

Living with Dementia

(England)

March 2020

Every person living with dementia and their carers, should have the care and support they need to maintain control over their daily lives and to live with dignity. People living with dementia should be enabled to be an active member of their community, and have access to inclusive services.



Key issues

Approximately 748 000 people in England are living with dementia, and this is expected to grow to 1.3 million by 2040ⁱ. For the families, friends and carers of people living with dementia there is also a large impact, with around 500,000 people caring for a person with dementia in England aloneⁱⁱ. Unpaid carers save the UK economy approximately £13.9 billion a yearⁱⁱⁱ, and one in three of all carers in the UK are aged over 80^{iv}.

Key statistics

748 000

People living with dementia in England

30%

Of people living with dementia in England do not have a diagnosis.

£13.9 billion

The amount of money the UK economy saves through unpaid carers supporting people with dementia.

What is dementia?

Dementia is a term used to describe a collection of symptoms that occur when certain diseases or conditions affect the brain. The symptoms will depend on the condition which is causing the dementia and which part of the brain is affected. Some of the most common symptoms include problems with memory; problems with thinking skills; disorientation; struggling to follow conversations; difficulty communicating, and mood and personality changes^v. The most common cause of dementia is Alzheimer's Disease.

The impact of dementia

As dementia progresses it can become more difficult for a person to safely complete daily tasks and meet their own needs without help^{vi}. 77% of people living with dementia also have one or more other long term health conditions^{vii}. This can mean that complex care needs stack up at the same time as a person's capacity to manage their health reduces. For example, taking medication or staying active will often require additional support, particularly as a person's condition progresses. Later changes to the brain can cause people to become physically aggressive at times, or lose sexual inhibitions^{viii}. It is therefore important that people with dementia have access to responsive care that is able to meet changing and complex needs including challenging behaviour.

Variable standards of care and support

Diagnosis rates vary across the country with an estimated 30% of people living with dementia having received no formal diagnosis. Information and support following a diagnosis can also be patchy^{ix}, meaning that people living with dementia and those close to them can struggle to prepare for the challenges ahead from the very beginning.

In some regions older people are completely unable to access the formal care they need whether or not they have dementia; for example 24% of postcodes in England have no care beds^x. Two thirds of people live with dementia in their own homes^{xi} but can wait up to a year for a needs assessment^{xii}, and far fewer people overall are entitled to have their social care funded by the local authority than they were in 2010-2011^{xiii}.

Areas where the number of formal care services is limited mean that people with dementia are at increased risk of poor care^{xiv}. People who have difficulty advocating for themselves and without loved ones to assist can be particularly vulnerable^{xv} to missing out on vital services, and the effects of dementia such as changing needs can create a further risk.

Additional barriers to accessing care can exist for people from Black and Ethnic Minority (BAME) backgrounds and the LGBT+ community, as experiences of prejudice and discrimination in health and social care services may deter them from seeking support they need, and finding care that is inclusive of their needs can be challenging^{xvi&xvii}.



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Many people working in social care now complete the care certificate which provides basic awareness of dementia^{xxviii}, however the turnover rate for care workers is 33.8% and vacancy rates are 6.6%^{xxix}, with the King's Fund describing employment in the care sector as "unstable"^{xxx}. The care sector is not equipped to ensure that all people providing dementia care have received adequate training.

Where people cannot access the formal care they need, they are forced to try to get by without, and this places an excessive burden on carers and families. Approximately 61% of unpaid carers for people with dementia report that caring has had a negative impact on their health^{xxxi}, and just over 37% of carers provide over 100 hours of care a week^{xxxii}. Around a fifth of women who care for someone with dementia have reduced their working hours or left the paid workforce altogether in order to do so^{xxxiii}.

Hospital and end of life care

People living with dementia do not receive the best hospital care; they are likely to stay in hospital five to seven times longer than older people without a cognitive impairment, and 98% of people affected by dementia reported feeling that not all hospital staff understand the needs of people with dementia^{xxxiv}. A national audit^{xxxv} has found deficiencies in nutrition provided to people with dementia, inconsistent documentation of their needs, and a need for better staffing and more support.



End of life care also varies^{xxxvi}. It can be hard to identify the 'right' time to discuss treatment someone may wish for should they lose the ability to make decisions^{xxxvii} and aggressive treatments are sometimes used at a time when palliative care may be more appropriate^{xxxviii}. Decreasing mobility and appetite can be distressing to witness and carers may experience a sense of loss whilst continuing to provide care^{xxxix}. It is vitally important that carers are involved and understand the decisions being made.

Better support in the community

Dementia-friendly communities and business are inclusive spaces which can help to reduce discrimination and stigma for people living with dementia, and enable people to actively participate in society. This stigma may contribute to 1 in 10 working people living with dementia reporting experiencing discrimination at work^{xxx}, and can be particularly prevalent amongst some Black and

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Minority Ethnic communities^{xxxii}. The increasing number of dementia-friendly communities and businesses^{xxxiii} is a positive step towards tackling this.

The NHS Long Term Plan^{xxxiii} includes a focus on supporting people to ‘age well’ by investing in primary and community healthcare services, providing personalised care, and reducing the risk of developing certain conditions. The Government should aim to implement World Health Organisation^{xxxiv} guidelines on improving public awareness of how lifestyle affects risk of developing dementia.



As part of the Long Term Plan, support for people with dementia is set to widen with increasing social prescribing programmes. This means GPs and other healthcare professionals can refer people for non-medical treatments, such as community groups and volunteering opportunities. In order to be sustainable, charity and community organisations need access to funding and support to ensure they can do this.

Public Policy Proposals

- More public and private sector organisations should take steps to become dementia-friendly, including tackling discriminatory practices and stigma in the language they use.
- The Government should urgently establish, in partnership with voluntary sector organisations, a minimum standard of good-quality post-diagnosis support for people with dementia and their carers. This should complement the monitoring of diagnosis^{xxxv}.
- The Government should work to reduce disparities in diagnosis rates and post-diagnostic information and support provision. This can partly be achieved through recognising the contribution of voluntary organisations and opening funding streams to ensure continuity of valued services.
- The Government needs to ensure all localities, particularly rural, have access to good quality care services that are able to meet the changing needs of people with dementia.
- All dementia care services must meet the duties and responsibilities outlined in the Equality Act, including recognising and meeting the needs of people under all protected characteristics (e.g. disability, race, religion/belief, sexual orientation).

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- Improvements need to be made to staff training in hospitals to ensure people with dementia who have acute hospital admissions have their needs fully met.
- All health and social care staff who have contact with people with dementia must undertake mandatory training in dementia skills and awareness.
- Health and social care professionals should be able to support people with dementia and carers to manage and behaviours that challenge, such as sexually uninhibited and aggressive behaviours.
- Implementation of social prescribing must come with appropriate funding and resources for community organisations that provide services to which people with dementia are referred.
- The National Institute for Health and Care Excellence should expand its dementia guidelines to provide specific guidance on appropriate palliative care for people with dementia.

Want to find out more?

Age UK has policy positions on a wide range of public policy issues, covering money matters, health and wellbeing, care and support, housing and communities. There are also some crosscutting themes, such as age equality and human rights, age-friendly government and information and advice

Further information

You can read our policy positions here; [www.ageuk.org.uk/our-impact/policy-](http://www.ageuk.org.uk/our-impact/policy-research/policypositions/)

[research/policypositions/](http://www.ageuk.org.uk/our-impact/policy-research/policypositions/)

Individuals can contact us for information or advice here;

www.ageuk.org.uk/informationadvice/ or call us on **0800 169 8787**

Further information

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