

Leading the fight  
against dementia

Alzheimer's  
Society

# Dementia advisers:

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A cost-effective approach  
to delivering integrated  
dementia care



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# Summary

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## Dementia is one of the biggest challenges facing the health and social care system today.

One person will develop dementia every three minutes, with nearly three-quarters of people with the condition also living with one or more other long-term conditions or disabilities.

Integrating health and social care provides a unique opportunity to transform the lived experience of people with dementia. Furthermore, if we get integrated care right for people with dementia, we get it right for everyone.

The government and NHS England (NHSE) have prioritised access to high quality post-diagnosis support for people living with dementia. This is a focus for national policy and frameworks. In order to meet these ambitions, it is crucial to know what works, as well as ensuring we are getting maximum value for money from public spending.

Alzheimer's Society commissioned NEF Consulting (NEFC) to undertake a social cost-benefit analysis of selected Dementia Adviser services in two locations – Bexley and West Lancashire. (For a description of the dementia adviser role see Section 2 Dementia and integrated care).

**The findings point to a significant return on investment, with every £1 invested in such post-diagnosis support resulting in nearly £4<sup>1</sup> worth of benefits.** If replicated elsewhere this could realise substantial savings.

This briefing sets out the economic and social case for everyone with dementia to have access to a dementia adviser. It also shows how, through integrated care, we can deliver significant improvements to the quality of life for both people living with dementia and their carers, as well as reducing reliance on statutory services.

For every **£1** invested in post-diagnosis support...



...nearly **£4** worth of benefits are created

<sup>1</sup>The SCBA conducted by NEFC found £3.84 worth of benefits.

# 1 The challenge of dementia

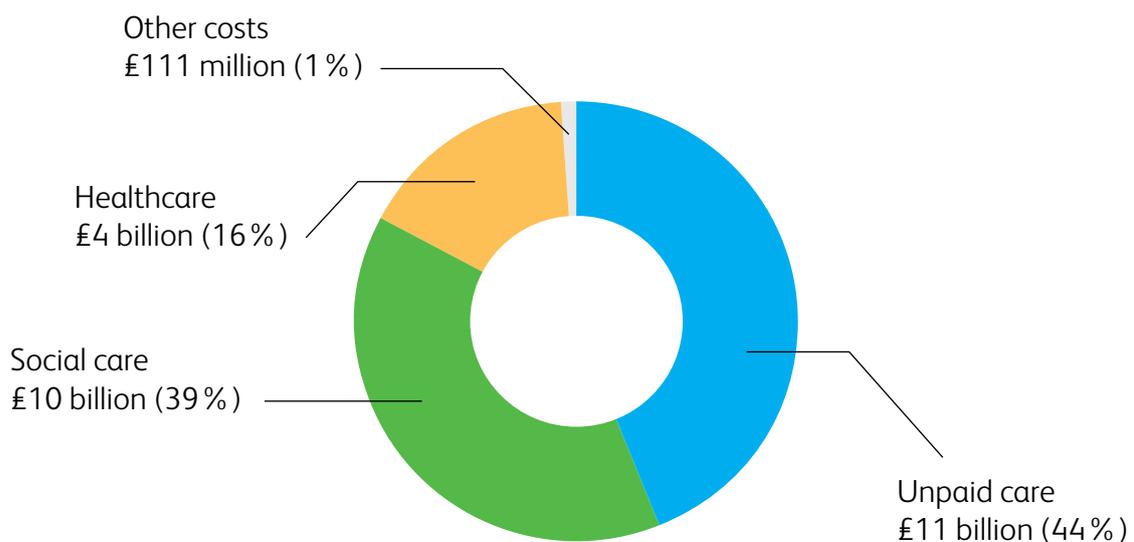
Dementia is the biggest health and social care challenge facing our country today. There are currently over 670,000 people living with dementia in England, and this number is increasing; one person develops dementia every three minutes (Alzheimer's Society, 2014b). We also know that dementia very rarely travels alone and that around 70 per cent of people with the condition have one or more other long-term conditions or a disability (Alzheimer's Society, 2014a).

Alongside this, for every person diagnosed there is someone who then becomes the main carer for their husband, wife, partner, mum, dad or close friend living with the condition. It is crucial that appropriate care and support for carers is also available.

