



July 2019

Oxfordshire

Local Dementia Profile



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Foreword

In Oxfordshire, there are approximately 8,422 people over the age of 65 living with dementia¹.

Healthier lifestyles and advances in medicine mean we are now living longer than ever before. An ageing population, however, also brings with it unprecedented pressures on our health and social care systems and on already immensely squeezed budgets. Dementia is the condition most feared by people over the age of 50. By the time of the next General Election, we expect more than 1 million people in the UK will be living with dementia.

While, at the time of writing, we await the Government's long-promised Green Paper on social care, councils are at the front line of the country's social care crisis. Given the numbers of people living with dementia, the social care crisis is a dementia crisis.

I'm proud to lead Alzheimer's Society; the UK's only charity that campaigns for change, funds research to find a cure and also delivers services and support to people living with dementia across the country. However, we know we can't deliver change alone. As a councillor, you have a significant role to play in ensuring that people living with dementia in Oxfordshire receive the best possible support.

In this local profile, we have outlined a few steps that you can take during your term of office to make the lives of those affected by dementia that little bit easier. We are keen to support you to deliver any of these recommendations – please contact the team at local@alzheimers.org.uk. If you adopt any of the measures outlined here – or have already done so – please do let us know so that we can share the good news with our supporters in Oxfordshire.



Yours faithfully,

Jeremy Hughes CBE
Chief Executive, Alzheimer's Society



What is dementia?

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language.

These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one.

The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

The different types of dementia tend to affect people differently, especially in the early stages. Other factors that will affect how well someone can live with dementia include how other people respond to them and the environment around them.

A person with dementia will have cognitive symptoms (to do with thinking or memory). They will often have problems with some of the following:

- Day-to-day memory – for example, difficulty recalling events that happened recently
- Concentrating, planning or organising – for example, difficulties making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal)
- Language – for example, difficulties following a conversation or finding the right word for something
- Visuospatial skills – for example, problems judging distances (such as on stairs) and seeing two dimensional objects in three dimensions
- Orientation – for example, losing track of the day or date, or becoming confused about where they are.

A person with dementia will also often have changes in their mood. For example, they may become frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad. With some types of dementia, the person may see things that are not really there (visual hallucinations) or strongly believe things that are not true (delusions).



You can find out more by visiting [alzheimers.org.uk/about-dementia/](https://www.alzheimers.org.uk/about-dementia/)

Preventing well

By 2025, there will be an estimated 10,968 people over the age of 65 living with dementia in Oxfordshire². However, dementia doesn't just affect older people. We estimate by 2025 there will also be approximately 2,600³ people aged between 30 and 64 living with dementia in the South East.

While the likelihood of developing dementia increases with age, it is not a natural part of the ageing process. There are more than 42,000 people in the UK under 65 currently living with the condition. Apart from in some rare cases, we know that most forms of dementia are not inherited. While we don't yet know what can be done to prevent the development of dementia, we know there are certain lifestyle choices that can increase the risk of dementia.

More than one third of cases of dementia are potentially avoidable through modifiable lifestyle factors. Changes in mid-life can have the most impact on reducing risk⁴. Regular exercise, mental stimulation, and maintaining a healthy weight can all help prevent us from developing dementia, or slow its onset. We also know that smoking and drinking too much can increase our chances of developing the condition, with smokers 50% more likely to develop dementia than non-smokers. Similarly, those with type 2 diabetes, high blood pressure in middle age or who are obese are at greater risk of developing the condition.

All adults aged 40–74 who don't have a pre-existing condition are eligible for a free NHS Health Check. Since 2018, risks around dementia and how to prevent it have been explicitly included in these 20 minute, painless assessments. Research shows us that awareness of the risks of dementia amongst those who attend a health check is significantly higher than those who don't⁵. However we know that take-up of these important health checks across the country is low. (NB. A previous version of this profile included Public Health England-provided data on provision of health checks. These numbers have been removed due to concerns about data clarity.)



We recommend

- Councils should ensure their healthy living messaging references dementia, alongside heart disease and cancers, recognising that what is good for the heart is good for the head.
- Councils, working with Health and Wellbeing Boards, should develop and affect a clear action plan to increase the invitation and take-up rates of NHS Health Checks year-on-year.
- Where they don't currently exist, councils should develop a Dementia Strategy that maps current and future needs along the well pathway and includes tangible actions to improve the health of, and support available to, people affected by dementia.

