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In this article...

- A description of the main types and causes of dementia
- The risk factors for developing dementia
- How to improve identification and diagnosis of dementia

Dementia 1: types, risk factors, and recognising signs and symptoms

Key points

Dementia is largely associated with old age but can occur at any age

There are 12 identified modifiable risk factors for dementia

Nurses are well placed to recognise some of the early signs of dementia

Once dementia is suspected, nurses need to be familiar with their local dementia diagnostic pathway to enable assessment

Early diagnosis can help people living with dementia to access the support they need

Author Karen Harrison Dening is head of research and publications, Dementia UK, and honorary professor of dementia nursing, De Montfort University.

Abstract Dementia is characterised by behavioural changes, and loss of cognitive and social functioning brought about by progressive neurological disorders. Undiagnosed dementia can have an insidious and devastating effect on outcomes for people with a possible dementia and their families, but we now know more about its causes and some of the factors – both modifiable and non-modifiable – that can increase a person's risk of developing the condition. This is the first article in a series to help nurses consider dementia and its recognition, assessment, treatment and management throughout its life course. Each article will build on an understanding of dementia that promotes the best possible care for those affected by the condition.

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Dementia is a syndrome occurring as a result of brain disease, which is usually chronic or progressive in nature. Several higher cortical functions – including memory, thinking, comprehension, calculation, learning, language and judgement – are impaired (Sandilyan and Dening, 2019). These impairments often accompany changes in emotional control, social behaviour or motivation. There are more than 200 subtypes of dementia, but the most common are Alzheimer's, vascular, Lewy body, mixed dementia (often a combination of Alzheimer's and vascular dementia), and frontotemporal dementias (Prince et al, 2014) (Table 1).

There are estimated to be 944,000 people living with dementia in the UK and projections are that this will increase to 1 million people by 2025 and nearly 2 million by 2050 (Wittenberg et al, 2019). While increasing age is considered the most significant risk factor for developing dementia in later life, people can develop it at any age (Kuruppu and Matthews, 2013). Of the total number of people with dementia in the UK, an estimated 7.5% (70,800) have young-onset dementia, whereby the onset of their symptoms occurred before the age of 65 years (Carter et al, 2022).

Types and causes of dementia

Alzheimer's disease is the most common form of dementia and is responsible for around 75% of cases, either on its own or with other forms of pathology (referred to as 'mixed dementia'). Although the cause of Alzheimer's disease has not been fully substantiated, it is suggested that it features the abnormal deposition of insoluble 'plaques' of a fibrous protein called amyloid and twisted fibres called 'neurofibrillary tangles' in the brain, which may play a role in its development (Attems and Jellinger, 2020). These plaques and tangles increasingly interfere with brain cell function. There is also deficiency of the neurotransmitter acetylcholine, which is important for learning and memory (Piggott, 2013).

In the early stages, memory loss for recent events and difficulties with

Table 1. **Common types of dementia**

Type, prevalence and cause	Characteristics

Alzheimer's disease
● Approximately 75% of all dementias
● Involves neurofibrillary tangles, amyloid plaque and atrophy of the brain
	● Slow, insidious onset with a progressive but steady decline, and symptoms that get worse over time
	● In the early stages:
	  ● Memory loss, especially for names and recent events
	  ● Word-finding difficulties
	● As the disease progresses:
	  ● Greater memory loss
	  ● Impaired visuospatial skills
	  ● Language difficulties
	  ● Impaired functioning of activities of daily living

Vascular dementia
● Approximately 20-30% of all dementias
● Abrupt or gradual onset as a result of the brain's blood supply being compromised by arterial disease
	● Formerly known as multi-infarct dementia
	● Focal neurological signs and of vascular disease, such as:
	  ● Hypertension
	  ● Diabetes mellitus
	  ● Arterial disease
	  ● Smoking
	● In addition to memory and language difficulties, the slowing of thinking processes, depression, anxiety and apathy are common

