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Definition

Dementia is typically a progressive clinical syndrome and an international public health priority.¹

The following Alzheimer's Society video answers the question "What is dementia?"

Alzheimer's Society – What is dementia?



There are several subtypes of dementia. These are some of the more frequent ones:

- Alzheimer's disease (the most common subtype at 50 to 75 percent of cases)
- Vascular dementia (up to 20 percent of cases)
- Dementia with Lewy bodies (10 to 15 percent of cases)
- Frontotemporal dementia (2 percent of cases)

Early-onset (or young onset) dementia is generally defined as dementia that develops before 65 years of age.² About a third of people with Parkinson's disease have some cognitive impairment at diagnosis, and it is estimated that 24 to 31 percent of people with later Parkinson's disease have Parkinson's disease dementia.³

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Prevalence and incidence

Since the **Prime Minister's challenge on dementia 2020**, published in 2015, the way in which data on dementia is collected has changed.

NHS Digital collect and publish data about people with dementia at each GP practice, so that the NHS (GPs and commissioners) can make informed choices about how to plan their services around their patient needs.⁴

Data from NHS Digital suggests that in June 2020, 426,525 people aged 65 and over in England have a recorded dementia diagnosis. This represents 1 in 25 people over 65 registered with a GP. The highest prevalence is among women aged 90 or over; one in four people in this group have a recorded dementia diagnosis.⁵

*** Please be aware that outbreak of Coronavirus (COVID-19) has led to unprecedented changes in the work and behaviour of General Practices and as a result this data will be impacted.⁵**

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Signs and symptoms

Symptoms of dementia vary between the different types. The following table contains information taken from the NHS *Symptoms of dementia* page.

Early dementia symptoms			
<p>Early symptoms of dementia are often termed mild cognitive impairment (MCI), including:</p> <ul style="list-style-type: none"> • memory loss • difficulty concentrating • finding it hard to carry out familiar daily tasks, such as getting confused over the correct change when shopping • struggling to follow a conversation or find the right word • being confused about time and place • mood changes. <p>Some people with these symptoms will remain the same and not worsen. But some people with MCI will go on to develop dementia.⁶</p>			
Symptoms more in keeping with Alzheimer's disease	Symptoms more in keeping with vascular dementia	Symptoms more in keeping with dementia with Lewy bodies	Symptoms more in keeping with frontotemporal dementia
<ul style="list-style-type: none"> • Memory problems – regularly forgetting recent events, names and faces. • Asking questions repeatedly. • Increasing difficulties with tasks and activities that require organisation and planning. • Becoming confused in unfamiliar environments. • Difficulty finding the right words. • Difficulty with numbers and/or handling money in shops. • Becoming more withdrawn or anxious. 	<ul style="list-style-type: none"> • Stroke-like symptoms: including muscle weakness or temporary paralysis on one side of the body (these symptoms require urgent medical attention). • Movement problems – difficulty walking or a change in the way a person walks. • Thinking problems – having difficulty with attention, planning and reasoning. • Mood changes – depression and a tendency to become more emotional. 	<ul style="list-style-type: none"> • Periods of being alert or drowsy, or fluctuating levels of confusion. • Visual hallucinations. • Becoming slower in their physical movements. • Repeated falls and fainting. • Sleep disturbances. 	<ul style="list-style-type: none"> • Personality changes – reduced sensitivity to others' feelings, making people seem cold and unfeeling. • Lack of social awareness – making inappropriate jokes or showing a lack of tact, though some people may become very withdrawn and apathetic. • Language problems – difficulty finding the right words or understanding them. • Becoming obsessive – such as developing fads for unusual foods, overeating and drinking.
Symptoms universal to the later stages of dementia			

- Memory problems – people may not recognise close family and friends, or remember where they live or where they are.
- Communication problems – some people may eventually lose the ability to speak altogether. Using non-verbal means of communication, such as facial expressions, touch and gestures, can help.
- Mobility problems – many people become less able to move about unaided. Some may eventually become unable to walk and require a wheelchair or be confined to bed.
- Behavioural problems – a significant number of people will develop what are known as behavioural and psychological symptoms of dementia (BPSD). These may include increased agitation, depressive symptoms, anxiety, wandering, aggression and sometimes hallucinations.
- Bladder incontinence is common in the later stages of dementia, and some people will also experience bowel incontinence.
- Appetite and weight loss problems are both common in advanced dementia. Many people have **trouble eating or swallowing**, and this can lead to choking, **chest infections** and other problems. Find out more about eating and nutrition.⁶