10,968

**Estimated number
of people aged 65+
living with dementia
in Oxfordshire by 2025**

Diagnosing well

Access to timely diagnosis of dementia is variable and support available to both people with dementia and their carers is patchy⁶. Of those estimated to be living with dementia in Oxfordshire, just 67.9% have received a diagnosis (as at April 2019)⁷.

A timely diagnosis provides huge benefits for the individual. It unlocks a range of information, advice and support which will enable them to cope with their condition but also live better now. It also provides for better management of any other conditions that may be affected by their dementia while also providing them with the time to plan ahead and make informed decisions about their future needs. The benefits of a diagnosis are not only beneficial for the individual, but the health and social care system too. Being able to plan and efficiently allocate scarce local resources, avoid unnecessary and costly crises and emergency admissions, and provide accurate clinical management of co-morbidities are just some of the benefits to the local health and social care systems.

We recommend that all diagnoses of dementia take place in a memory service, also called a memory assessment service, or a memory clinic. Some diagnoses take place within mental health assessment teams, but we would discourage this as people with dementia report better experiences when they receive specialist support. GPs carry out initial reviews of cognitive and physical health and refer to specialist secondary services for full diagnostic assessments. This is the National Institute for Health and Care Excellence (NICE) recommended process.

The most recent Memory Clinic Audit⁸ by the Royal College of Psychiatrists found huge variation in waiting times from GP referral to initial appointment at the memory service, and between initial appointment and diagnosis.

The range of time between referral and initial appointment is 1–32 weeks, and between initial appointment and diagnosis is 1–40 weeks⁹. This means many people must wait over six months to receive a dementia diagnosis.

We recommend

- **Health and Wellbeing Boards should monitor the time it takes for a dementia diagnosis to be made – this should be a maximum of 12 weeks between concerns first being raised (usually with a GP) and a diagnosis being received (usually at a memory clinic).**
 - **Working alongside Health and Wellbeing Boards and local Clinical Commissioning Groups, Oxfordshire should adopt an ambitious diagnosis rate target, accompanied by a robust strategy to deliver this.**
 - **Health and Wellbeing Boards should ensure that all local memory services/memory clinics are accredited to the Royal College of Psychiatrists' Memory Services National Accreditation Programme (MSNAP).**
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Just

67.9%

of people estimated to be living with dementia in Oxfordshire have received a diagnosis

A diagnosis should be made at the point when a person's symptoms are beginning to have an impact on their daily life.

Living well

In Oxfordshire, there are approximately 5,719 people over the age of 65 living with dementia who have received a diagnosis¹⁰. There are also estimated to be approximately 36,000 people in England aged between 30 and 64 who are living with young-onset dementia¹¹.

In the early stages of dementia, a person's symptoms will be noticeable and will affect their day-to-day life. However, someone in the early stages of dementia will be fairly independent and should be able to do most things with a little help, or perhaps a little differently.

Following a timely diagnosis, people living with dementia require access to good quality post-diagnostic support. This should include cognitive stimulation therapy – a light-touch, non-drug treatment that's often delivered in a small group setting and designed to keep the brain active. This intervention has been proven to be as effective as many drug therapies for those with mild or moderate dementia¹².

We know that deprivation can have a significant impact on the ability of people with dementia to live well^{13,14}. There is also evidence to suggest that people with dementia living in more deprived areas are less likely to complete an annual care review¹⁵; an important review that seeks to ensure service users receive appropriate and timely care support.

Following a diagnosis, people living with dementia should be provided with relevant and timely information to access any benefits – this being particularly pertinent for those of working age who have developed young-onset dementia – they might be entitled to, as well as any passported benefits. For example, under the 'severely mentally impaired' category of the Local Government Finance Act 1992 (section 6, paragraph 4), people living with dementia are entitled to a council tax discount or exemption. However, awareness among people affected by dementia and council officers is low, with the application process often unduly complex. Further, the Department for Transport will extend eligibility for Blue Badges to people affected by dementia in 2019¹⁶. These vital benefits can make a substantial difference in improving the quality of life for people with dementia.

Scotland: Five pillars of post-diagnostic support

Dementia diagnosis rates in Scotland are high. Five key pillars are recognised as essential to support people following a diagnosis:

- Understanding the illness and managing symptoms
- Planning for future decision making
- Supporting community connections
- Peer support
- Services to support quality of life

The Scottish Government guarantee, for a minimum of one year, a named person who has the flexibility to work alongside the person, their partner and family and ensure that each person is given help and support to work through the five pillars.