Lewy body dementia
● Approximately 10-15% of all dementias
● Lewy bodies are small aggregations of a protein that occur in neurons in various areas of the brain, including the cerebral cortex in dementia with Lewy bodies
	● Shares several characteristics with Alzheimer's disease and Parkinson's disease
	● Characteristic features are:
	  ● Visual hallucinations
	  ● Recurrent falls
	  ● Marked fluctuations in levels of conscious awareness
	  ● Disturbed sleep and/or nightmares
	● Features similar to Parkinson's disease include:
	  ● Trembling in limbs
	  ● Shuffling when walking
	  ● Reduced facial expression

Frontotemporal dementia
● Approximately 2-10% of all dementias
● Affects frontal regions of the brain responsible for planning, emotion, motivation and language
	● Formerly known of as Pick's disease
	● Affects a younger age group
	● Characteristic features include:
	  ● Disinhibited and socially inappropriate behaviours, and impaired judgement
	  ● Apathy
	  ● Decreased motivation

Mixed dementia	● More than one type of dementia can co-exist, causing mixed dementia. The most common type is mixed Alzheimer's and vascular dementias, when there are clinical characteristics and brain changes common to both conditions. This becomes much more common with advanced age (beyond 80 years)

Source: Adapted from Sandilyan and Dening (2019)

word-finding are the most common features (Taylor and Underwood, 2020). As the disease progresses, memory loss and language difficulties, alongside anxiety and lack of motivation, worsen over time (Castillo-Garcia et al, 2022).

Vascular dementia is the second most common type of dementia after Alzheimer's disease. The brain's blood supply is compromised by arterial disease, which results in reduced neuronal function and, eventually, the death of brain cells (Stewart, 2020). Many vascular risk factors contribute, including hypertension, hyperlipidaemia, diabetes, smoking, and unhealthy diet and obesity (Livingston et al, 2020).

Diabetes causes an increased risk of dementia, not only through vascular disease, but also through the cerebral deposition of compounds derived from the hormone amylin (Livingston et al, 2020). Vascular dementia may develop after a stroke, but progression is more often gradual rather than step-wise. In addition to memory and language difficulties, as in Alzheimer's disease, the slowing of thinking processes, depression, anxiety and apathy are common (Stewart, 2020).

Dementia with Lewy bodies is the third most common type of dementia, accounting for around 10-15% of cases (Rongve and Aarsland, 2020). It shares several characteristics with Alzheimer's disease and Parkinson's disease – the latter of which can also cause cognitive impairment and, eventually, dementia (Rongve and Aarsland, 2020).

QUICK FACT
944,000
Estimated number of people living with dementia in the UK in 2019

Lewy bodies, which are characteristic of this group of diseases, are small aggregations of a protein called alpha-synuclein that occur in neurons in various areas of the brain, including the cerebral cortex in dementia with Lewy bodies (Attems and Jellinger, 2020). Clinical features may include memory loss, as seen in

Alzheimer's disease, but visuospatial deficits are more prominent. There is difficulty in maintaining alertness, disorientation to space and difficulty in planning.

Characteristic features of dementia with Lewy bodies are visual hallucinations, recurrent falls, marked fluctuations in levels of conscious awareness and disturbed sleep and/or nightmares, which can be equally as distressing for family carers as for the person who has dementia (Brown et al, 2022). Features that are similar to those that occur with Parkinson's disease include trembling in limbs, shuffling when walking and reduced facial expression.

Frontotemporal dementia is a relatively uncommon type of dementia and covers a range of conditions that affect the frontal regions of the brain that are responsible for planning, emotion, motivation and language (Bocchetta and Rohrer, 2020). Half of people affected present with behavioural changes (behavioural variant frontotemporal dementia) and about half present with problems in speech and language.

Behaviour changes may affect the personality causing, for example, disinhibition, lack of empathy, lack of mental flexibility and difficulty in planning. Eating habits may also change, such as overeating and a preference for sweet foods.

Language problems may include difficulty in producing speech (primary progressive aphasia) or losing the meaning of words and concepts (semantic dementia) (Bocchetta and Rohrer, 2020).

