the 1950s where cancer went undiagnosed, or was diagnosed very late and there was little help or support provided to people with cancer and their carers. In total, the NAO estimated that only one third of people with dementia are currently getting a diagnosis, meaning that more than half the people with the disease remain undiagnosed.¹⁵ See Figure 4.1

Under the current Quality and Outcomes Framework, as part of the GP contract, GPs keep registers of the numbers of people with dementia on their patient lists. It is possible to take these numbers and compare them to estimated numbers of people with dementia in a PCT area. Data from GP registers of people with dementia for 2007/08 shows that only 40% of people with dementia in England are currently being identified on GP registers. By looking in more detail at this data by locality it is possible to see significant variation in identification rates. The data shows that the proportion of people with dementia identified on GP dementia registers ranges significantly from 20% to 70%.¹⁶ See Appendix 2 and Figure 4.2 for more detail on the prevalence statistics in your local area.

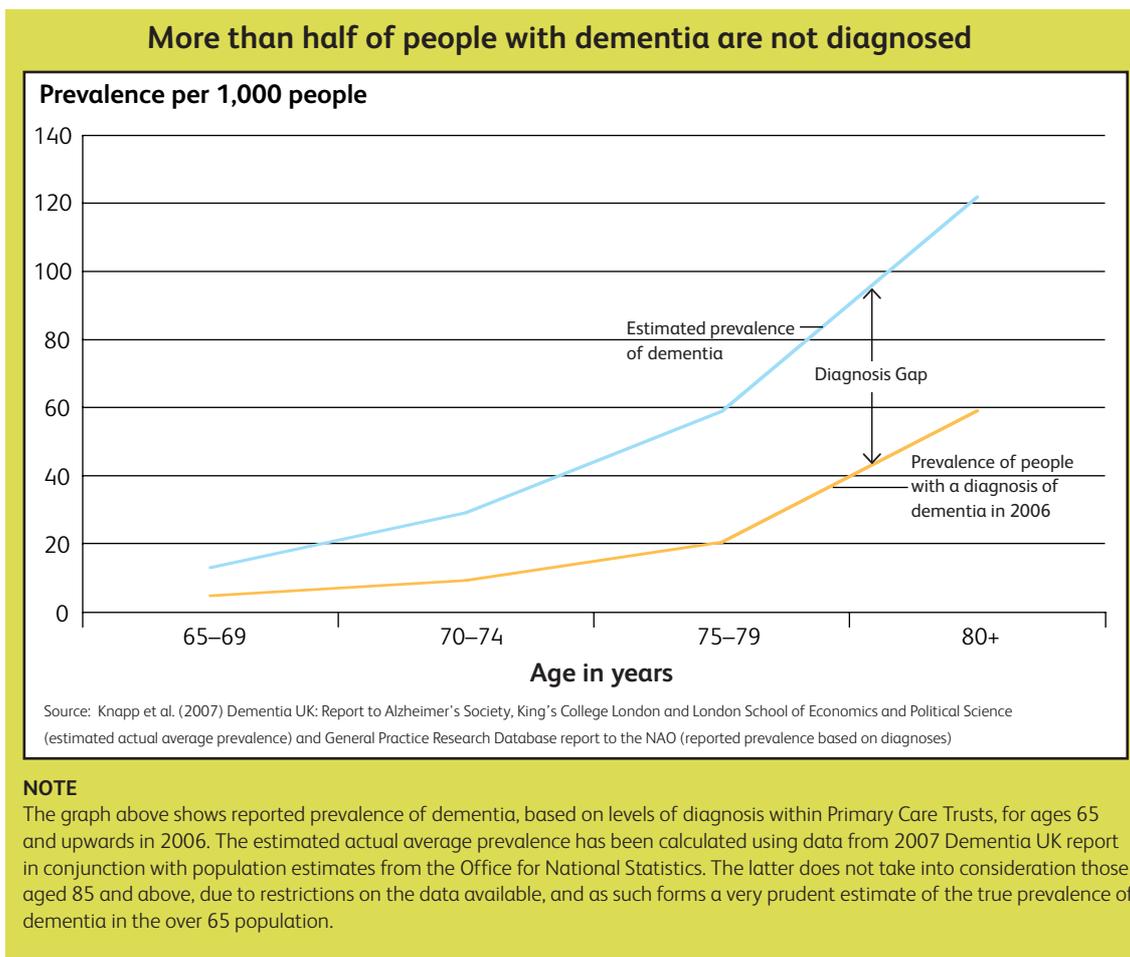
12 Alzheimer's Society, *Dementia UK*, 2007

13 McCrone, P., Knapp, M. et al. *Paying the Price*. King's Fund 2008

14 Alzheimer's Society, *Dementia: Out of the shadows*, 2008

15 National Audit Office, *Improving services and support for people with dementia*, 2007

16 NHS Information Centre, *Quality and Outcomes Framework Data, 2007–08*

**Figure 4.1**

Reprinted with permission from the National Audit Office report 2007

A series of other reports in the last 12 months have also shown that in care homes, where one in three people with dementia live, services are struggling to deliver good quality dementia care.