Training for health and social care staff

People with dementia occupy at least a quarter of hospital beds, 70% of care home places, and make up 60% of homecare recipients. This means the vast majority of health and care professionals will be supporting someone with the condition. Our evidence¹⁷ shows that at the root of poor quality care is a lack of understanding of dementia from the health and social care workforce, tied to training, support and leadership.

More than a fifth of organisations offering dementia care are rated as failing by the Care Quality Commission (CQC)¹⁸, which is higher than the overall service average, even though dementia services normally cost more. These failings are often not due to a lack of effort or compassion, but due to a lack of knowledge. The latest statistics available from Skills for Care suggest only 68% of direct care staff are trained to at least Tier 1 of the Department of Health and Social Care-backed Dementia Training Standards Framework. We believe that all care staff working directly with people living with dementia should be trained to at least Tier 2¹⁹, which provides basic training about the most common forms of dementia, their underlying causes, and some of the major impairments and difficulties people with dementia may face as the condition progresses.

We recommend

- Councils should ensure all their direct and commissioned services staff who are working with people living with dementia are trained to Tier 2 of the Department of Health and Social Care-backed Dementia Training Standards Framework.
 - Alongside local health providers, councils should set out an accessible local offer for people with a dementia diagnosis that covers what services and support are available to them, as well as any entitlements.
 - Councils should adopt a simplified 'severely mentally impaired' application form for council tax discounts, similar to that used in Wales²⁰.
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People with dementia occupy at least a quarter of hospital beds.

Side by side

Case study

What is Side by Side?

Side by Side is a new Alzheimer's Society service that helps people get out and about with the support of a volunteer doing an activity of their choice, for example joining a local club, visiting a café or a walk in the park.

This extra support can make it easier for people with dementia, who might sometimes feel isolated or find it difficult to leave their homes, to do things others might take for granted and feel part of their local community. The service is highly flexible and built around the individual and their needs. The service can also be used as a form of social prescribing.

Side by Side is available in 59 locations across England, Wales and N. Ireland, and we are hoping to roll this out to more locations in the future.

How is Side by Side making a difference to people living with dementia?

- Enabling people with dementia to lead fulfilling lives, and reducing isolation and loneliness
- Ensuring people with dementia are not excluded from their local services and community activity, and encouraging informal, community-based support networks for people with dementia
- Supporting people with dementia to identify their own personal talents, strengths and capabilities, and what they can bring to their peers and the wider community



35%

of people with dementia reported moderate to severe loneliness²¹

Supporting well

Carers

Carers of people with dementia are vital contributors to our health and social care system. Unpaid carers account for £11.6 billion²² of the economic cost of dementia yet many of them are struggling in silence, often dealing with myriad challenges including practical, financial and emotional difficulties including stress, loneliness and depression.

Caring is a long-term commitment. In 2016/17, 30% of adult carers for people with dementia had been doing so for between 5 and 10 years and 22% for over 10 years. The majority of carers (58.5%) spend more than 35 hours per week providing care, while over a third of carers (35.7%) provide care for over 100 hours per week²³.

Caring is also expensive to the individual. In research commissioned by Alzheimer's Society, academics found that of those caring for people with only mild or moderate dementia, total costs – including unpaid, paid and out of pocket costs – were estimated at £4,008 per person over a three-month period. Unpaid carers of people with dementia are disproportionately shouldering the burden of care – covering 75% of the total costs (£2928) and giving upwards of 470 hours of their time over a three-month period to care for people with dementia; equivalent to an average of 36 hours a week, and five hours a day²⁴.

Through the Care Act 2014, all carers are entitled to a 'carers assessment' from their local authority, which should look at the current and future needs of the carer and cared-for person. However, through Alzheimer's Society helpline and our online peer-support network, we know thousands of carers across the country are left without access to the support they need.

58.5%
of carers spend more than
35 hours
per week providing care²³

Anti-psychotic stats

Ninety percent of people with dementia experience behavioural and psychological symptoms (BPSD), such as aggression, agitation, loss of inhibitions and psychosis (delusions and hallucinations). These symptoms can be distressing for the person and their carers as well as putting the person at risk.

