Keywords Recognition of dementia/ Diagnosis/Care settings

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In this article...

- Why it is important to make an early diagnosis of dementia
- How health professionals in different care settings can help with this process
- Assessment tools and methods that are appropriate to different settings

Diagnosis of dementia in different care settings: a guide for nurses

Key points

The risk of acquiring dementia is closely associated with increasing and advanced old age

A diagnosis of dementia made as early as possible enables people to access effective care

Understanding how to initiate an assessment for dementia is essential for all nurses and health professionals

It is important to be familiar with resources that are appropriate to different contexts

Recognition and assessment processes differ across primary care, acute hospital care and care home settings

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Abstract Dementia is a syndrome resulting in cognitive function deteriorating more quickly than it normally would in the ageing process. Although it is sometimes diagnosed when people are aged <65 years, the risk of acquiring a dementia is closely associated with increasing and advanced old age. If left undiagnosed, dementia can have a devastating impact on the health outcomes for both the person with dementia and their family carers and supporters. It is important that health professionals working in a range of care settings recognise the signs of a possible dementia and initiate assessment processes. This article discusses recognition and assessment processes across primary care, acute hospital care and care home settings, using illustrative case studies.

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Dementia is a global issue described by the World Health Organization (WHO) (2023) as a syndrome in which cognitive function deteriorates at a rate faster than would be expected as a consequence of normal ageing. There are many causes of dementia and, in Western countries, Alzheimer's disease is the most common, followed by vascular dementia, then mixed dementia (WHO, 2023). While dementia is sometimes diagnosed in mid life, the risk of acquiring dementia is closely associated with increasing and advanced old age, with one in four people aged >80 years living with it (Prince et al, 2014).

Globally, there are estimated to be ~55 million people living with dementia, with this figure projected to increase to 78 million by 2030 (Alzheimer's Disease International, no date). In the UK, estimates vary from ~950,000 people with dementia (Wittenberg et al, 2019) to around one million (Livingston et al, 2020); however, researchers who have generated these estimates agree that these numbers are significant and are set to rise over the next decade (Livingston et al, 2020; Wittenberg et al, 2019).

In a recent All-Party Parliamentary Group on Dementia (2023) report, it was stated that the current national diagnosis rate was only 63.8%, meaning that ~115,000 people are left undiagnosed and lacking care and support. The Department of Health's (2016) *Challenge on Dementia 2020* plan set out its mission to enable equal access to a dementia diagnosis for everyone through the Dementia Well Pathway, with GPs and primary care staff having a key role in diagnosis and in receiving meaningful care.

Diagnosing dementia

The National Institute for Health and Care Excellence (NICE) (2018) guideline, among many other things, recommends that people who are thought to have dementia

receive early and timely access to an assessment. Dementia, if left undiagnosed, can have an insidious and devastating impact on the health outcomes for both patients and their families, while timely access to information, support and services can help mitigate against distress and burden (Burgdorf and Amjad, 2023).

People with dementia usually present first to their family GP, or their concerns are picked up by another member of the primary healthcare team, and an initial assessment may take place, or a referral on to a specialist memory assessment service (Harrison Dening, 2023). A diagnosis made as early as possible enables people with dementia and their families to access effective care management and post-diagnostic support early in the course of the disease, which can greatly enhance their quality of life throughout the trajectory of the condition (Harrison Dening and Aldridge, 2021).

"Fear and stigma are still evident around dementia, presenting challenges for those requiring assessment"

Nurses can play a key role in the recognition and assessment of dementia in a range of care settings and contexts. For example, community and primary care nurses, especially where they are monitoring other long-term conditions, such as diabetes or chronic obstructive pulmonary disease, are in a unique position of not only being able to offer dementia risk reduction advice (Harrison Dening, 2023) but also in observing changes in the cognition of their patients (Harrison Dening and Aldridge, 2021). Similarly, nurses who are involved in various in-reach projects and programmes to care homes, such as enhanced health in care homes, can support the detection and diagnosis of dementia in this population (NHS England, no date).