The financial cost of dementia is enormous. Today, it costs the UK economy over £26 billion annually and this is increasing (Alzheimer's Society, 2014b).

This currently equates to over **£30,000 a year per person with dementia.**

Figure 1 Cost of dementia care by location and type



It is easy to see how these costs come about, when we look at the statistics of people with dementia and usage of health and social care (see below):

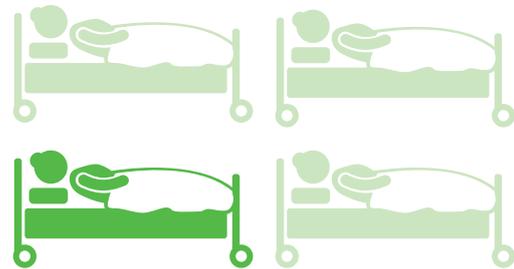
## Two-thirds

of people with dementia live in the community.



**60** per cent

of people receiving homecare have dementia.



**A quarter**

of hospital beds – and in some cases nearly 40 per cent – are taken by a person with dementia.



**70** per cent

of those in residential care have dementia.



**72** per cent

of people with dementia have one or more other long-term conditions and/or disabilities.

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We know currently that much of the cost of dementia care supports a system that is not delivering good value for money. This consequently puts increased financial pressures on an already stretched NHS and social care system, through an absence of accessible and timely support to prevent crisis and high cost intervention.

However, there is potential to reduce costs through more timely care in the community, preventing crisis and reducing pressure on acute services through integrated health and social care.

## Dementia – a priority for the NHS and social care

NHS England (NHSE) has made dementia a priority, both in terms of diagnosis and post-diagnosis support. The 2016–17 NHS mandate states the ambition to:

- ‘maintain a diagnosis rate of at least two-thirds
- improve quality of post-diagnosis treatment and support for people with dementia and their carers’ (Department of Health, 2016a).

The Prime Minister’s Challenge on Dementia 2020 also sets out actions to focus the health and care system towards providing person-centred and meaningful post-diagnosis support, which meets the needs of people affected by dementia (Department of Health, 2015).

Encouragingly, led by GPs, clinical commissioning groups and memory clinics, we have seen significant increase in dementia diagnosis to around two-thirds of people living with the condition now receiving a formal diagnosis, compared to around a third in 2009 (Health and Social Care Information Centre).

The focus now is not only to build on the recent progress of diagnosis rates, but to improve the quality and reach of post-diagnosis support. We want everyone with a diagnosis, no matter where they live or what their circumstances are, to know they can access support; starting with one key point of contact – such as a dementia adviser.

Expanding post-diagnosis support is reflected in the ‘Supporting well’ component of the NHSE Transformation framework: the well pathway for dementia. This sets out a commitment between government, NHSE, local government, the third sector and relevant parties to deliver better quality post-diagnostic support, accompanied by commitment from the Department of Health to ensure concrete action nationally and locally to support this.

The CCG Improvement and assessment framework also indicates the importance of both diagnosis and post-diagnosis support, with the inclusion of an agreed care plan – a vital component of person-centred support, which can be supported by a dementia adviser.