People with dementia who experience BPSD are often, and sometimes inappropriately, prescribed antipsychotic drugs used to treat schizophrenia. Antipsychotic drugs do reduce psychotic experiences such as delusion. However, they are also linked to serious side effects, have a moderate benefit and do not address underlying causes of BPSD. A Department of Health study concluded of the 180,000 prescriptions for people with dementia overall, 140,000 are inappropriate²⁵.

Inappropriate prescription of antipsychotic drugs is extremely harmful. Research has shown that there is up to a nine-fold risk of stroke in the first four weeks²⁶ and that there is almost a doubling in the risk of mortality²⁷. Inappropriate prescription of antipsychotic drugs contributes to 1,800 deaths a year²⁸.

In recent years, there has been an increased focus on reducing the incidence rate of anti-psychotic medication inappropriately being prescribed for people living with dementia which has led to positive results. Between 2008–2011 anti-psychotic use reduced from 17% to just 7%. However, since then, new stats show numbers have risen again to 9.3% – but also demonstrate regional variation as in some areas it is as much as 15%²⁹. It is therefore hugely important that this increased scrutiny continues.

We recommend

- Councils' carers' strategies should include a specific focus on carers of people with dementia, detailing the support to them, including access to psychological support and practical training for unpaid carers.
- Health and Wellbeing Boards and/or council Overview and Scrutiny Committees should regularly review the use and rates of anti-psychotic medication for the treatment of dementia.

Dementia Connect

Case study

Dementia Connect is Alzheimer's Society's new personalised service for people affected by dementia, connecting them to the right support, in the right way.

Our expert Dementia Advisers and trained volunteers will provide relevant information and advice by phone or face-to-face, helping people with dementia take back control of their lives and be more independent for longer.

As part of Dementia Connect, our Side by Side (see page 10) volunteers are already helping those living with dementia to get out and about in their community and do the things they love.

How does it work?

The service is for people living with dementia, as well as their carers, family and friends. It can be accessed by either contacting us directly, or after a referral

from a GP or another healthcare professional. Following a referral, a specially trained Dementia Adviser will be in touch to assess any needs and connect the person to the right support. We'll then keep in touch, providing each person with ongoing support and services when they need it. We believe no-one should face dementia alone. And with Dementia Connect, no-one will have to.

Where does it operate?

We are currently delivering Dementia Connect in parts of East Lancashire, Blackburn with Darwen, Birmingham and Solihull, and throughout Wales. We are aiming to roll it out nationwide by 2022. If you want to find out more, please contact your local area manager whose contact details are at the end of this report.



Dying well

Dementia is now one of the leading cause of death in the UK³⁰. It is also the only condition in the UK's top 10 causes of death that doesn't currently have any treatment to prevent, cure or slow its progression.

When a person with dementia is approaching the end of their life, it can be a very difficult time for them and the people around them. Planning for the end of life is important for anyone who has a life-limiting condition. For a person with dementia, it is important to try and have these conversations as early as possible, while they can make decisions for themselves.

Health and social care staff should ensure that individuals' care plans are always up-to-date and include end-of-life plans. It may be appropriate to ensure that advanced decisions are made by the individual early due to the fact that they may lack the mental capacity in the future. Advance decisions are legally binding as long as they meet certain conditions. This means that they must be followed by doctors and other medical professionals and are shared with those involved in the person's care. Some areas have special staff who co-ordinate end-of-life care for people with dementia.

Only half of people who express a preference to die at home actually die at home³¹. This places pressure on the NHS and adversely impacts on the quality of care received by a person with dementia³². Alzheimer's Society supports the government's goal of ensuring that more people die in a place of their choosing³³. To achieve this, the Society has been calling for the implementation of the Palliative Care Funding Review³⁴. This would provide commissioners with funding for palliative care, regardless of setting, in line with a person with dementia's wishes.

We recommend

- Councils should ensure that all care plans include advanced decisions.
 - Councils should ensure that all directly delivered or commissioned residential or care homes meet the National Gold Standards Framework on end-of-life care.
-



Only half of people who express a preference to die at home actually do so.

Summary of recommendations

Our ageing population means that more people are living longer, and so are more likely to develop dementia. By 2025, one million people will be living with dementia in the UK, with that number set to double by 2050³⁵. There are now more than 2.8 million Dementia Friends across the UK and dozens of Dementia Friendly Communities, all working to help people living with dementia to continue to live in the way they want in their communities.