Diagnosis in primary care

For many people worried about their memory, their first port of call may be their GP or other health professional who is already involved in the care of other long-term conditions, such as diabetes or asthma. Similarly, a family member may be the person to raise concerns about a relative who they feel has worsening memory problems, forgets to take medication or has deteriorated in their day-to-day functioning (Harrison Dening, 2019).

Box 1. Primary care diagnosis of late-onset dementia

Carol Morrison* is the only daughter of George and Gladys Wilson, who are 78 and 74 years old, respectively. Ms Morrison lives in the same village as her parents, having married a local boy. Her relationship with her parents is good and Ms Morrison drops in to see them every Sunday morning for coffee and they occasionally visit Ms Morrison for a Sunday lunch. Mr Wilson has largely been in good health over the years, rarely needing to see his GP, however, he has not recently been quite well and, after investigations, received a late diagnosis of advanced lung cancer. This came as a shock to all. The prognosis was discussed, from which Mr Wilson decided he did not want any chemotherapy or other treatments but to spend his last few months with his wife and family. After her father's death, Ms Morrison started to notice some problems in her mother's memory and general functioning around the home. Mrs Wilson was also very anxious after Mr Wilson's death and would frequently telephone Ms Morrison to ask where he was, forgetting that he had died. Ms Morrison took Mrs Wilson to see the GP for a check over.

*Patient's name has been changed

The case scenario in Box 1 illustrates the recognition and diagnosis of dementia in a person over the age of 65 years, known as late-onset dementia. Reviewing case studies offers ideas on how a nurse can improve both their clinical practice and, so, patient outcomes. It can also generate a deeper and multifaceted understanding of complexities encountered in a real-life clinical context (Seshan et al, 2021).

Recognising and diagnosing late-onset dementia

The population is ageing, with age being the greatest risk factor for dementia (Harrison Dening and Aldridge, 2021). Unlike young-onset dementia –dementia diagnosed under the age of 65 years, largely influenced by the original national retirement age (Alzheimer's Society, no date) – some of the earliest and most common symptoms of late-onset dementia are memory problems.

As noted earlier, for many people worried about memory loss, their first port of call may be their GP or other health professional already involved in the care of other conditions. However, not all older people experiencing memory problems are aware of these (termed 'anosognosia'), or they may simply put it down to old age. It may be that those close to them, such as family members or neighbours, gradually note differences and irregularities from the person's usual state. It may also be other primary care staff, such as a podiatrist with a longstanding relationship with an older person or a respiratory clinic nurse, who start to notice early signs of cognitive changes, such as missed appointments, increased falls or non-compliance with medication (Moore et al, 2023).

Spouses can often compensate for each other, and when one of the partners starts to experience memory problems or other signs and symptoms of possible dementia, may work to keep things appearing as normal as possible or be in denial of the possibility of dementia (Parker et al, 2022). Parker and colleagues, in qualitative semi-structured interviews, found that some carers created a "bubble of normalisation" around themselves and the person living with dementia to reject the label of dementia and protect the person with dementia from a loss of independence, discrimination and prejudice they felt would be the result of a diagnosis (Parker et al, 2022). However, if something happens to them, as in the case of Mr Wilson, the deficits of the person with a possible dementia can then be dramatically exposed. Sadly, fear and stigma are still evident around dementia, presenting challenges for those requiring assessment and reducing opportunities to access initial treatment and support.

The often-gradual onset and variable symptoms of late-onset dementia, especially in the early stage, can make it difficult for others to identify it. Sometimes, the individual with dementia may lack insight into their difficulties, which can also lead to delays in diagnosis. However, Ms Morrison (Box 1) was aware of the problems that her mother was experiencing and so took action. In the UK, while primary care professionals play a crucial role in identifying signs of dementia, they are also key to triggering a referral to secondary services for confirmation of diagnosis. Clinicians at the primary care level need to be familiar with warning signs that may indicate a suspected dementia and respond appropriately when family carers, such as Ms Morrison, raise concerns (Moore et al, 2023).