More than one type of dementia can coexist, causing mixed dementia. The most common type is mixed Alzheimer's and vascular dementias, when there are clinical characteristics and brain changes that are common to both conditions. This becomes much more common with advanced age – that is, beyond the age of around 80 years – and a mixture of Alzheimer and vascular pathology is often seen at post-mortem examination (Stewart, 2020).

Risk factors

We may not have yet found a cure for dementia, but there are several contributory risk factors to consider, of which some are modifiable and others non-modifiable (Livingston et al, 2020). A third of all cases of dementia can be attributed to factors that are modifiable (Livingston et al, 2020), which suggests that having a better awareness of the risks could reduce the likelihood and impact of a person developing dementia later on in their life; as such, a focus on preventive measures across a person's life course is needed.

Table 2. Modifiable risk factors

Risk factor	Action to help reduce risk
Education	• Provide all children with primary and secondary education
Hearing	• Encourage use of hearing aids for hearing loss • Reduce hearing loss by protecting ears from excessive noise exposure
Air pollution	• Reduce exposure to air pollution and second-hand tobacco smoke
Traumatic brain injury	• Take precautions to prevent head injury, especially in sport-related activities
Alcohol	• Limit alcohol use, as alcohol misuse and drinking >21 units weekly increases the risk of dementia
Smoking	• Avoid smoking and support smoking cessation – this reduces the risk of dementia even in later life
Hypertension	• Aim to maintain systolic blood pressure of ≤130mmHg in midlife (from the age of ~40 years). Antihypertensive treatment is the only known effective preventive medication for dementia
Obesity	• Reduce obesity and the linked condition of diabetes. Sustain midlife, and possibly later-life, physical activity
Reduce inequalities	• Tackle inequality and protect people with dementia. Many risk factors cluster around inequalities that occur, in particular, in Black, Asian and minority ethnic groups, and vulnerable populations

Depression/ social isolation/ exercise	• Addressing other putative risk factors for dementia (such as poor sleep) through lifestyle interventions will improve general health. Tackling these factors will involve, not only health promotion, but also societal action to improve the circumstances in which people live their lives. Examples include:
	  ◦ Creating environments in which physical activity is a norm
	  ◦ Reducing, through better patterns of nutrition, the population profile of blood pressure rising with age
	  ◦ Reducing potential excessive noise exposure

Source: Adapted from Livingston et al (2020)

The 12 modifiable risk factors identified by Livingston et al (2020) are outlined in Table 2, and account for around 40% of worldwide dementias that could be prevented or delayed through a healthy lifestyle. Nurses have a role to play in terms of promoting and supporting healthier lifestyles in their patient populations.

Modifiable risk factors

Depression

People who have depression have greater difficulty remembering things, and individuals who have a history of depression or midlife stress seem to have an elevated risk of dementia; however, whether depression actually causes dementia is less clear (Sandilyan and Dening, 2019).

Depression or stress can accelerate the progression of dementia symptoms and lead to depression and dementia in later life. Those who are living with multimorbidity and frailty find opportunities to socialise increasingly scarce, which can lead to feelings of loneliness and increase the risk burden of dementia (Curelaru et al, 2021).

Cardiovascular and circulatory conditions

High blood pressure is the greatest risk factor for stroke, which can lead to vascular dementia. Stroke, in turn, is the single most important risk factor for developing vascular dementia and there is some evidence that it can also increase the risk of Alzheimer's disease (Kuller and Lopez, 2011).

Heart conditions such as atrial fibrillation and heart failure are also associated with greater risk of developing dementia.

People with diabetes are at an increased risk of developing dementia because of the harmful effect of high blood glucose on the brain and because of the effects of diabetes on small blood vessels (Livingston et al, 2020).

Lifestyle

Given the increased risks that are associated with cardiovascular and circulatory

conditions, lifestyle changes – such as eating a healthy diet and maintaining a healthy weight, not smoking, taking regular exercise and limiting alcohol consumption – to reduce the risk of developing these conditions can also reduce the risk of developing vascular dementia.