## 2 Dementia and integrated care

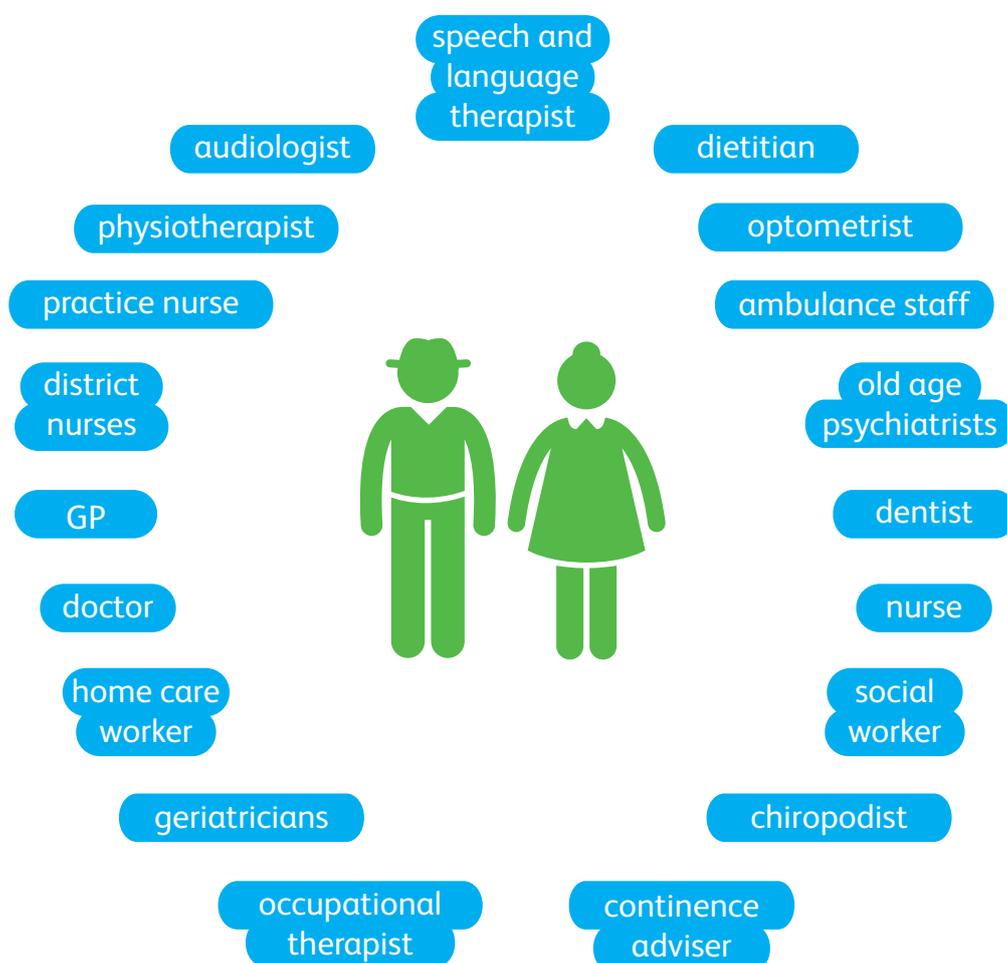
The drive to deliver better integrated health and social care provides a unique opportunity to transform dementia services. Indeed a wide range of initiatives have already started to recognise the importance of dementia and are making dementia a key part of their delivery plans. These include:

- Sustainability and transformation plans
- NHSE new models of care vanguards
- Better care fund programmes.

However, as the diagram below demonstrates, there is a huge range of health and social care professionals to which people with dementia and their carers often require access throughout their journey.

The complexity of the current disjointed system is creating a barrier for people with dementia to access the support they need to live well. The right care in place, at the right time, means that this system can be joined up. Better quality of care for people with dementia leads to improved wellbeing and independence.

**Figure 2** Some of the health and social care services that people with dementia and their carers need to access



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## Current provision of post-diagnosis support

A recently commissioned Department of Health report highlighted Alzheimer's Society as the provider of 75 per cent of commissioned one-to-one support services surveyed (Ipsos Mori, 2016). However, demand for such services exceeds provision across the country. Current access to high quality post-diagnosis support is very patchy, and in many cases does not meet the needs of people with dementia or their carers. This lack of support is reinforced by those on the front line. A survey of GPs conducted by medeConnect found that:

- 70 per cent cite the lack of accessible local services as the main barrier to support for people with dementia
- half don't think their patients with dementia get enough support from the NHS
- over two-thirds (67 per cent) of GPs don't think their patients with dementia get enough support from social services.

Worryingly, the lack of services can also have an impact on diagnosis. The same survey indicated that over a quarter of GPs say they would be less likely to refer people with suspected dementia for a diagnosis if there is not enough local support in place.

The Department of Health's implementation plan to the Prime Minister's Challenge on Dementia 2020 stated:

'We heard a consistent message from people who reported that on receiving their diagnosis, they faced a bewildering future and felt alone in facing this. People with dementia and carers told us of their urgent need for information, advice and support both immediately after diagnosis and to help them through the stages of their journey with dementia.'

(Department of Health, 2016)

Therefore, for people with dementia to live well with the condition we urgently need to increase both the quality and reach of post-diagnosis support.