Table 1. **Cognitive screening tools used in primary care**

Tool	Source	Description
GPCOG (General Practitioner assessment of Cognition)	Brodaty et al (2002)	Two components: patient and informant questionnaire. The informant questionnaire is usually only necessary if results from cognitive testing are equivocal
6CIT (Six-item Cognitive Impairment Test)	Brooke and Bullock (1999)	Consists of six items. Easy to translate linguistically and culturally, and useful in milder dementia
Mini-Cog	Borson et al (2003)	A brief cognitive screening test that is simple and quick to use, taking three minutes to complete

After the initial GP consultation, where other potential conditions have been ruled out or effectively treated, the dementia assessment can begin – with the patient's consent. The GP or nurse will take a history of symptoms along with an assessment of cognition using an evidence-based brief screening tool (Fernandes et al, 2021). Table 1 shows the most commonly used assessment tools in primary care.

If dementia is suspected, the GP or other primary health professional may make an onward referral to the local memory assessment service where further tests, such as neuropsychological tests and a brain scan, may be carried out before the formal diagnosis is made. However, it is important to note that there is a waiting time for many memory assessment services, which has been exacerbated by the Covid-19 pandemic (Royal College of Psychiatrists, 2022). The Resources section features more information.

Recognising and diagnosing young-onset dementia

Gaining an assessment and diagnosis is not always straightforward for some, and especially so when the person is under the age of 65 years and experiencing possible young-onset dementia, which will often necessitate a specialist assessment.

Recognising the signs of dementia in a person under the age of 65 years can present more of a problem to generalist practitioners (health and social care professionals who are not specialised in dementia care) than in a person over the age of 65 years. Young-onset dementia (or early-onset dementia as it is also sometimes called) can bring with it a wide range of symptoms, including memory problems, confusion, personality changes, language issues or visual problems, though memory problems are less likely to be a first-line symptom, as it is in late-onset dementia (Gardner and Pepper, 2023). Early-onset dementia is not easy for GPs to recognise, so it is essential to rule out other possible causes of the symptoms that are experienced and seek a specialist referral to either a neurologist, clinical psychologist or psychiatrist (Kuruppu and Matthews, 2013) (see Resources). The course of gaining a diagnosis will then involve further investigations, such as a brain scan (for example, a computerised tomography (CT) or magnetic resonance imaging (MRI) scan; see Resources) and neuropsychological screening (Gardner and Pepper, 2023).

"Primary care professionals are key in triggering a referral to secondary services for confirmation of diagnosis"

For many people under the age of 65 years, and generalist health practitioners, it can come as both a surprise and, indeed, a shock that dementia could be a possible cause of their problems, as many may still believe that it is a condition that only affects older people. For some, there may be a reluctance to seek a diagnosis, even if they suspect this may be the cause of their symptoms, due to fear of stigma in their community or workplace. Many people with early-onset dementia often are still in employment and also may have a young family and financial commitments, such as a mortgage. For the purposes of employment, dementia is classified as a disability, so employers of people with young-onset dementia will need to provide support and adjustments, as the person has certain rights at work and has protection under disability and equality laws, such as the Equality Act 2010, not to be discriminated against at work because of their condition (Dementia UK, 2024).