The recommendations we have outlined in this local profile are tangible changes that councils and Health and Wellbeing Boards can affect to ensure that people with dementia are better supported. With reasonable adjustments, many people with dementia can live well. Councils have an important role to play in ensuring that the community in which people live, and the policies that direct support services, are appropriate to ensure those people with dementia are able to live well, live safely and, as much as possible, continue to live independently.

Our key recommendations to help people affected by dementia during your time in office are:

Preventing well

- Councils should ensure their healthy living messaging references dementia, alongside heart disease and cancers, recognising that what is good for the heart is good for the head.
- Councils, working with Health and Wellbeing Boards, should develop and effect a clear action plan to increase the invitation and take-up rates of NHS Health Checks year-on-year.
- Where they don't currently exist, councils should develop a Dementia Strategy that maps current and future needs along the well pathway and includes tangible actions to improve the health of, and support available to, people affected by dementia.

Diagnosing well

- Health and Wellbeing Boards should monitor the time it takes for a dementia diagnosis to be made – this should be a maximum of six weeks between concerns first being raised (usually with a GP) and a diagnosis being received (usually at a memory clinic).
- Working alongside Health and Wellbeing Boards and local Clinical Commissioning Groups, Oxfordshire should adopt an ambitious diagnosis rate target, accompanied by a robust strategy to deliver this.
- Health and Wellbeing Boards should ensure that all local memory services/memory clinics are accredited to the Royal College of Psychiatrists' Memory Services National Accreditation Programme (MSNAP).

Living well

- Councils should ensure all their direct and commissioned services staff who are working with people living with dementia are trained to Tier 2 of the Department of Health and Social Care-backed Dementia Training Standards Framework.
- Alongside local health providers, councils should set out an accessible local offer for people with a dementia diagnosis that covers what services and support are available to them, as well as any entitlements.
- Councils should adopt a simplified 'severely mentally impaired' application form for council tax discounts, similar to that used in Wales³⁶.

Supporting well

- Councils' carers' strategies should include a specific focus on carers of people with dementia, detailing the support to them, including access to psychological support and practical training for unpaid carers.
- Health and Wellbeing Boards and/or council Overview and Scrutiny Committees should regularly review the use and rates of anti-psychotic medication for the treatment of dementia.

Dying well

- Councils should ensure that all care plans include advanced decisions.
- Councils should ensure that all directly-delivered or commissioned residential or care homes meet the National Gold Standards Framework end-of-life care.

About us

Alzheimer's Society is the only UK charity that campaigns for change, funds research to find a cure and supports people living with dementia today.

Too many people face dementia alone. People with dementia have told us how difficult it is to find out who to turn to or where to go for information and support. We deliver a range of services at a national and local level across England, supported by expert staff and trained volunteers.

In 2017/18, through our services we directly reached and supported 210,000 people affected by dementia. In the same period, we provided indirect expertise and information to 6.5 million people and we now have registered more than 2.8 million Dementia Friends.

To find out more about what Alzheimer's Society does in Oxfordshire, please find below the contact details for your local area manager and head of region below:

Oxfordshire Area Manager

Linda Goddard

linda.goddard@alzheimers.org.uk
07766 206582

Head of Region covering Oxfordshire

Marion Child

Marion.Child@alzheimers.org.uk
07484 133887

To find out more about our Dementia Friends initiative, you can use the above contacts or visit dementiafriends.org.uk

If we can support you to introduce any of the measures contained within this profile, or if you have any questions about the profile, please contact us at local@alzheimers.org.uk

Get support

If you, or anyone you know, is affected by dementia and require advice or support you can access it using some of our national services outlined below.

Dementia Helpline

You can call our helpline on 0300 222 11 22. It is open seven days a week providing information, advice and emotional support to anyone affected by dementia.

Talking Point

Our online community is a place where you can ask questions, share experiences and get information and practical tips on living with dementia. It's free to use, open 24 hours a day and all you need is an internet connection. alzheimers.org.uk/talkingpoint

Find support near you

Our comprehensive directory allows you to find advice and information support services. Simply enter your postcode or location. alzheimers.org.uk/get-support

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Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

To keep up to date on the latest news from our research programme, sign up to receive our research magazine at alzheimers.org.uk/careandcure

All of the dementia research we support is fully funded by voluntary income. You can donate to our research programme online at alzheimers.org.uk/donate

If we can support you to introduce any of the measures contained within this profile, or if you have any questions about the profile, please contact us at local@alzheimers.org.uk

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