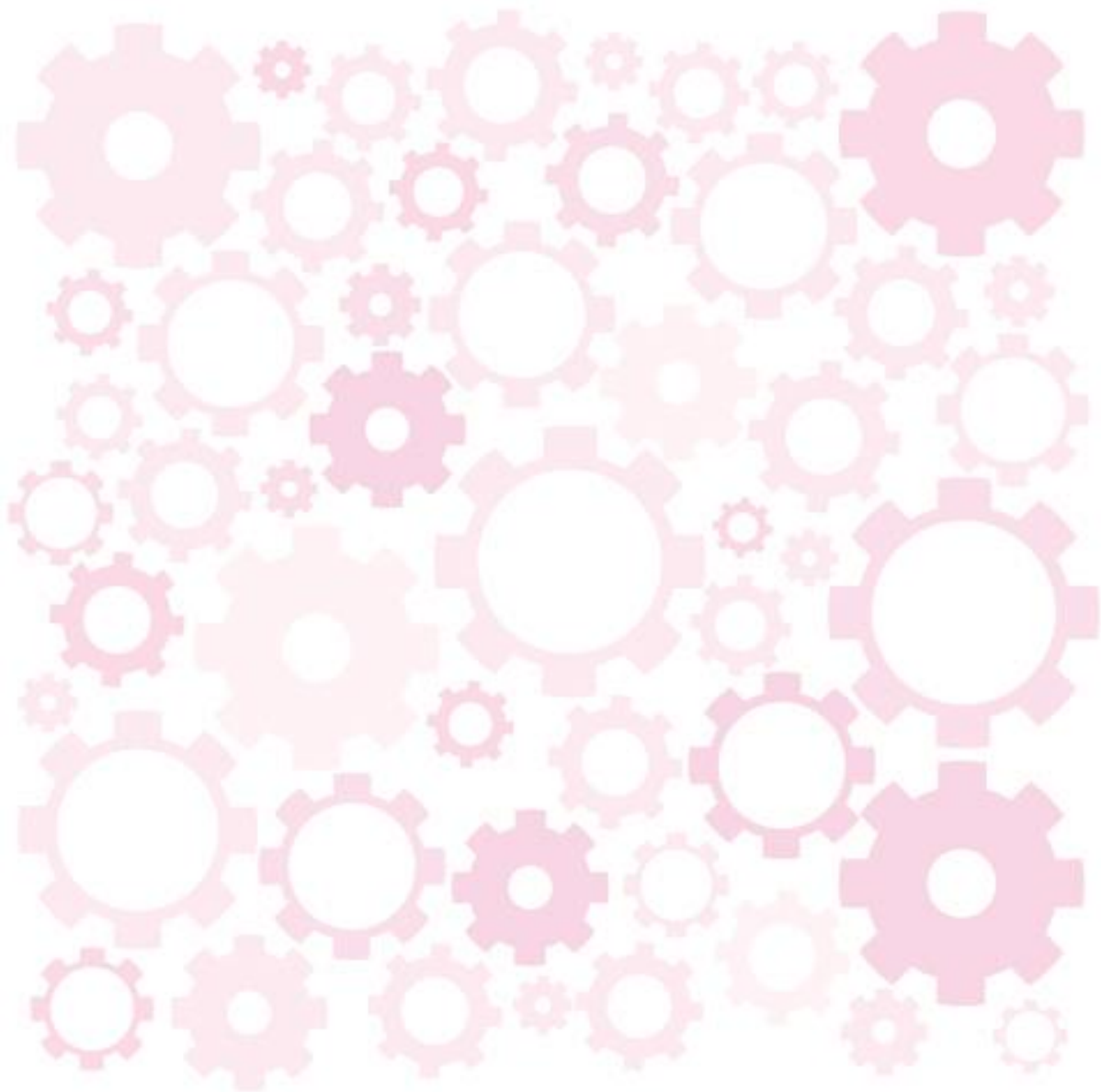


# Dementia services

## Findings from the Healthwatch network

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## Executive summary

**With the number of people with dementia in England estimated to rise from around 700,000 to over a million by 2025<sup>1</sup>, it's more important than ever that services give people the support they need.**

Over the past year local Healthwatch have spoken to people across the country about their experiences of dementia care - from help provided by GPs and pharmacists to support offered through hospitals and social care.