Diagnosing dementia in acute hospitals

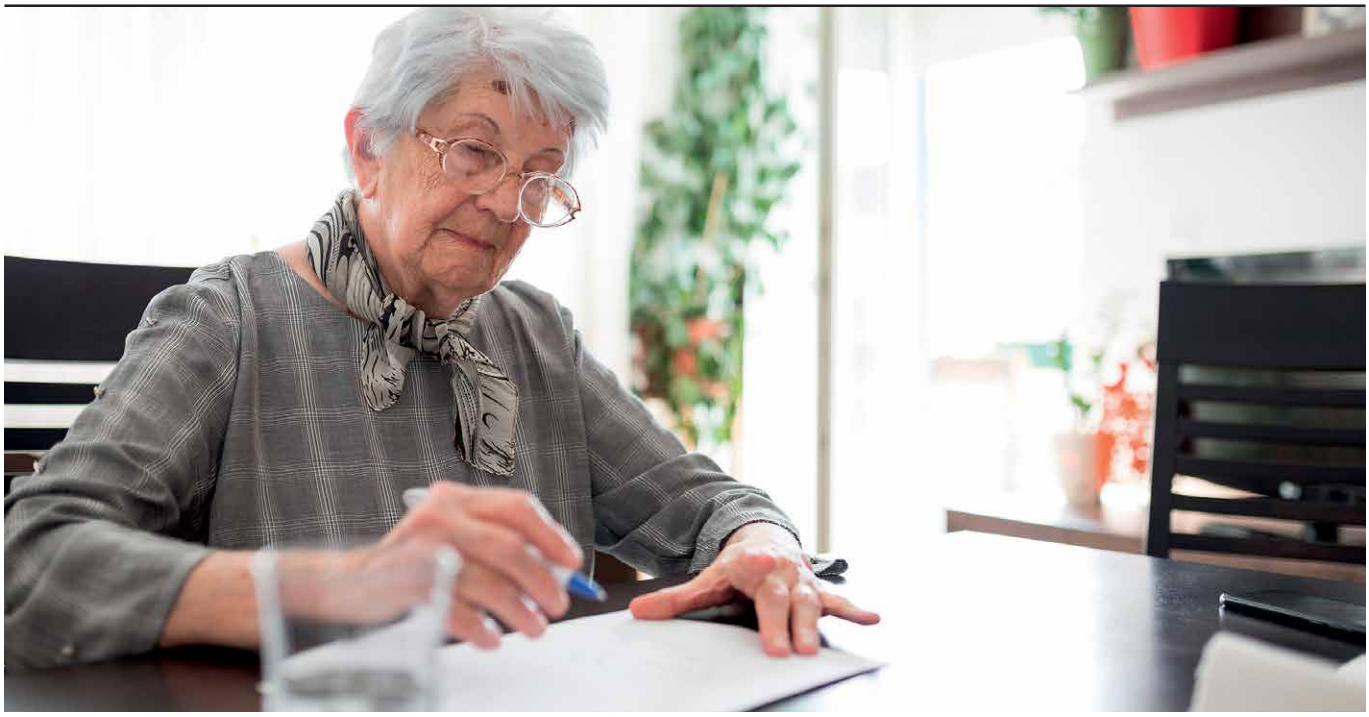
People above the age of 65 years with dementia, on average, have three or more physical comorbidities in addition to their dementia (Foster and Harrison Dening, 2023), which, at some point may necessitate a hospital admission. The prevalence of a pre-existing dementia in hospital ranges between 30% and 45% in adults over 70 years old, many of whom may not have been diagnosed (Timmons et al, 2015).

Acute hospital admission has been identified as a key opportunity for people with previously undiagnosed dementia to access appropriate assessment and diagnosis, not only to improve their care and treatment while in hospital, but to facilitate appropriate early discharge and enable access to a full range of post-diagnostic support and interventions (NICE, 2018). Diagnosing dementia when a person has a planned admission to hospital may

Box 2. **Diagnosis in an acute setting**

Rob Palmer* was found lying in the street early one morning outside his home by neighbours on their way to work, seemingly having fallen. They knew Mr Palmer and so called his GP, who advised them to call an ambulance. Mr Palmer was distressed and bleeding profusely from a large skin tear on his left arm and was unable or unwilling to stand. His neighbours told the ambulance staff his full name and address and the name of his GP, but then had to head off to work as they were already late. The ambulance staff took Mr Palmer to the local acute hospital and passed on what little information they had. Hospital clinicians were struggling to get much information from Mr Palmer as he was distressed, confused, disoriented and unable to find the right words, telling staff that he must get home to his wife. Mr Palmer was unable to provide his personal details or background, or give an account of what had happened.