## Dementia adviser – a dedicated support worker

There are a number of titles or names used for a one-to-one role supporting someone with dementia and their carer, but the most common name is a dementia adviser. They hold the key to delivering high quality post-diagnosis support and integrated care.

The most effective route to accessing post-diagnosis support is by ensuring there is a systematic offer of support from a dementia

adviser. This should come through the memory assessment service, and should be provided for all people receiving a diagnosis. Alternatively someone with dementia can refer themselves to a Dementia Adviser service or can be referred by a GP or community organisation to access tailored post-diagnosis support.

The dementia adviser makes it easier for people with dementia to self-manage, live more independently and seek out the right support at the right time. Dementia advisers deliver high quality, personalised dementia care.

Figure 3 Personalised dementia care from a dementia adviser



## Cost-effectiveness of dementia advisers

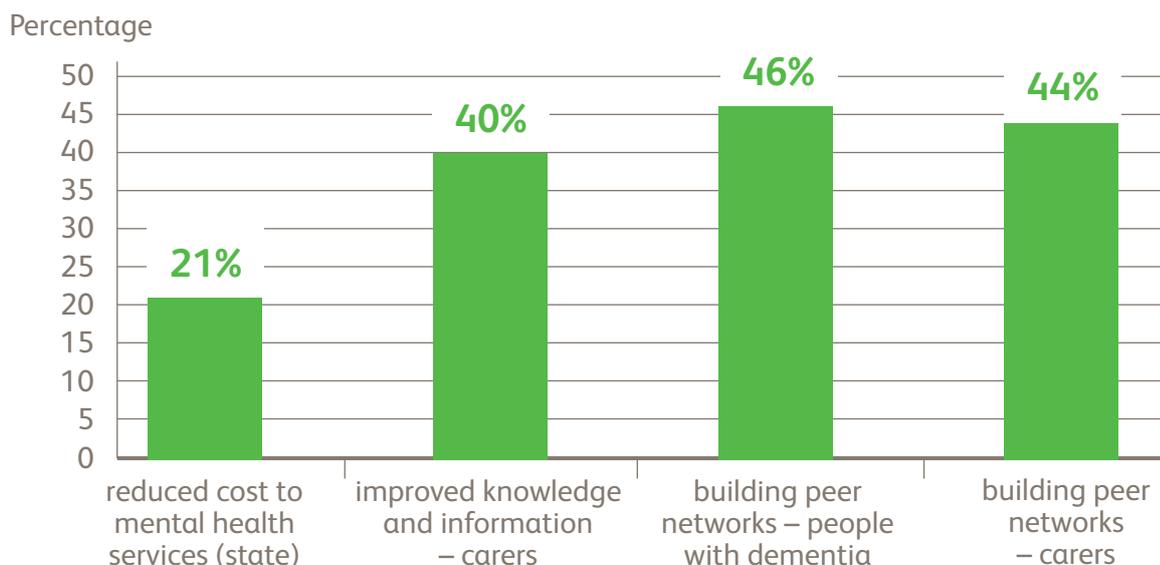
Alzheimer's Society commissioned NEF Consulting to evaluate the dementia adviser role, using services in Bexley and West Lancashire as case study locations.

The SCBA found that the key outcomes with the greatest value created were:

- **a reduction in the cost of mental health services to the state**, by avoiding carer breakdown
- **an increase in information and knowledge for carers** as evidenced by their awareness of support services available in the community, knowledge of strategies that help them to cope with caring for someone with dementia, and their ability to keep the person they care for safe from harm
- **an increase in building peer support for both people with dementia and carers** from having more contact with other people with dementia or carers.

The Social Cost Benefit Analysis (SCBA) conducted showed that for every £1 invested in these services, £3.84 worth of value is created for stakeholders.

Figure 4 Change in outcome by stakeholder



Percentages in figure 4 refer to the scale of change in the outcome attributable to the use of the service. Further evidence in the next section demonstrates what this means in practice, and how these changes may lead to further positive outcomes.

# 3 The impact of integrated care

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Getting integrated care right can have a range of benefits for people with dementia and carers. Three specific areas are outlined below.