While in most cases people found care to be compassionate and considerate, there is still much to be done to ensure that all people with dementia experience a high standard of care. Local Healthwatch found that people want to see improvements in three main areas:

- Information: Improving dementia awareness amongst the public and professionals.
- Support: Making sure that people with dementia and their carers have the support they need, when they need it.
- Environment: Places should be more dementia-friendly.

This briefing brings together findings from 121 visits to care homes by local Healthwatch and 14 focused reports on dementia, as well as recommendations for improvements based on what people said.

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<sup>1</sup> Alzheimer's Research UK (2014), Defeat Dementia - the evidence and a vision for action

## Understanding the issue

**Dementia is already the leading cause of disability in people over 65 in the UK. The Alzheimer's Society estimates that the number of people with dementia will increase by more than half within the next decade.**

68% of people with dementia are over 80 years old and one third of people with dementia live in care homes, making up 69% of the residential care home population.

While lower as an overall proportion of the population, the number of people from a Black and Minority Ethnic background expected to develop dementia is estimated to increase seven-fold over the next 40 years.<sup>2</sup>

NHS England estimates that there are around 540,000 carers for people with dementia in England. Half of these carers are employed, and it's estimated that some 66,000 of these people have already cut their working hours to care for a family member, and a further 50,000 have left work altogether<sup>3</sup>.

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“When people go for diagnosis, I think that information needs to be there for them... Because they go away and they've been told 'You've got dementia.' But they've got nothing, they've got no one to call, nowhere to go.”

*A carer speaking to Healthwatch Norfolk*

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<sup>2</sup> Department of Health (2015). Prime Ministers Challenge on Dementia 2020

<sup>3</sup> <https://www.england.nhs.uk/mentalhealth/dementia/>

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## The national picture

**Since the beginning of 2015, local Healthwatch across the country have spoken to more than 1,000 people about their experiences of dementia and dementia care.**

This has taken place in a range of communities to understand how people's experiences differ - from *Healthwatch Barnet's* conversations with 120 Asian women in their borough, to *Healthwatch Oxfordshire's* work with rural communities.

While the exact findings have varied depending on the local context, several key themes have emerged:

### Information

- The availability and type of information regarding services and support following diagnosis helps to set the tone for the experiences of those with dementia and their carers.
- Support for carers is not always as clearly signposted or explained as it could be.
- Dementia awareness and education is improving amongst both professionals and the public, however, some GPs are unable to spot when patients have dementia.

### Support

- Specialist services for people with dementia, like memory cafes, are said to be very good, but are not always accessible to those who would most benefit from using them.
- More generally, many people felt that the quality of services themselves was inconsistent, sometimes within the same locality.

### Environment

- More work needs to be done to make public spaces dementia-friendly by improving elements such as lighting and signage.

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## Findings from 121 local Healthwatch care home visits

In the first six months of 2016 alone, dementia came up in 121 summaries written by 52 local Healthwatch following visits to care homes.

The issues they identified included:

- Care homes engaging residents in activities including singing, pet therapy, and simple arts and crafts. The use of themed activity rooms with sensory and audio equipment was also highlighted positively. However, some reported a lack of suitable activities.
- Mixed levels of dementia training and awareness amongst staff: around half of those asked felt they had had sufficient training to deal with residents with dementia, while half felt that they could use more training.
- A desire from residents to be able to go out more to visit their local areas.
- Not all care homes were dementia-friendly environments. Some people said that the décor could be improved, including signage, lighting and colour-coding. However, overall, most reports spoke positively about care home décor.

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## What people said

**In this section, we look into what local Healthwatch heard from their communities about each area for improvement.**

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### Information

*Healthwatch Essex* spoke to people about their experiences of caring for friends and loved ones with dementia. They heard that many find it difficult and confusing to understand what support is available. The local Healthwatch produced a handbook, which aims to answer many of the questions people have when a family member has dementia or dementia symptoms.

Working in partnership with the nursing staff from Mid Essex Hospital Trust and dementia campaigner Tommy Whitelaw, Healthwatch Essex also developed a training film called 'Putting the Care into Dementia Care'. The film is now part of the nursing induction programme at Broomfield Hospital, Chelmsford.

Healthwatch Essex is working with Essex County Council on its Dementia Voices Project to ensure that the voice and experience of those living with dementia informs the commissioning of the new model for Community Dementia Support Services. The project's findings will be used to inform the commissioning of support for people with dementia in Essex from October 2017.