Smokers have a 50-80% risk factor for developing Alzheimer's disease; similarly, prolonged, heavy alcohol consumption or binge drinking can cause alcohol-related dementia (Taylor and Underwood, 2020). This is because increased alcohol consumption can cause damage to nerve cells and blood vessels in the brain. However, there is some evidence to suggest that the moderate consumption of red wine – that is, ≤14 units per week – is beneficial as part of a Mediterranean diet, and can also help to protect against dementia (Sabia et al, 2018).

Physical exercise and mental stimulation have also been shown to protect against cognitive decline (Valenzuela et al, 2012), with even regular low-intensity exercise potentially reducing risk (Winblad et al, 2016).

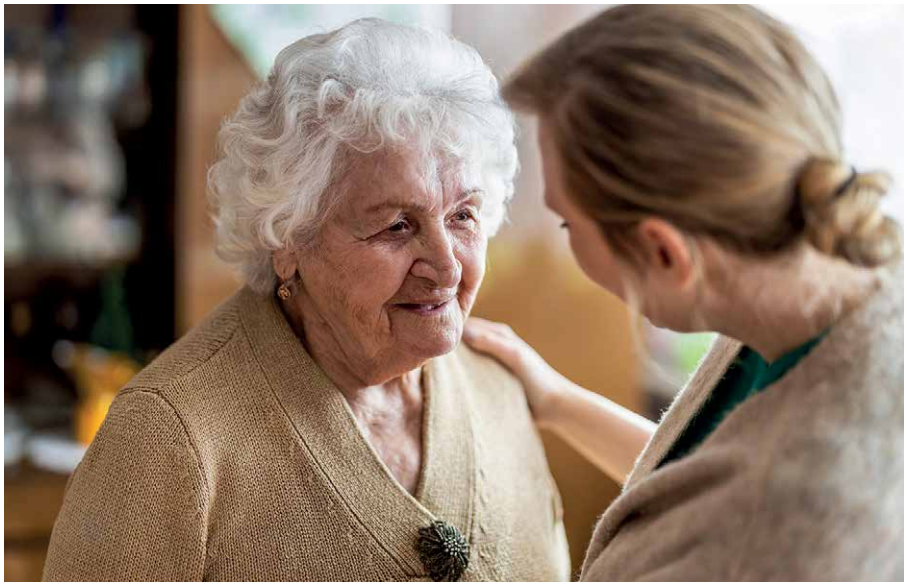
Untreated hearing loss

Untreated midlife hearing loss can increase the risk of dementia in later life as a result of cognitive overload, and reduced cognitive stimulation as the hearing loss progresses (Ray et al, 2018).

Non-modifiable risk factors

Age and gender

Age is the strongest risk factor for dementia: the highest diagnosed population are aged >65 years and more women are affected than men (Livingston et al, 2020). Although age itself is not a modifiable factor, delaying the onset of dementia through some health-promotion activities could lead to a reduction in the number of people who go on to develop the condition in later life.



"Nurses are in a unique position of being able to offer dementia risk-reduction advice and observe for changes in a patient's cognition"

Genetic factors

There is an increased risk of developing dementia for those with a family history of three or more generations of Alzheimer's disease: 86% of dementia diagnoses feature a mutation in the gene APOE, type e4 (Loy et al, 2014). The prevalence of dementia in people with a learning disability is two to three times greater than that of the general population, particularly for those people who have Down's syndrome (Holland et al, 2000).

Ethnicity

Black, Asian and minority ethnic communities all have differing cultural, biological and social dementia risk-factor burdens. These relate to a higher prevalence of diabetes, hypertension and cardiovascular disease than in White populations, as well as genetic variations and socioeconomic factors, such as levels of cultural understanding (Shiekh et al, 2021).

Improving identification and diagnosis

The National Institute for Health and Care Excellence (NICE) (2018) guideline recommends that people thought to have dementia should receive timely access to an assessment. A timely diagnosis enables people with dementia and their families to access effective care management and post-diagnostic support as early as possible in the course of the disease (Aldridge and Harrison Dening, 2019).