## Reduced use of mental health services

The NEFC study found that by improving carers' wellbeing, the Dementia Adviser service could reduce the cost of mental health services by approximately 21 per cent, by helping carers to avoid breakdown. Feedback from carers supports this:

*'I used to get depressed before and I didn't used to ask for help. You have given me a lot of support and introduced me to some wonderful people. I have made lots of new friends.'*

*'I have received invaluable support, information and guidance from my dementia support worker. I do not feel alone and have the confidence to support my mother. I do not know how I would have coped without this help.'*

These findings are reinforced by previous studies that have found a significant correlation between caregiver burden and increased use of mental health services (Tommiss et al, 2009). There is also evidence that the stress levels of carers of people with dementia are particularly high, due to its complex, unpredictable and progressive nature (Carers Trust, 2013). This is supported by evidence showing nearly nine in 10 people caring for someone with dementia say it has had a negative impact on their mental health and half of carers of people with dementia say they have experienced depression (Carers Trust, 2013).

Other studies have found evidence of an impact from providing support for carers on the health of the person they care for. One of these found that providing carers with emotional support can significantly delay the need for the person receiving care to go into residential care (Mittelman et al, 1996).

## Increase in knowledge and information

NEFC found that the Dementia Adviser service improves knowledge and information of the carer by 40 per cent. This can enable greater independence, build resilience and increase access to timely care and support.

*'She brought up things we would have never thought about. What comes up later... you don't know what it will be like in six months' time...'*

*'I learnt more from her in one hour than I had in the previous six months. It was very useful.'*

*'[Without the service...] We would be totally unaware as to the support that could and will be available in the future regarding my wife's illness.'*

Supporting these findings, there is evidence that information and advice can have an impact on health and wellbeing, helping people with dementia to remain independent and well for longer (Department of Health, 2013). There is also evidence linking the navigation aspect of the service with improved health outcomes. An evaluation of care navigator services found that 75 per cent of carers said the condition of the person they

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care for would have worsened more quickly without the support of the service, and 50 per cent said they had made fewer visits to hospitals as a result of receiving support (Building Health Partnerships, 2014).

The strength of the information provided by the Dementia Adviser service may be in the way it is delivered – it is personalised and tailored. The 2013 Carers Trust report, *A road less rocky – supporting carers of people with dementia*, highlighted the varying individual needs of carers and research has shown that the Dementia Adviser service provides, ‘the right information and advice at the right time for them’ (Department of Health, 2013), and that this personalisation can also be key for crisis prevention.

Access to services, enabled through the dementia adviser, can also help people to find new meaning and purpose – people with dementia can find ways to enjoy life, build new relationships and get the support they need (Department of Health, 2013).

## Increase in building peer networks

The study found that the Dementia Adviser service facilitates social support through increasing peer networks for both the person with dementia and the carer, with an increase of 46 per cent and 44 per cent respectively. Carers commented:

‘It’s stopped her feeling so alone. It’s nice to feel that there is someone out there that understands.’

‘Having people to talk to. Apart from going shopping he doesn’t chat with anyone. Seeing other people with dementia helps a bit, seeing how things can develop.’

‘[Without the service...] Very isolated for both of us. He would have been in a home by now.’

Increased peer support can make a transformational difference to the lived experience of dementia. Other research has found unique benefits to peer support, in contrast to other forms of social support, where a more positive attitude emerges from, ‘identification with others, a commonality of experience and reciprocity of support’ (Keyes et al, 2014).

Peer support is also important in reducing loneliness – particularly prevalent in people with dementia, as 40 per cent of people with dementia have felt lonely recently (Alzheimer’s Society, 2014a) and 33 per cent of people with dementia have lost friends after their diagnosis (Alzheimer’s Society, 2013). This can have an impact on the healthcare system as research shows that loneliness can have negative health impacts as damaging as smoking 15 cigarettes a day (Holt-Lunstad et al, 2010).

# Conclusion

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Access to timely and quality post-diagnosis support is essential for people affected by dementia.

This case study SCBA has shown that Dementia Adviser services, as described, can deliver significant benefits to the person living with dementia, their carer, and public services in a highly cost-effective way.

There are clear local and national policy commitments to improve access to high quality post-diagnosis support.

The Dementia Adviser service provides a national framework that can be locally adapted to meet specific need. In doing so, this will not only improve the quality of life and independence of the increasing number of people living with dementia, but ensure that public resources are used effectively and delivering a significant value for money.

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**Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.**

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