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**"Living with dementia is extremely challenging, but the Healthwatch Essex dementia handbook is very useful. Everything was so easy to read and follow and with links available in each section. I found it very beneficial."**

*Carer speaking to Healthwatch Essex*

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Healthwatch Barnet spoke to over 170 people about dementia, with a particular focus on the experience of Asian women in the borough, who made up 120 of the participants.

They heard that:

- Professionals generally show compassion, care and respect towards patients' needs. However, dementia awareness amongst health professionals was mixed, with some GPs unable to spot when patients had dementia.
  - Dementia awareness among the general public was also low. Individuals and carers surveyed said that they did not have any information about dementia prior to diagnosis.
  - There is a lack of information on dementia among ethnic minority groups who are less likely to access support and services, and more likely to experience isolation. Overall, 32% of people with dementia are not known to their GPs or to professionals.
  - Some information provided on dementia is too clinical and difficult to understand, and, when translated into other languages, can be inaccurate.
  - Patients said that they are given sufficient time to have their questions answered or to raise any concerns relating to their health, management of medication or coping mechanisms.
  - However, some patients said that they had no access to a dementia specialist or psychiatrist, which implies that they do not necessarily have the knowledge that this service is available through their GP.
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- People experiencing the early stages of dementia are unable to access Day Centre Services due to the introduction of means testing for funding. This group of people would benefit more from Day Centres than those in the later stages.

Healthwatch Barnet made the following recommendations:

- To raise awareness of dementia among primary care professionals.
- To raise awareness of dementia among ethnic minority communities.
- To involve carers in the patient's treatment as an essential part of providing care.
- To provide regular follow-up appointments with GPs, and to provide emergency appointments.
- To offer community day services for early-stage dementia.

Since publication, Healthwatch Barnet has been invited to take part in a working group by its local council to inform the council's dementia work. The council aims to develop a better understanding of the information residents need to know about dementia and how to share it. The group will begin meeting in January 2017.

*Healthwatch Torbay* produced a guidebook for care home staff to help them better understand dementia. The guide was produced with input from people with dementia, care home staff and the Torbay Dementia Action Alliance (TDAA), as part of their 'Purple Angel' campaign to make Torbay the first dementia-friendly resort in the country.

To help promote greater awareness and understanding of dementia, community volunteers from the TDAA talked to people on the high street and a man living with dementia provided dementia awareness training to care home staff. Many local care homes received this training and all received copies of the guidebook, with many care home staff saying how invaluable it was in helping them to support residents with dementia.

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## Support

*Healthwatch Greenwich* spoke to 130 people (including 61 people with dementia and 41 carers) to find out about the effectiveness of local dementia support and whether services were meeting their needs. They found that GPs could be better equipped to identify indicators of dementia, and that people struggled because of a lack of information and awareness about the condition. The local Healthwatch wrote a report detailing its findings, which contributed to the development of a Dementia Action Group consisting of local authority commissioners, the voluntary sector and NHS providers. The Royal Borough of Greenwich has also employed a Dementia Action Coordinator to facilitate the meetings of the Action Group and implement the actions.

To find out about the the experiences of people living with dementia, their families, carers and professionals, *Healthwatch Hampshire* worked with the Alzheimer's Society and Andover MIND to visit numerous support groups, carers groups and day centres.

While they found a great deal of good practice, including dementia-friendly GP surgeries and information on local services provided by West Hampshire's *dementia roadmap*, Healthwatch Hampshire identified three key areas needing improvement:

- Signposting to support services after diagnosis.
- Awareness of available financial support and how to access it, especially amongst carers.

- Consistency of care in the home, with a perceived lack of adequate training among paid carers.

Healthwatch Hampshire recommended that:

- There should be one point of access for signposting and support information.
- All new health and social care settings commissioned, built or re-designed should consider the needs of patients with dementia and become dementia-friendly.
- All staff who come into contact with people living with dementia should have adequate awareness training.
- All commissioners should encourage GP surgeries to become dementia-friendly.

As a result of Healthwatch Hampshire's report, the county council and three local Clinical Commissioning Groups (CCG) explained how they were working towards meeting the recommendations, including an increased focus of the local Dementia Advice Service on support for carers, and improved signage within GP surgeries.

*Healthwatch Lambeth* spoke to carers and people with dementia to find out how well services work for people after they've received a diagnosis.