- 1 Alzheimer's Society Home from home report found that people with dementia socially interact for two minutes in an average six hour period in a care home.¹⁷
- 2 The Commission for Social Care Inspection report See me, not just the dementia found that over half of all care homes surveyed are failing to provide good dementia care.¹⁸
- 3 The All Party Parliamentary Group on Dementia report Always a last resort found that over 100,000 people with dementia are being inappropriately prescribed sedative antipsychotic drugs due to inadequate care.¹⁹

17 Alzheimer's Society, Home from home, 2007

18 Commission for Social Care Inspection, See me, not just the dementia, 2008

19 All Party Parliamentary Group on Dementia, Always a last resort, 2008

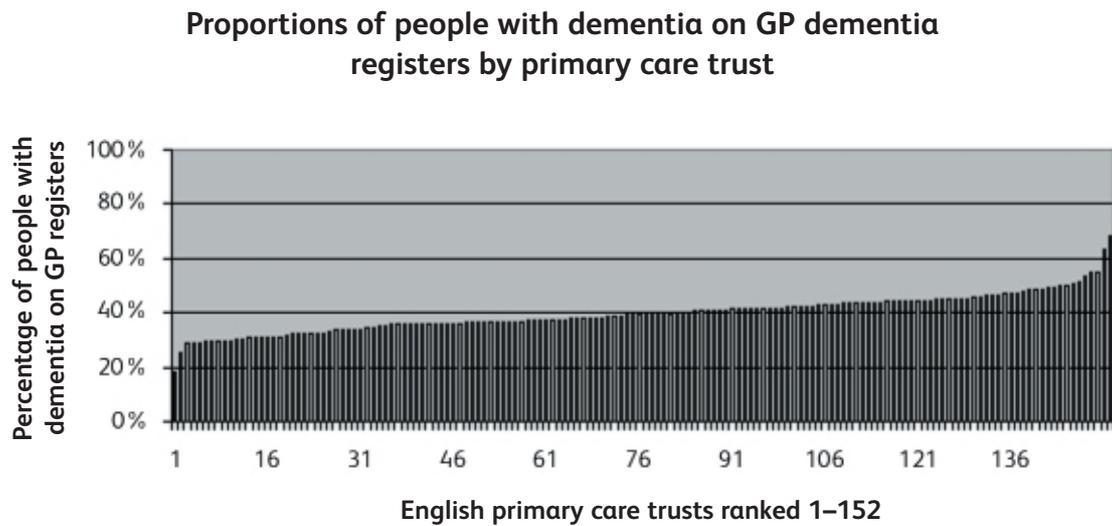


Figure 4.2 (For individual PCT numbers see Appendix 2)

Improving quality across home care, hospital care, intermediate care and in care homes will require significant focus and new investment. However, the NAO found that there are also ways to make money available by providing better care and over time this will release significant investment. As part of a case study in Lincolnshire, the NAO found that it was possible to release £6 million per annum from an acute setting through more effective provision of community dementia services and a partnership response to service delivery.

5 The National Dementia Strategy for England

The National Dementia Strategy for England sets out the Department of Health's vision for the transformation of dementia services in the next five years from April 2009 to March 2014. It has been developed following consultation with thousands of people with dementia, carers and health and social care professionals with an interest in dementia. The overarching purpose of the Strategy is to explain how to transform services for people with dementia and their carers within the five years of the Strategy, to put people with dementia more in control of their lives. To see the full Dementia Strategy go to www.dh.gov.uk/dementia

The Dementia Strategy sets out the key opportunities for transformation under four themes. These are:

- Raising awareness and understanding.
- Early diagnosis and support.
- Living well with dementia.
- Making the change.

There are then 17 specific recommendations which are as follows:

Raising awareness and understanding

1 A public information campaign to improve public understanding about dementia

A public awareness campaign is proposed to improve public understanding about dementia, to emphasise the importance of early diagnosis and to challenge discrimination and reduce stigma. The work on this proposal needs to take place nationally, supported by local campaign activity. The impact of this recommendation will be to ensure earlier diagnosis, putting people in control earlier and potentially delaying institutionalisation and the need for more complex and intensive care. It should also mean less social stigma and more sensitive and effective interactions between people with dementia, services and other people.

Early diagnosis and support

2 Early diagnosis through the development of specialist memory assessment services

The Strategy proposes the development of community based specialist memory services, which can diagnose and treat people with dementia, provide information and signpost to further support. The Strategy uses the Croydon Memory Service as a model of the type of service that could be envisaged and advises that PCTs would be the lead commissioner for memory services working with local authority partners. The impact of this proposal will be to ensure that many more people with dementia get a formal diagnosis and get access to the information and advice they need earlier.

3 Improving access to information about dementia following diagnosis

This proposal identifies the need for better access to information to help people with dementia and carers to be informed about dementia and what help is available. Some information can be commissioned nationally on symptoms of dementia, care needs and types of help available and provided locally. Information on local help available will need to be commissioned and delivered locally. The impact of this recommendation will be to ensure people with dementia and carers can support themselves more effectively and access help appropriately.

4 The development of a dementia care adviser role

One of the strongest messages from people with dementia and carers in the consultation on the Strategy is that people want a single, local, named contact to advise them about dementia and where they can get help. This proposal envisages that dementia advisers would be available in localities as named contacts for people with dementia and their carers from diagnosis to provide information and advice. This is not intended as an intensive outreach role, but one which can support significant numbers of people. This meets the Darzi review²⁰ proposal for people with long-term conditions to have a named contact. Many localities are beginning to commission dementia advisers. In addition, the Department of Health has said that it intends to have a series of demonstrator sites to establish evidence for the most effective models of dementia adviser.

5 Developing peer support networks for people with dementia and their carers

People with dementia and carers have said that they draw significant benefit from being able to meet other people with dementia and carers to share practical tips about how to live with and cope with dementia. Some of these networks already exist as 'dementia cafés' or support groups. The Dementia Strategy envisages people with dementia having access to a larger range of these types of services

20 Department of Health, High Quality Care for All, NHS Next Stage Review Final Report, 2008

commissioned by the NHS and social care. The Department of Health has also announced that it intends to have demonstrator sites to establish evidence for the most effective models of peer support.

Living well with dementia

6 Improved community personal support

Two thirds of people with dementia live in their own homes, either on their own or with a carer. The Dementia Strategy proposes the development of community services that support people with dementia and their carers to remain more independent. In the context of personalisation, this will mean a significant variety of possible support options. In particular, commissioners will want to consider how to upskill their home care workforce to support people with dementia better. Other areas of opportunity include increased use of carer support and access to peer support networks.