*Patient's name has been changed



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be a very different scenario to an unplanned admission. It can be challenging to interpret a situation and determine what is going on when an older person with possible dementia is admitted to an acute hospital at a point of crisis, often for other health-related emergencies (Moore, 2019).

As shown in the case study (Box 2), there are some common issues to consider when an admission to an emergency department is unplanned.

Differential diagnosis of dementia and delirium in acute care

Many older people with dementia may attend an emergency department alone and as a result of a crisis, as did Mr Palmer, (Box 2) and be unable to give a personal history or account of events to the admitting and assessing clinician. There may be several diagnoses that you will need to differentiate between – such as delirium, dementia and frailty – and this may be difficult to do, especially if the person is unaccompanied and seemingly unable, as Mr Palmer was. The ideal would be for Mr Palmer to be able to provide information to guide clinicians in their assessment, which would enable a full physical and cognitive, behavioural and psychological assessment and (if possible) the impact symptoms have on daily life. However, this was not possible in Mr Palmer's case.

Both delirium and dementia would be possible diagnostic hypotheses when a person presents with a new confusion, alongside the need to exclude other potential causes or combinations of causes (Moore, 2019). Delirium can be diagnosed on a person's presenting medical history and tests of their mental status (Bond and Goudie, 2015). If indicators of delirium are identified, a health professional, trained and competent in the diagnosis of delirium, should carry out the assessment using an appropriate tool. If there is difficulty distinguishing between the diagnoses of delirium and dementia, the rule of thumb is to always consider delirium first, as it presents a clinical emergency (Jackson et al, 2017). Some quick and simple tools are available to use, such as the Single Question in Delirium tool (SQiD) (Sands et al, 2010), and 4AT, an assessment test for delirium and cognitive impairment (MacLullich and Hall, 2011).

QUICK FACT
408,000
Approximate number of people living in a care home in the UK in 2022

Some of the most common cognitive measures used are similar to those used in primary care, such as the Abbreviated Mental Test Score (AMTS) (Hodkinson, 1972), the Six-item Cognitive Impairment Test (6CIT), and the General Practitioner assessment of Cognition (GPCOG) (Brodaty et al, 2002) (Table 1). However, in a study by Casey et al (2023), they compared measures for their reliability, administration time and usability and found that the AM-PAC ACISF had the optimum mix of performance and feasibility for the fast-paced acute care setting. Though in a review of the many available measures, Velayudhan et al (2014) concluded that practitioners should use tests as appropriate to the setting and individual patient, and that some require further validation rather than the development of new ones.

Diagnosing dementia in care homes

In 2022, there were just over 408,000 people living in a care home in the UK, most of whom (around 360,000) were in England (Statista, 2023). It is estimated that about 70% of all care home residents will have dementia or some degree of a cognitive impairment (Prince et al, 2014). While many residents may already be in receipt of a diagnosis before they move into residential care, there are some that will develop dementia later, after their initial admission.

The Diagnosing Advanced Dementia Mandate (DiADeM), a diagnostic tool that can be accessed at diadem.apperta.org, was developed by the Yorkshire and Humber Dementia Clinical Network in 2015 and designed to increase the rate of diagnoses among residents showing signs and symptoms of cognitive impairment but not formally diagnosed with dementia. In these cases, a referral to memory assessment services may not be feasible or desirable and is likely to be both burdensome and distressing for the individual. The

Box 3. **Care home diagnosis**

Dawn Carter*, a 73-year-old woman, moved from her own home into a care home as she was extremely frail and became unable to manage by herself. Family members were unable to support Ms Carter at home to the extent she now needed due to their working and family commitments. During her first few weeks, care home staff felt that Ms Carter had signs of a possible dementia, such as trouble finding the rights word, disorientation over time and place, increased confusion and short-term memory loss. They raised concerns with the GP and the family, and all agreed to progress with using the Diagnosing Advanced Dementia Mandate tool to enable a dementia assessment rather than refer to the local memory assessment service. They started by undertaking physical health checks and tests to rule out other possible pathologies that may underlie her presentation. During this time, the care home staff and GP took a detailed history of Ms Carter's presentation and background when in good health, and then in the time leading up to her admission to the care home. All tests for other causes were returned negative and the GP administered a General Practitioner Assessment of Cognition, which revealed Ms Carter scored only three out of a possible nine, which indicates a cognitive impairment. A diagnosis of Alzheimer's disease was made without the need to refer to a secondary provider of a memory assessment service.