They heard that:

- Carers were frustrated by delays and difficulties in making contact with key agencies and a lack of dementia awareness among professionals, including district nurse teams and domiciliary carers.
- The 'one-size-fits-all' approach to support for carers does not do enough to meet individual needs.
- The most valuable investment commissioners could make would be for respite cover, befriending schemes and other face-to-face contact. This would support the wellbeing of the person with dementia, their carers and relatives.

In March 2016, Healthwatch Lambeth hosted a meeting with NHS Lambeth and Lambeth council commissioners where they discussed these findings. As a result, commissioners committed to working as a group to develop a plan to improve dementia services in the borough.

*Healthwatch Manchester* conducted a survey which 21 people completed about their experiences of dementia services. They heard that carers and people with dementia found Admiral nurses to be a vital service, and appreciated the support given by dementia cafes, although they often found local support groups difficult to access. Referral times to memory clinics were also variable across Manchester, with some people having to wait years for a referral to specialists. People also found there was a lack of information about the services available to them.

Healthwatch Manchester met with Manchester Mental Health and Social Care Trust to ensure that people's views informed the redesigning of their dementia diagnosis pathway. It is hoped that a more community-based care approach will reduce referral times and provide a more consistent standard across Manchester. Healthwatch Manchester plans to undertake an evaluation of these new services in 2017. They also shared their findings with the local council and CCGs to help them develop the new Dementia Strategy for Manchester.

## Environment

*Healthwatch Middlesbrough* surveyed people with dementia and their carers in 2015. They found that people with dementia struggled when faced with poor signage, lighting and seating, and that carers felt more could be done to support them, including a greater level of information and understanding among the public.

These findings were used by Middlesbrough Borough Council when it reviewed its checklist for dementia-friendly environments, and led to a greater emphasis on these factors in its guidance.

Healthwatch Oxfordshire looked at the ways that support groups in rural communities were making their county more dementia-friendly.

It has made four recommendations which call for:

- Someone in each GP practice in the county to take the lead in building relationships between the practice and dementia support groups, as many people felt that they had little support from their nearest or local doctor.
- The development of a formal referral system between GP practices and community groups.
- An informed discussion between Oxford CCG and GP federations to take place straight away regarding a new way to help look after people with dementia in their own communities, involving doctors and voluntary groups, as well as the health service and the county council.
- Oxfordshire health and social care commissioners to commission community development work and provide funding to boost dementia support groups, and to help them access training, cover incidental costs and recruit new members.



## Thank you

### **Thank you to everyone who has shared their experiences and ideas with local Healthwatch about dementia.**

Special thanks go to the following local Healthwatch whose work has informed this briefing:

Barking and Dagenham, Barnet, Bath and North East Somerset, Blackburn with Darwen, Blackpool, Brent, Bromley, Buckinghamshire, Calderdale, Cambridgeshire, Cheshire West and Chester, County Durham, Coventry, Croydon, Derbyshire, East Riding of Yorkshire, Essex, Gloucestershire, Greenwich, Hackney, Halton, Hampshire, Havering, Hertfordshire, Kirklees, Lambeth, Lancashire, Leeds, Lincolnshire, Liverpool, Manchester, Medway, Middlesbrough, Newcastle upon Tyne, Norfolk, North East Lincolnshire, North Lincolnshire, North Somerset, North Yorkshire, Northamptonshire, Oxfordshire, Richmond upon Thames, Rutland, Sandwell, Sheffield, Shropshire, Somerset, South Gloucestershire, St Helens, Suffolk, Sunderland, Surrey, Telford & Wrekin, Torbay, Tower Hamlets, Warrington, Warwickshire, West Berkshire, West Sussex, Wirral and Wiltshire.

Over 40 local Healthwatch are members of the Dementia Action Alliance, an umbrella organisation that brings together regional and local members to help create dementia-friendly communities. Local Healthwatch are ideally placed to help contribute to this goal, and more information can be found at [www.dementiaaction.org.uk](http://www.dementiaaction.org.uk).

## About us

**We are the independent consumer champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.**

A local Healthwatch exists in every area of England. We support them to find out what people want from health and care services and to advocate for services that work for local communities. Local Healthwatch also act as our eyes and ears on the ground, telling us what people think about local health and social care services. We use the information the network shares with us and our statutory powers to ensure the voice of the public is strengthened and heard by those who design, commission, deliver and regulate health and care services.



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If you would like further information or if you have any queries, please contact [enquiries@healthwatch.co.uk](mailto:enquiries@healthwatch.co.uk).

Please contact us if you would like this document in another language or format, for example in large print, in Braille or on CD.

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