It should be noted that dementia can be difficult to identify as symptoms are nonspecific, vary from person to person and develop gradually over time. People with early dementia may deny symptoms or accommodate their cognitive changes and functional ability.⁷

For an insight into the signs, symptoms and progression of dementia watch *Barbara, the whole story*. This film was produced to educate staff at Guy's and St Thomas' NHS Foundation Trust. It's an emotional story about Barbara Reece who suffers from dementia. It has changed attitudes to dementia in hospitals across the world.

Guy's and St Thomas' NHS Foundation Trust – Barbara, the whole story



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Causes/risk factors

In addition to the conditions that have already been outlined (for example, Parkinson's disease), there are several other conditions that can cause dementia:

- progressive supranuclear palsy – a rare brain disorder that can mimic Parkinson's disease
- Huntington's disease – a genetic degenerative disorder affecting the brain
- prion disease such as Creutzfeldt-Jakob disease (CJD) – a fatal disease affecting the brain caused by an abnormal infectious protein called a prion
- normal pressure hydrocephalus – a syndrome caused by accumulation of cerebral spinal fluid in the ventricles of the brain
- chronic subdural haematoma – collection of blood on the surface of the brain

- benign brain tumours – these typically grow over a long period of time
- metabolic and endocrine disorders (such as chronic hypocalcaemia and recurrent hypoglycaemia)
- vitamin deficiencies (such as B12 and thiamine deficiency)
- infections (such as HIV infection and neurosyphilis).^{3,8}

As per the National Institute for Health and Care Excellence (NICE) clinical knowledge summary (CKS) **Dementia**, risk factors for dementia include:

- increasing age (it should be noted that dementia is not a natural part of aging)⁶
- mild cognitive impairment
- **learning difficulties**
- genetics
- risk factors for cardiovascular disease (such as diabetes, smoking, hypercholesterolemia, and hypertension)
- **stroke**
- depression
- heavy alcohol consumption
- low educational attainment
- low social engagement and support.

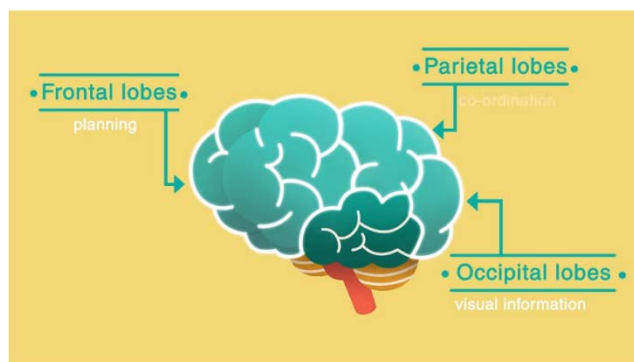
For further details, visit NICE CKS **Dementia, Risk factors**.

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Pathophysiology (mechanism of disease)

The Alzheimer's Society has produced a series of videos looking at how the brain and brain cells work, and how this is affected in each type of dementia. Access the first video below or access the full playlist.⁹

Alzheimer's Society - How does the brain work?



Looking at Alzheimer's dementia specifically, the 'Amyloid Cascade Hypothesis' has been proposed as the cause. The following *Brain* article explores this theory and the role of acetylcholine and neurofibrillary tangles and amyloid plaques: **Therapeutic approaches to Alzheimer's disease**.

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Prognosis and complications

Dementia is a life-limiting condition with no cure. The World Health Organization (WHO) describes the three stages of dementia, early, middle and late, and outlines approximate time periods for the progression of the condition:

- 'early stage – first year or two;

- *middle stage – second to fourth or fifth years;*
- *late stage – fifth year and after.*¹

It has been reported that people with dementia aged 65 years or older survive an average (median) of three to nine years after diagnosis of dementia, while some people may live for a further 20 years.¹⁰

Complications of dementia include disability, dependency and morbidity, BPSD, institutionalisation, carer morbidity and financial hardship. For more information about prognosis and complications, access the NICE CKS **Dementia, Prognosis** and **Complications** pages.