7 Implementing the Carers' Strategy for people with dementia

The Dementia Strategy emphasises the importance of short breaks services for people with dementia and their carers to help them cope with living at home together for longer. In line with the Carers' Strategy, the provision of short breaks services in an appropriate setting, which may include at home, will improve quality of life and may delay institutionalisation²¹.

8 Improved care in general hospitals

This recommendation has three core proposals to improve quality of dementia care in hospitals and reduce unnecessary stays.

- Appointment of a dementia clinical lead in hospitals.
- Development of a dementia care pathway in hospitals.
- Creation of older people's mental health liaison teams in hospitals.

The impact of these proposals will be to make hospital environments more dementia friendly, ensure that dementia is identified and managed alongside other conditions, leading to better care, quicker and more effective discharge from hospital into the community with less recourse to long term care.

9 Improved intermediate care for dementia

The Department of Health is developing new guidance on intermediate care for people with dementia to make clear that intermediate care services should be accessible for people with dementia. Providing better access to appropriate intermediate care will ensure that people with dementia, where appropriate, can remain independent in their own homes for longer.

21 Department of Health, Carers' Strategy, 2008



10 Supportive housing and telecare

The Dementia Strategy recognises the importance of supportive housing and telecare options for people with dementia to support them in living at home for longer. It calls for development of the evidence base on these options.

11 Improved care home care

At least two thirds of people in care homes have a form of dementia and the Dementia Strategy proposes three key options for improving quality of care in care homes.

- Appointment of dementia leads in care homes.
- In-reach services into care homes.
- Local authorities contracting for quality with care homes.

If implemented effectively alongside the workforce development and registration and inspection recommendations, this recommendation will deliver higher quality care for people with dementia and create a more stimulating environment for people living with dementia in care, based more on positive interventions and less on the use of medication.

Separately, the Care Minister announced in June 2008 that, alongside the Dementia Strategy, a separate plan will be published in 2009 to reduce the use of antipsychotic medication.

12 Improved end of life care

The Dementia Strategy recognises that end of life care for people with dementia and their carers is often limited. It emphasises that the principles and priorities outlined in the End of Life Strategy²² and best practice in mental capacity and palliative care need to apply to care for people with dementia.

Making the change

13 Improving workforce education

This proposal suggests that there should be a national set of agreed core competencies for dementia which are incorporated into pre- and post-registration curricula and ongoing vocational development. Increased emphasis on dementia skills and training should flow across the health and social care workforces in particular. Although getting the competency framework and curricula developed will take time, the local approach should be to identify priority staff for workforce development in dementia and to prepare learning and development plans. Early work could include dementia awareness training. The impact of this proposal will, over time, be to ensure higher quality care, more efficient care and less institutionalisation.

14 Joint planning

The Dementia Strategy emphasises the importance of joint local planning on dementia to improve access and quality of dementia services. This is particularly important given the complexity of the dementia pathway and the range of professionals and services who need to understand dementia.

15 Performance monitoring and evaluation including inspection

The Strategy proposes that the new system of registration and inspection under the Care Quality Commission needs to reflect the needs of people with dementia. In particular, it emphasises the fact that the majority of people in care homes have dementia. Separately, the Chair of the Care Quality Commission has stated that dementia is going to be a priority area for work by the inspectorate.

16 Dementia research

In the Dementia Strategy, the Department of Health has committed to work with the Medical Research Council and research funders across the public, private and voluntary sectors to develop a plan for the future of dementia research in the UK.

17 Effective national and regional support for implementation

The Department has agreed that there will be support to help localities improve dementia care.

22 Department of Health, End of Life Care Strategy, 2008

6 How implementing the Dementia Strategy will deliver against broader commissioning goals

- Up to a quarter of people in general hospitals at any one time have dementia.²³
- There are 400,000 people with dementia living in the community with differing levels of need for support.
- Two thirds of people in care homes have a form of dementia.
- Dementia in England costs £15 billion a year and is forecast to increase to £23 billion a year by 2018.
- The National Audit Office has stated that the poor state of dementia care is similar to the state of cancer care in the 1950s.

People with dementia are significant users of health and social care services. In the next ten years the number of people with dementia will grow significantly. In addition the biggest growth in dementia will be amongst the ‘oldest old’ – people with dementia in their 80s and 90s with particularly complex needs compounded by a range of co-morbidities. This will put significant pressure on services that are already unable to respond effectively unless change is delivered.

The vision set out in the Department of Health publications, *Our health, our care, our say*²⁴ and *Putting people first*²⁵, and the World class commissioning programme seeks to move the current sickness and crisis revolution response to a more developed system of prevention and community based care where people are in control of their health and care. Given the significant and rising needs of people with dementia, this vision cannot succeed unless the challenge of dementia is tackled. The Dementia Strategy provides the route map for commissioners.

Given the reliance of people with dementia on a large range of health and social care services, getting dementia care right will underpin work to move care out of acute into the community. In addition, the personalisation agenda in *Putting people first* will not be deliverable unless the range of solutions available to support community based care is dementia friendly. Self directed support cannot be secured in the scale envisaged

23 Royal College of Psychiatrists, *Who cares wins*, 2005

24 Department of Health, *Our health, our care, our say: a new direction for community services*, 2006

25 Department of Health, *Putting people first: A shared vision and commitment to the transformation of adult social care*, 2007

across a local health and social care community unless people with dementia are supported to access a larger and more diverse range of services. Alongside this, proposals for a new adult social care system will need to respond specifically to the challenge of dementia if it is to deliver a sustainable solution which guarantees quality of life. This is why dementia must form a key strand in forward plans to deliver independence, well-being and choice.

Is dementia being recognised in strategic frameworks?