Nurses – and, in particular, practice and primary care nurses – play a key role in monitoring and supporting their patients with long-term conditions, which puts them in the unique position of, not only being able to offer dementia risk-reduction advice, but also to observe for changes in a patient's cognition that may be an

Table 3. **Early features of dementia**

Function	Normal cognition	Early dementia
Memory	Occasional lapses	Loss of memory for recent events
Orientation	Full in time, space and person	Variable disorientation in time and place
Judgement and problem solving	Solves everyday problems	Some difficulty with complex problems
Outside home	Independent functioning	Engaged in some activities but not independently – may appear 'normal self'
At home	Activities and interests maintained	More difficult tasks and hobbies abandoned
Personal care	Fully capable	Needs some prompting

Source: Adapted from Hughes et al (1982)

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early sign of a possible dementia. Nurses are also likely to be the first point of contact when people are concerned that they, or a family member, may have dementia (Robinson et al, 2015).

The conversations that primary care and practice nurses have with their older patients – added to their observations while checking blood pressure, weight, glucose levels or lung function – can contain clues about any worsening cognitive function (Iliffe, 2019). Having an awareness of the symptoms and changes that might occur at the beginning of the dementia process is important to ensure that people living with dementia and their families are able to access the support they need as early as possible (Aldridge and Harrison Dening, 2019).

When a person is suspected of having a dementia, it is important both to:

- Understand what can be attributed to normal ageing (Table 3);
- Identify and treat reversible conditions that mimic dementia.

Some conditions should be ruled out by relevant investigations before moving on to consider the cause of the problems being dementia. These include:

- Depression;
- Thyroid dysfunction;
- Nutritional deficiency;
- Infections;
- Metabolic disorders.

Opportunities to identify the condition

Many patients at higher risk of developing dementia are invited to annual health reviews for long-term conditions in primary care as part of the expectations laid out in the NHS's Quality and Outcomes Framework; this is an incentive scheme that rewards GP practices in England and Wales that improve the quality of care provided to their patients and helps standardise improvements in the delivery of primary care (Barrett and Burns, 2014). The Scottish equivalent is the Promoting Excellence 2021 framework.

There may be situations when a nurse seems to be alone in identifying changes in an individual. The person themselves may not recognise the extent of change or they may consider the changes to be an inevitable part of the ageing process. Family members, although often the first to recognise that something is different or wrong, may not recognise or seek advice about the changes they observe. They may also have anxiety about the changes they see in their family member or they may attribute them to other factors or life events (Robinson et al, 2015). A nurse, however, may be left feeling that these explanations do not fully explain these changes (Iliffe, 2019). Some nurses may feel that there is a risk of harm or of causing offence if they raise their concerns with the individual or with their family, but this is rarely the case (Iliffe, 2019).

A diagnosis of dementia should not be made on concerns about memory alone. As identified, many signs and symptoms may indicate a possible dementia. As part of the annual health review process for many long-term conditions, patients are asked the question: "Do you have any concerns about your memory?", when they can give a response of 'yes' or 'no'. Maximising on health checks and reviews can be vital in offering people with dementia and their families the opportunity to seek a timely diagnosis.

"A diagnosis of dementia should not be made on concerns about memory alone"

Although general population screening is neither welcomed by clinicians nor validated by research, there is some justification to consider screening those patients who are in a high-risk population – for example, those who have diabetes and people who have heart failure (Barrett and Burns, 2014).

Cognitive assessment measures – which one to use?

When testing or measuring a person's cognition, a validated, brief and structured cognitive instrument should be used (NICE, 2018). This may not be straightforward, as there are many brief cognitive assessment tools available for use. Lorentz et al (2002) contrasted and compared the utility of several brief cognitive measures and identified three that are both easy to administer and sensitive to identifying a possible dementia:

- Mini-Cog;
- Memory Impairment Screen;
- General Practitioner assessment of Cognition.

It is important for a care team to agree on which tool they will use for consistency of recording and acknowledging the results in their clinical interactions.

Whichever tool is used, consent from the patient must be obtained before administration; patients have the right to refuse. However, if a patient is thought to lack capacity, and is then deemed to lack capacity following an assessment conducted as outlined in the Mental Capacity Act 2005, health professionals may consider administering a cognitive assessment tool in their best interests.