*Patient's name has been changed

DiADeM tool gives several prompts for the assessing clinician to consider, which are dissimilar to that undertaken in other care settings, and include:

- Consider whether the care home resident has functional impairment;
- Assess the resident for cognitive impairment using an abbreviated cognitive assessment tool, such as those noted above;
- Corroborate a possible diagnosis of dementia by determining whether the resident has a history of gradual cognitive decline, using information from their clinical records and medical history and information from care staff, relatives and friends;
- Carry out tests and investigations, such as blood tests and brain scans (where appropriate), to rule out other causes;
- Exclude an acute underlying and potentially treatable cause, such as delirium, mood disorder or psychosis.

People with advanced dementia, their families and staff caring for them can still benefit from a formal diagnosis. Generalist health and social care professionals may lack both the knowledge and confidence in assessing residents for cognitive impairment and in understanding the elements of the process to do so. The DiADeM provides a framework which allows care staff and other health professionals – including generalist practitioners and other primary care staff – to complete an assessment and, if necessary, refer to memory assessment services when they feel the presentation is more complex. Having an established formal diagnosis of dementia enables access to appropriate care and services to meet individual needs. It also prompts staff to consider issues that come under the focus of the Mental Capacity Act 2005 and in other circumstances where care might involve the application of a Deprivation of Liberty Safeguard to maintain the safety of a person with dementia from leaving the confines of the care home. However, it should always be borne in mind that, for some, their mental capacity can fluctuate (see Resources).

There are instances where a diagnosis of dementia can be facilitated when a person is resident in a care home that does not involve invoking the full processes of referral to a memory assessment service. This is especially the case where the presentation is relatively straightforward and there are no complicating factors, such as distressed behaviours, as in the presence of behavioural and psychological symptoms of dementia. However, it is important to still make a diagnosis of dementia in such circumstances, as it allows access to appropriate care and support for all involved.

For Ms Carter in the case scenario in Box 3, the benefits of a diagnosis enabled her care to be person-centred and embrace the disabilities arising from her dementia, such as in appropriate responses to communication difficulties (Pepper and Harrison Dening, 2023), as well as enhancing her quality of life. Aldridge et al (2023) suggested that there are positive outcomes for the use of the DiADeM in a care home setting, such as skilling and enabling staff to identify unmet needs, deliver person-centred care, adopt a palliative care approach and continue to discuss advance care planning. They go on to argue that the potential negative outcomes of a lack of a diagnosis of dementia, such as unnecessary hospital admissions, suboptimal pain management, and futile or burdensome treatments at the end of life, can be mitigated against (Aldridge et al, 2023).

Resources

- **Alzheimer's Research UK** *All You Need to know about Brain Scans and Dementia* (online)
- **Dementia UK** *Getting a Diagnosis of Dementia* (online)
- **Dementia UK** *Young Onset Dementia* Mental Capacity Act 2005 (online)
- **Social Care Institute for Excellence** *Deprivation of Liberty Safeguards (DoLS) at a Glance* (online)

Conclusion

Dementia is increasing globally and is of growing concern to health and social care services. Most cases of dementia occur in older adults, although they can occur in people under the age of 65 years, as in young-onset dementia. Recognising and understanding how to initiate an assessment is essential for all health professionals, irrespective of care setting. While there are some assessment tools and processes that may be specific to some care settings, it is important to be familiar with resources that are appropriate to different contexts. There are many benefits to be gained in receiving a timely diagnosis of dementia for both the person themselves and for their family members, as it can mitigate against many potentially negative health outcomes. **NT**

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