The rising policy priority of dementia can be seen across key recent health initiatives. It is recognised in the Darzi work across England where strategic health authority visions have picked up on the challenge. In addition, the NHS Operating Framework for 2009/10 contains the following:

The National Dementia Strategy will be a comprehensive framework aimed at driving up standards of health and social care services to improve the quality of life and quality of care for people with dementia and their carers. PCTs will want to work with local authorities to consider how they could improve dementia services.²⁶

Alongside the Dementia Strategy, the Department of Health has also published specific world class commissioning guidance on dementia, as part of the Dementia Strategy.

At the National Children and Adult Services conference in October 2008, the Secretary of State for Health explained that the National Dementia Strategy would be a central plank of his reform agenda in the years ahead. In addition, Baroness Young, Chair of the Care Quality Commission has said that dementia will be a priority for the new regulator as it takes over the regulation of health and social care in 2009. Delivering on dementia is being recognised as one of the core commissioning challenges.

26 Department of Health, The Operating Framework for 2009/10 for the NHS in England, 2008

7 Where to start

The Department of Health is developing specific guidance to help commissioners implement the Dementia Strategy. However, as a starting point, Alzheimer's Society suggests that some of the following steps will help local commissioners understand how to respond:

Step 1 Understanding the current local dementia need

Map the current needs of your population using local data on people with dementia and through speaking to people with dementia and their carers.

- Good data now exists on estimated numbers of people with dementia by locality and projections to 2021. See Appendix 1 for your local area or go to alzheimers.org.uk/dementiauk
- The other useful source of data available at locality level is quality and outcomes framework data on numbers of people with dementia on GP dementia registers. Comparing this data with the estimated prevalence numbers described above, will give commissioners an understanding of how well their locality is performing in identifying people with dementia. Please also see Appendix 1 for this data.
- Provision of a more detailed picture of needs will require discussions with local people with dementia and carers. Get in touch with your local Alzheimer's Society if you aren't already. If you don't know who to contact, a list of area contacts is shown in Appendix 2.

Step 2 Understanding the care pathway and current quality

It is possible that this work has already been done as part of the work on Darzi regional reviews or as part of annual service planning in your area. If dementia service and quality mapping against a pathway has not yet been done this is a very useful exercise to complete. Local Alzheimer's Society managers can help with this work and put commissioners in touch with people with dementia and carers who can offer thoughts on current local provision compared to the vision and recommendations outlined in the Dementia Strategy. Because people with dementia interact with a large range of services across local communities, it makes more sense than ever to consider delivery and priority planning by drawing together a range of local partners.

Step 3 Decide on priorities for change

Once current needs have been mapped and a full understanding of delivery has been achieved, it should be possible to look at priorities for development. Because of the scale of the challenges surrounding dementia, this will take time. The Dementia

Strategy envisages transformation of support for people with dementia and their carers over the five years of the Dementia Strategy, beginning in financial year 2009/10.

Commissioners will naturally be looking to achieve a range of outcomes and will be using these when deciding how to prioritise action against some of the key recommendations in the Strategy. Alzheimer's Society's response to the consultation on the Dementia Strategy emphasised the key messages for change from people with dementia and their carers who said they wanted, as far as possible, to be put in control of their lives. This meant that they wanted information and support to be able to take control of their condition to get on with living with dementia. The key priorities nationally for people with dementia and their carers were:

- improving public and professional awareness and understanding about dementia
- access to information through dementia adviser and peer support
- getting an early diagnosis.

Step 4 Develop a local implementation plan

Understanding how priorities for change might be implemented is clearly in part dependent on finding resources to deliver change. Some of the changes required can be delivered effectively with only limited resources (eg identifying leaders for change), while others will be more financially dependent (dementia adviser, memory service, care home in-reach). The Department of Health announced that, with the launch of the National Dementia Strategy, an extra £150 million is being made available in total over the first two years to support implementation, with £60 million in year one and £90 million in year two. It will also be important to identify how other funds can be used effectively at local level to deliver change such as transformation grants, carers' strategy funding, end of life care strategy funding and workforce development grants.

Over time, it should be possible to redesign services to deliver better value for money. However, in the short term, it is unlikely to be possible to deliver significant savings for reinvestment, given the low level of services for people living with dementia and their carers.

The Department of Health has said that there will be implementation support for the Strategy and more details have been published alongside the Strategy.

8 How Alzheimer's Society can help you deliver

Alzheimer's Society has built the case for change on dementia and worked closely with the Department of Health to create the first National Dementia Strategy for England. Now, the Society is working hard to support local communities to implement the Strategy and change the lives of people with dementia and their carers for the better.

The Society supports the breadth of the recommendations in the Strategy and will continue to campaign for full implementation. However, alongside that campaigning work, the Society has also been developing our service response to the Strategy recommendations. In particular, the Society has been looking at how its expertise can be used to deliver a range of services for people with dementia and their carers, working in partnership with the NHS and social care professionals to meet all the challenges connected with dementia. We are well placed to do this for the following reasons:

- Alzheimer's Society is the largest and oldest dementia charity in the UK. We have daily contact with more people affected by dementia than any other organisation.
- Thirty years of experience has given us the expertise needed to continuously develop and improve our services.
- We provide information, education, support and care, when they are most needed, to help people live their lives to the full.
- We know that providing choice and putting people in control of their lives gives them the quality of life they deserve.

To help commissioners meet some of the priorities identified by the Dementia Strategy, the Society can offer a range of services. The specific recommendations where the Society is well placed to support delivery of the Strategy are as follows:

- improving public awareness of dementia
- improving the skills of the health and social care workforce
- commissioning of a dementia adviser service
- development of information about dementia and about local services for people with dementia and their carers
- supporting the local development of peer support networks for people with dementia and carers.



To discuss local needs and receive details about the specification and costs of services that Alzheimer's Society delivers, please contact your local service, or your local area manager. Area office contact details are in Appendix 2.