Many people with dementia will eventually need the support of a care home.¹¹ NICE quality standard (QS) **Dementia [QS184]** covers care for people with dementia provided by health and social care staff in hospital, community and specialist care settings.

The British Geriatric Society published a report in August 2021 which gives recommendations for people living in care homes.¹³ Two key areas which are particularly relevant for people with dementia are:

- 4.1 Cognitive impairment and mental health
- 4.6 Medicines optimisation

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Diagnosis/detection

NICE guidance **Dementia: assessment, management and support for people living with dementia and their carers [NG97]** Section 1.2, *Diagnosis*, outlines recommendations for initial assessment in non-specialist settings, diagnosis in specialist settings, and diagnostic tests used for the subtypes of dementia.

Section 3, *Diagnosing dementia*, of Book 1 in CPPE's **Dementia - focal point** distance learning explores diagnosis in detail and describes the different assessment tools available. Note that there may be an update document associated with this programme.

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Treatment

A single health or social care professional should co-ordinate dementia treatment and take a holistic approach by combining interventions to promote cognition, independence and wellbeing along with pharmaceutical treatment.¹²

The following video from Alzheimer's Society explores the different treatments for dementia, including pharmacological and non-pharmacological treatments for dementia and treating depression and anxiety.

Alzheimer's Society – Treatments for dementia: The dementia guide

In this section:

Drug treatments for dementia

NICE guidance ***Dementia: assessment, management and support for people living with dementia and their carers [NG97]*** outlines recommendations for initial assessment in non-specialist settings, diagnosis in specialist settings, and diagnostic tests used for the subtypes of dementia.

Section 4, *Management of dementia*, of Book 1 in CPPE's ***Dementia - focal point*** distance learning explores treatment options in detail, including the different pharmacological treatment options.

Behavioural and psychological symptoms of dementia (BPSD)

The following resources explore the management of BPSD.

Alzheimer's Society, ***Drugs used to relieve behavioural and psychological symptoms.***

NICE key therapeutic topic (KTT), ***Antipsychotics in people with dementia [KTT7].***

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Patient support

The Alzheimer's Society has a page, ***Get support***, which offers a range of information and support for those who suffer from dementia and for those who know someone suffering from dementia. Under this section, they offer the ***This is me*** document. *This is me* is a simple form for anyone with dementia, or who is experiencing delirium or communication difficulties, and receiving professional care. It is a space to provide details about who the person is.¹⁴

The Alzheimer's Society has the ***Dementia Friends*** programme which is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition.

Dementia UK offer information, advice and support for individuals and families affected by dementia.

The NHS offers a ***Help and support for people with dementia*** page.

Locally there are organisations that offer support to those suffering from dementia, examples of these include:

- ***Together Dementia Support*** is a not-for-profit community interest company offering support and therapeutic activities in Manchester for people living with dementia and their carers and supporters.
- ***Dementia Support*** is a young, unique West Sussex charity that provides complete dementia services under one roof in their new facility, Sage House.

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Further resources

CPPE's **Dementia** gateway page contains a variety of dementia related resources including:

- CPPE's **Dementia – focal point** distance learning
- **Dementia** e-learning developed and provided by Social Care Institute for Excellence and available via CPPE's website. This e-learning programme has been produced to support anyone who has contact with a person living with dementia.

There are several reports and publications that have influenced dementia care internationally and in the UK:

World Health Organization. **Dementia: A public health priority**. 2012.

Knapp M, Prince M, et al. **Dementia UK: The full report**. London: Alzheimer's Society; 2007.

Department of Health. **Living well with dementia: A national dementia strategy**. 2009.

Department of Health. **Prime Minister's challenge on dementia 2020**. 2015.

Alzheimer's Society. **Dementia 2013: The hidden voice of loneliness**. 2013.

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External websites

CPPE is not responsible for the content of any non-CPPE websites mentioned on this page or for the accuracy of any information to be found there.

All web links were accessed in August 2021.

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References

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2. National Institute for Health and Care Excellence. Clinical knowledge summary. **Dementia. Definition**. October 2020.
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12. National Institute for Health and Care Excellence. NICE guideline 97: **Dementia: assessment, management and support for people living with dementia and their carers**. June 2018.
13. British Geriatrics Society. **Ambitions for change: Improving healthcare in care homes**. August 2021.
14. Alzheimer's Society. **This is me**. No date.

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Last review: August 2021

Next review due: August 2022