Brief cognitive screening tools should not be seen as a diagnostic tool, but as an indicator for further investigation. Similarly, if a score does not indicate a problem with cognition, but the patient or someone close to them offers information that suggests that there are difficulties, referral to a memory assessment service for a fuller assessment is recommended (NICE, 2018).

Young-onset dementia

As with older people who have dementia, younger people may experience a wide range of symptoms, especially in the early stages. Identifying early symptoms in a younger person may be challenging and may also include:

- Depression and anxiety;
- Changes in behaviour;
- Neurological disorders;
- Systemic disorders;
- Mild cognitive impairment (MCI) (Draper and Withall, 2016).

Symptoms of young-onset dementia can be broadly categorised into three groups:

- Cognitive symptoms;
- Behavioural and neuropsychiatric symptoms;
- Neurological and other physical health symptoms.

Cognitive symptoms

Younger people with dementia are less likely to have memory loss as one of their first symptoms, as we will show in the next article in this series. However, these individuals may have:

- Problems with planning;
- Problems with organisation;
- Executive-function difficulties, such as not coping with work demands or making frequent mistakes at work or at home (May and Dening, 2020).

Behavioural and neuropsychiatric symptoms

Behavioural and neuropsychiatric symptoms are common in all dementias that affect the frontal lobes, particularly behavioural variant frontotemporal dementia. The latter, which presents with features such as apathy, social withdrawal, lack of empathy, socially inappropriate behaviour or out-of-character behaviour without any obvious memory impairment (Piguet and Hodges, 2013).

Neurological and other physical health symptoms

The term 'dementia-plus syndrome' may be used to refer to disorders in which cognitive impairment is associated with neurological or systemic symptoms (Sampson et al, 2004). Problems may be experienced with:

- Movement;
- Walking;
- Coordination or balance.

The course of young-onset dementia follows that of the underlying disorder that is causing it and, as with later-life dementia, is progressive, leading to a worsening of cognitive symptoms and a decrease in functional ability (May and Dening, 2020). People who develop young-onset dementia are less likely to get a timely diagnosis as their symptoms may be attributed, initially, to other causes, such as chronic depression, the menopause, MCI or stressful life events. As such, it essential that health professionals are aware of the risk factors and early signs.

Receiving a diagnosis of young-onset dementia can have significant consequences as the person may still be at work, have financial commitments (such as a mortgage) and be more likely to have dependent children. They are likely to be more physically active than people who develop dementia later in life, and so will have very different requirements for social and activity-based interventions.

Young-onset dementia should be considered as a potential diagnosis much earlier than often happens (Grunberg et al, 2021). It particularly needs to be considered if a person persistently adopts behaviours that are not in keeping with their character and previous behaviours (May and Dening, 2020).

Next steps in the diagnostic pathway

Alongside the administration of a brief cognitive assessment, nurses need to be aware of the further tests that should be carried out before making an onward referral to memory assessment. This should include:

- Dementia-screening blood tests and urinalysis to exclude other medical reversible causes of their symptoms;
- Where appropriate, screening for depression and anxiety (Arvanitakis et al, 2019).

After other reversible or treatable causative factors for cognitive changes have been excluded, it may be necessary to refer the person to the local memory assessment service for specialist assessment (May and Dening, 2020). Nurses should be familiar with local processes for further memory assessment, allowing them to be responsive in offering patients advice and information on what to expect next in the diagnostic pathway.

It is also important to offer the patient and their family information on where they can access specialist support and information, such as the Admiral Nurse Dementia Helpline.

Conclusion

Greater awareness of the risk factors for dementia throughout its life course can be used to good effect when it comes to applying health-promotion measures in a primary care setting. When dementia is suspected, a timely diagnosis is important to ensure there is adequate support and interventions and, where appropriate, access to treatment for families affected by dementia, be the dementia of young or late onset.

Primary care and practice nurses may often be the first port of call for people worried about their cognition or families who are concerned about a loved one. In particular, the possibility of young-onset dementia requires increased vigilance in primary care and there are many simple steps that can be taken to start the diagnostic process. **NT**

- The second article in this series will discuss young-onset dementia in more detail.

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