In areas of the Dementia Strategy where the Society will not be delivering a service but where commissioners are looking for additional advice and support, the Society can advise on appropriate sources of information and specialist advice. We will also continue to build the public and political case for implementation at a national and local level.

The Society has a wide range of in-house expertise to advise commissioners on best practice evidence in relation to dementia. In particular it is possible for anyone to access our dementia knowledge centre by visiting alzheimers.org.uk/dementiacatalogue

The following section gives detail on the areas where the Society can help local commissioners to deliver against the National Dementia Strategy for England.

1 Improving public awareness of dementia

The evidence for change

Public awareness about dementia, its symptoms, the importance of getting a diagnosis and the help available is very limited. The result is that people with dementia are diagnosed late and often receive inadequate and inefficient support and care. In addition there is significant social stigma attached to dementia. A

survey by Alzheimer's Society in 2008 showed that 50% of the general public believe that there is a social stigma attached to dementia, a higher number than believe the same to be true for cancer or heart disease.²⁷ Improving public awareness of dementia would improve quality of life for people with dementia and their families by putting them in a stronger, informed position to seek a diagnosis, plan for the future, and make more appropriate use of health and social services. In this work, particular attention will need to be given to both improving awareness amongst hard to reach groups and to reducing stigma.

How Alzheimer's Society can help

Through a network of local branches, supported by our central team, Alzheimer's Society has been working with a range of partners for 30 years to raise awareness of dementia. This year, with funding from the Department of Health, we launched the first national Worried about your memory? campaign into GP surgeries to encourage people to seek help when they recognise symptoms. We are committed to continuing this programme of work.

Local Alzheimer's Society services use a range of our materials, developed to raise general awareness about dementia amongst public and professional audiences, consistent with recommendation 1 in the Dementia Strategy. These include leaflets, booklets, posters and short films and are used as part of local awareness campaigns.

To discuss local needs and receive details about the specification and costs of services that Alzheimer's Society delivers, please contact your local service, or your local area manager. Area office contact details are in Appendix 2.

2 Improving the skills of the health and social care workforce

The evidence for change

The consultation on the Dementia Strategy has shown that one of the biggest priorities for improving the effectiveness and efficient delivery of dementia care is improving the skills of people working across health and social care. People with dementia are not diagnosed early enough and often care either does not exist or does not recognise dementia, resulting in poor outcomes and increased institutionalisation. Improving the ability of the health and social care workforce to respond to dementia will improve quality of life by supporting independence and well-being and reducing over-reliance on services.

How Alzheimer's Society can help

For the past ten years, the Society's learning and education department has been developing training tools that are at the forefront of best practice in dementia care. We have produced a range of practice guides and training resources which

27 Alzheimer's Society, Dementia: Out of the shadows, 2008

can be used in a variety of work environments. We are currently developing a new training programme that will support the full range of training needs from those who need to improve their basic understanding of dementia through to service providers across all sectors. In addition, we have successfully completed a pilot of a new programme, Dementia champions, for the development of dementia care leaders and we plan to extend this programme in 2009.

The Society will work with local commissioners and providers to identify dementia skills development priorities and deliver packages of education and training to meet needs across different environments. In 2009–11, we will be working with curricula bodies and training bodies to develop a nationally agreed set of core competencies for dementia and to ensure that pre- and post-registration, as well as ongoing vocational training, provide the education required for an effective dementia skilled workforce.

To discuss local needs and receive details about the specification and costs of services that Alzheimer's Society delivers, please contact your local service, or your local area manager. Area office contact details are in Appendix 2.

3 Commissioning dementia advisers to act as a named contact to help people access services following diagnosis

The evidence for change

One of the strongest messages that came from people with dementia and their carers during the consultation on the Dementia Strategy was that they would benefit from access to a named person who can give them information and advice about dementia and services available to support them. This is an emerging theme coming from people with a range of long-term conditions and has also been highlighted as a priority in the Darzi review. The development of a dementia adviser service will provide people with a named contact to help them to access the information and advice they need as dementia develops, thus ensuring the efficient use of appropriate services.

How Alzheimer's Society can help

Alzheimer's Society operates through a network of branches in England, Wales and Northern Ireland offering a range of information, education, support and care services. In particular, we have a strong track record in employing information workers who support people with dementia and their families, providing choice and putting people in control of their lives so they have the quality of life they deserve. The Society is keen to work with local commissioners to deliver a dementia adviser service across England, Wales and Northern Ireland. In particular, we will be offering the following to commissioners:

- An information and signposting service, with dementia advisers employed by Alzheimer's Society, working in partnership with local statutory and voluntary services, including memory services and community mental health teams.

Our new service will:

- put people with dementia first. This includes people who have a diagnosis and people who are in the process of seeking a diagnosis
- be based on what people with dementia say they want and need
- provide and support people in accessing and understanding information appropriate to their needs at any time in their dementia journey
- actively seek those who traditionally find us difficult to access
- put people in control – support and promote self-help.

We also welcome the opportunity to work in partnership with others at planned demonstrator sites. To discuss local needs and receive details about the specification and costs of services that Alzheimer's Society delivers, please contact your local service or your local area manager. Area office contact details are in Appendix 2.

4 Development of information about dementia and about local services for people with dementia and their carers

The evidence for change

People with dementia and their carers say that they struggle to access information about dementia at the right time. In particular, they want information about the progression of dementia, the services and support available locally and planning that they might need to live their lives to the full. They want appropriate, accessible information at the right time.

How Alzheimer's Society can help

Through its network of branches, Alzheimer's Society is able to provide information to people with dementia and their carers, either face-to-face or over the phone. Local staff are able to draw on a large range of high quality information materials, produced by Alzheimer's Society and available in printed form and online. Packages of core information are available to health and social care professionals. In addition, our staff are able to provide information about local services that will support people with dementia and their families.

Our national helpline service also provides information about dementia and about local services.

To discuss local needs and receive details about the specification and costs of services that Alzheimer's Society delivers, please contact your local service, or your local area manager. Area office contact details are in Appendix 2.

5 Supporting the local development of peer support networks for people with dementia and their carers

The evidence for change

People with dementia and their carers want to take control of their own lives to care for themselves as much as possible. One of the most effective ways of doing this is through contact with other people living with dementia and their carers. Support groups and dementia cafés already exist in many parts of England and, when provided in a structured way, can provide an important learning and sharing environment which enhances the ability of people living with dementia to cope in a cost-effective way.



How Alzheimer's Society can help

The Society is already providing hundreds of peer support networks for people living with dementia across England. The most common are facilitated support groups for both carers and people with dementia. In addition, dementia cafés provide the opportunity for peer support alongside information giving, in a safe and friendly environment.

The Society works in partnership with health, social care and others, locally and nationally. We would like to work with health and social care partners to deliver a more ambitious, nationwide range of peer support networks providing support in a structured way, integrating advice from health and social care professionals. However, currently, there are not enough peer support opportunities, particularly for those who find it more difficult to access support because of language, culture, isolation, and a range of other factors.

The Society also currently provides an online discussion forum, Talking Point at alzheimers.org.uk/talkingpoint which primarily aims to support people caring for others.

To discuss local needs and receive details about the specification and costs of services that Alzheimer's Society delivers, please contact your local service, or your local area manager. Area office contact details are in Appendix 2.

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Helpful websites

Alzheimer's Society: alzheimers.org.uk/commissioningdementia

Department of Health on dementia: www.dh.gov.uk/dementia

Social Care Institute for Excellence: www.scie.org.uk

Appendix 1. Local numbers of people with dementia, projections and proportions on the dementia register

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Ashton Leigh & Wigan	2,886	4,125	42.9 %	1,141	39.5 %	74th
Barking & Dagenham	1,362	1,262	-7.4 %	423	31.0 %	138th
Barnet	3,707	4,435	19.6 %	1,761	47.5 %	16th
Barnsley	2,564	3,545	38.3 %	1,001	39.0 %	80th
Bassetlaw	1,334	1,931	44.7 %	526	39.4 %	75th
Bath & Somerset NE	2,219	2,833	27.7 %	746	33.6 %	125th
Bedfordshire	3,751	5,753	53.4 %	1,456	38.8 %	82nd
Berkshire E Teaching	3,079	4,103	33.2 %	1,247	40.5 %	68th
Berkshire W	3,852	5,380	39.7 %	1,517	39.4 %	76th
Bexley Care Trust	2,069	2,640	27.6 %	900	43.5 %	40th
Birmingham E & N	3,718	4,081	9.8 %	1,616	43.5 %	41st
Birmingham S	2,671	2,964	11.0 %	1,694	63.4 %	2nd
Blackburn WTH						
Darwen TCH	1,364	1,633	19.7 %	653	47.9 %	15th
Blackpool	2,255	2,648	17.4 %	649	28.8 %	150th
Bolton	2,699	3,553	31.7 %	1,142	42.3 %	51st
Bournemouth & Poole TCH	5,344	6,315	18.2 %	2,332	43.6 %	38th
Bradford & Airedale TCH	5,211	6,701	28.6 %	2,374	45.6 %	23rd

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Brent	1,779	2,202	23.8 %	708	39.8 %	71st
Brighton & Hove City TCH	3,196	3,076	-3.8 %	948	29.7 %	144th
Bristol Teaching	4,125	4,364	5.8 %	1,540	37.3 %	90th
Bromley	3,571	4,327	21.2 %	1,452	40.7 %	66th
Buckinghamshire	4,875	7,103	45.7 %	1,795	36.8 %	98th
Bury	2,124	2,811	32.4 %	887	41.8 %	54th
Calderdale	2,043	2,631	28.8 %	852	41.7 %	55th
Cambridgeshire	5,953	9,225	55.0 %	2,273	38.2 %	85th
Camden	1,402	1,652	17.8 %	619	44.2 %	37th
Cheshire E	5,652	8,353	47.8 %	2,194	38.8 %	81st
Cheshire W	2,911	4,303	47.8 %	1,207	41.5 %	58th
City & Hackney Teaching	1,200	1,124	-6.4 %	436	36.3 %	105th
Cornwall & Isles of Scilly	7,964	11,699	46.9 %	2,654	33.3 %	127th
County Durham	6,040	8,435	39.6 %	2,393	39.6 %	73rd
Coventry Teaching	3,236	3,800	17.4 %	1,268	39.2 %	78th
Croydon	2,944	3,599	22.3 %	1,252	42.5 %	50th
Cumbria	6,632	9,657	45.6 %	3,008	45.4 %	24th
Darlington	1,438	1,898	32.0 %	594	41.3 %	61st
Derby City	2,817	3,551	26.0 %	1,061	37.7 %	89th
Derbyshire County	9,184	13,358	45.4 %	3,339	36.4 %	104th
Devon	12,177	17,518	43.9 %	3,527	29.0 %	149th
Doncaster	3,223	4,508	39.9 %	1,404	43.6 %	39th
Dorset	6,673	9,624	44.2 %	1,952	29.3 %	147th
Dudley	3,432	4,630	34.9 %	1,242	36.2 %	108th
Ealing	2,223	2,408	8.4 %	962	43.3 %	45th
East Riding of Yorkshire	4,759	7,733	62.5 %	1,192	25.0 %	151st

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Enfield	2,476	2,910	17.6 %	905	36.6 %	100th
Essex NE	2,901	4,173	43.8 %	1,312	45.2 %	27th
Essex SE	3,053	4,392	43.8 %	1,686	55.2 %	3rd
Essex SW Teaching	3,511	5,051	43.8 %	1,432	40.8 %	65th
Essex W	2,595	3,733	43.8 %	1,176	45.3 %	26th
Gateshead	2,214	2,782	25.6 %	1,090	49.2 %	10th
Gloucestershire	7,386	10,390	40.7 %	2,825	38.2 %	84th
Gloucestershire S	2,629	4,006	52.4 %	855	32.5 %	129th
Greenwich Teaching	1,798	2,018	12.3 %	800	44.5 %	33rd
Gt Yarmth & Waveney TCH	2,708	4,022	48.5 %	1,352	49.9 %	9th
Halton & St Helens	2,922	3,982	36.3 %	1,269	43.4 %	43rd
Hammersmith & Fulham	976	1,113	14.0 %	349	35.7 %	116th
Hampshire	15,506	22,688	46.3 %	7,109	45.8 %	22nd
Haringey Teaching	1,202	1,322	9.9 %	522	43.4 %	42nd
Harrow	2,021	2,467	22.0 %	703	34.8 %	120th
Hartlepool	1,018	1,454	42.8 %	313	30.7 %	140th
Hastings & Rother	3,462	4,557	31.6 %	1,253	36.2 %	109th
Havering	2,440	3,014	23.5 %	1,015	41.6 %	56th
Heart of Birmingham TCH	2,956	3,219	8.9 %	537	18.2 %	152nd
Herefordshire	2,575	4,048	57.2 %	862	33.5 %	126th
Hertfordshire E & N	5,605	7,645	36.4 %	2,204	39.3 %	77th
Hertfordshire W	5,681	7,758	36.6 %	2,030	35.7 %	117th
Hillingdon	2,070	2,447	18.2 %	675	32.6 %	128th
Hounslow	1,438	1,559	8.4 %	718	49.9 %	8th
Hull Teaching	2,628	3,115	18.5 %	778	29.6 %	145th
Isle of Wight Healthcare	2,577	3,620	40.5 %	837	32.5 %	131st

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Islington	938	938	0.0 %	640	68.2 %	1st
Kensington & Chelsea	1,320	2,037	54.3 %	425	32.2 %	133rd
Kent Eastrn & Coastl TCH	9,191	12,722	38.4 %	3,296	35.9 %	113th
Kent W	8,382	11,603	38.4 %	2,525	30.1 %	142nd
Kingston	1,417	1,594	12.5 %	525	37.0 %	94th
Kirklees	4,209	5,695	35.3 %	1,791	42.5 %	49th
Knowsley	1,363	1,745	28.1 %	700	51.4 %	6th
Lambeth	1,544	1,528	-1.0 %	829	53.7 %	5th
Lancashire Central	5,811	8,135	40.0 %	1,881	32.4 %	132nd
Lancashire E	4,944	6,921	40.0 %	1,774	35.9 %	112th
Lancashire N	4,168	5,835	40.0 %	1,954	46.9 %	18th
Leeds	7,517	9,064	20.6 %	3,170	42.2 %	53rd
Leicester City Teaching	2,606	3,023	16.0 %	1,100	42.2 %	52nd
Leicestersh Co & Rutland	7,194	11,114	54.5 %	2,575	35.8 %	115th
Lewisham	1,661	1,657	-0.3 %	750	45.1 %	28th
Lincolnshire N	2,042	3,133	53.5 %	664	32.5 %	130th
Lincolnshire NE	1,991	2,752	38.3 %	617	31.0 %	139th
Lincolnshire Teaching	9,640	15,698	62.8 %	3,454	35.8 %	114th
Liverpool	4,608	5,113	11.0 %	1,983	43.0 %	46th
Luton Teaching	1,339	1,803	34.7 %	556	41.5 %	57th
Manchester	4,121	4,259	3.4 %	1,762	42.8 %	47th
Medway Teaching	2,257	3,172	40.5 %	825	36.6 %	101st
Mid Essex	3,206	4,612	43.8 %	1,300	40.5 %	67th
Middlesbrough	1,568	2,019	28.8 %	487	31.1 %	137th
Milton Keynes	1,558	2,555	64.0 %	690	44.3 %	36th

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Newcastle	2,895	3,259	12.6 %	1,297	44.8 %	29th
Newham	1,256	1,245	-0.8 %	690	54.9 %	4th
Norfolk	9,602	14,260	48.5 %	3,566	37.1 %	93rd
Northamptonshre Teaching	6,950	10,347	48.9 %	2,774	39.9 %	70th
Northumberland Care TRST	4,177	6,255	49.8 %	1,432	34.3 %	121st
Nottingham City	2,473	2,549	3.1 %	1,208	48.8 %	12th
Notts County Teaching	7,971	11,498	44.2 %	2,902	36.4 %	103rd
Oldham	2,295	2,877	25.4 %	1,023	44.6 %	32nd
Oxfordshire	6,182	8,763	41.8 %	2,521	40.8 %	64th
Peterborough	1,429	2,009	40.6 %	542	37.9 %	87th
Plymouth Teaching	3,162	4,222	33.5 %	1,063	33.6 %	124th
Portsmouth City Teaching	2,155	2,387	10.8 %	956	44.4 %	35th
Redbridge	2,262	2,646	17.0 %	769	34.0 %	123rd
Redcar & Cleveland	1,736	2,411	38.9 %	629	36.2 %	107th
Richmond & Twickenham	1,685	1,877	11.4 %	620	36.8 %	99th
Rochdale Heywd & Middletn	2,243	2,951	31.5 %	891	39.7 %	72nd
Rotherham	2,822	4,047	43.4 %	1,223	43.3 %	44th
Salford Teaching	2,266	2,461	8.6 %	930	41.0 %	63rd
Sandwell	3,079	3,438	11.7 %	1,434	46.6 %	19th
Sefton	4,244	5,499	29.6 %	1,603	37.8 %	88th
Sheffield	6,006	6,968	16.0 %	2,919	48.6 %	13th
Shropshire County	4,017	6,317	57.3 %	1,541	38.4 %	83rd
Solihull	2,240	2,956	32.0 %	835	37.3 %	91st
Somerset	7,640	11,495	50.5 %	2,425	31.7 %	134th

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Somerset N	3,510	5,090	45.0 %	1,095	31.2 %	135th
Southampton City	2,113	2,443	15.6 %	1,072	50.7 %	7th
Southwark	1,563	1,553	-0.6 %	699	44.7 %	30th
Staffordshire N	2,489	3,859	55.0 %	879	35.3 %	118th
Staffordshire S	7,048	10,926	55.0 %	2,538	36.0 %	111th
Stockport	3,201	4,104	28.2 %	1,451	45.3 %	25th
Stockton-on-Tees						
Teach (North Tees)	1,963	3000	52.8 %	745	37.9 %	86th
Stoke on Trent						
Teaching	2,669	3,230	21.0 %	1,072	40.2 %	69th
Suffolk	9,110	13,448	47.6 %	2,688	29.5 %	146th
Sunderland Teaching	3,226	4,286	32.8 %	1,377	42.7 %	48th
Surrey	13,227	17,354	31.2 %	5,182	39.2 %	79th
Sussex E Downs & Weald	6,430	8,463	31.6 %	1,908	29.7 %	143rd
Sussex W Teaching	12,658	16,692	31.9 %	4,413	34.9 %	119th
Sutton & Merton	3,443	3,938	14.4 %	1,269	36.9 %	97th
Swindon	1,687	2,373	40.7 %	826	49.0 %	11th
Tameside & Glossop	2,369	3,050	28.8 %	1,051	44.4 %	34th
Telford & Wrekin	1,423	2,308	62.2 %	485	34.1 %	122nd
Torbay Care Trust	2,775	3,726	34.3 %	845	30.5 %	141st
Tower Hamlets	932	915	-1.8 %	432	46.3 %	21st
Trafford	2,298	2,784	21.2 %	848	36.9 %	96th
Tyneside N	2,590	3,220	24.3 %	1,155	44.6 %	31st
Tyneside S	1,956	2,475	26.6 %	908	46.4 %	20th
Wakefield	3,364	4,707	39.9 %	1,584	47.1 %	17th
Walsall PCT	2,775	3,663	32.0 %	809	29.2 %	148th
Waltham Forest	1,589	1,651	3.9 %	767	48.3 %	14th
Wandsworth						
Teaching	1,996	1,963	-1.7 %	727	36.4 %	102nd

Primary Care Trust area	Estimated number of people with dementia in 2007	Estimated number of people with dementia in 2021	Projected increase in number of people with dementia by 2021	Numbers of people with dementia on a GP register April 2007 – March 2008	Percentage of the numbers of people with dementia on the register	Position of PCT area compared to other PCTs where 1st is the PCT with the highest proportion of people on a register and 152nd is the lowest
Warrington	2,050	3,001	46.4 %	845	41.2 %	62nd
Warwickshire	5,830	8,662	48.6 %	2,409	41.3 %	60th
Westminster	1,431	1,895	32.5 %	529	37.0 %	95th
Wiltshire	5,520	8,367	51.6 %	1,716	31.1 %	136th
Wirral	4,294	5,500	28.1 %	1,775	41.3 %	59th
Wolverhampton City	2,802	3,474	24.0 %	1,016	36.3 %	106th
Worcestershire	6,899	10,519	52.5 %	2,491	36.1 %	110th
Yorkshire N & York	10,851	15,917	46.7 %	4,030	37.1 %	92nd
Total	571,469	775,003	35.6 %	220,246	38.5 %	

Appendix 2. Alzheimer's Society local area contacts

Alzheimer's Society can help commissioners by providing advice on how local services might be developed to provide better treatment and support and can also provide a range of local services to meet local priorities. Please contact your area team with questions or to discuss in more detail what support Alzheimer's Society can offer you.

Central West Area. Berkshire, Buckinghamshire, Hampshire, Oxfordshire and Wiltshire. Telephone Bob Moore, Area Manager on 0118 959 6482

East Anglia and Central Area. Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk and Suffolk. Telephone Paul Dunnery, Area Manager on 01284 753886

East Midlands Area. Derbyshire, Leicestershire, Lincolnshire, Nottinghamshire and Northamptonshire. Telephone Ian Howarth, Area Manager on 01636 642804

London Area. Greater London boroughs. Telephone Maggie Owolade, Area Manager on 020 7264 5980

North East Area. Cleveland, County Durham, Northumberland and Tyne and Wear. Telephone Caroline Burden, Area Manager on 0191 217 3810

North West Area. Cheshire, Isle of Man, Cumbria, Lancashire, Merseyside, Greater Manchester and the Lancaster and Morecambe. Telephone Helen Foster, Area Manager on 01925 572239

Northern Ireland, North and East Area. Telephone Thelma Abernethy, Area Manager on 028 9038 7784

Northern Ireland, South and West Area. Telephone Danny McQuillan, Area Manager on 028 9038 7785

South East Area. Kent, Surrey, East Sussex and West Sussex. Telephone Chris Wyatt, Area Manager on 01403 276649

South West Area. Bristol, Channel Islands, Cornwall and Isles of Scilly, Devon, Dorset, Gloucestershire and Somerset. Telephone Debbie Donnison, Area Manager on 0117 967 2975

Wales, North Area. Telephone Carol Jones, Area Manager on 01248 677137

Wales, South Area. Telephone Sue Phelps, Area Manager on 029 2048 0593

West Midlands Area. Herefordshire, West Midlands, Shropshire, Staffordshire, Warwickshire and Worcestershire. Telephone Elaine Ivis, Area Manager on 01543 255955

Yorkshire Area. East Yorkshire, North Yorkshire, South Yorkshire, West Yorkshire. Telephone Nicki Dyson, Area Manager on 01904 633804