

Why you should read this article:

- To understand why diagnosing dementia is important in care homes
- To reflect on how a diagnosis of dementia enables nurses to deliver person-centred care
- To learn how dementia diagnosis rates in care homes might be improved

Dementia in care homes: increasing the diagnosis rate among undiagnosed residents

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Conflict of interest

Zena Aldridge is consultant editor for *Nursing Older People* and clinical adviser (dementia) for NHS England in the East of England. She is supporting pilot sites to replicate the model described in this article in collaboration with the national NHS England team. None of the other authors have any conflict of interest to declare

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Abstract

It has been estimated that 70% of care home residents have dementia on admission or develop it after admission, but that many do not have or receive a formal diagnosis of dementia. People with dementia often have significant care needs and it is important that the condition is diagnosed even at an advanced stage. This will enable nurses to predict the person's care needs, develop appropriate care plans and arrange pre-emptive decisions. In 2021-22, a quality improvement project took place in care homes in West Norfolk.

This project piloted an abbreviated memory assessment model based on the Diagnosing Advanced Dementia Mandate (DiADeM) tool to increase the rate of diagnoses among residents showing signs and symptoms of cognitive impairment but not formally diagnosed with dementia. Out of 109 residents assessed, 95 were diagnosed with dementia. The pilot is being extended locally and replicated across England.

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Keywords

advanced dementia, care homes, clinical, dementia, diagnosis, differential diagnosis, neurology, nursing care, older people, patient assessment, patients, professional, signs and symptoms

DIAGNOSING DEMENTIA is important because it enables healthcare professionals to identify unmet needs, deliver person-centred care and adopt a palliative care approach. Diagnosing dementia also supports advance care planning, pre-emptive decision-making and setting care goals. It has been estimated that 70% of care home residents have dementia on admission or develop it after having been admitted, but that many of these residents do not have, or do not receive, a formal diagnosis of dementia (Prince et al 2014, Organisation for Economic Cooperation and Development (OECD) 2018). Furthermore, there is a lack of

knowledge, skills and resources for diagnosing dementia in primary care and in care homes, which can negatively affect the timely recognition of signs and symptoms as well as care home residents' access to assessment and diagnosis (OECD 2018).

This article describes a quality improvement project conducted in 2021-22 in care homes in West Norfolk, England to increase the rate of diagnoses among residents, especially those with undiagnosed advanced dementia, by using an abbreviated memory assessment model based on the Diagnosing Advanced Dementia Mandate (DiADeM) tool (Alzheimer's Society 2023).

Importance of diagnosing dementia

In 2016 there were 11.8 million people aged 65 years and over in the UK, representing 18% of the population. It is estimated that by 2066 this number will increase to 20.4 million people, which will represent 26% of the population (Office for National Statistics (ONS) 2019). Older people often have complex health and social care needs and are at a higher risk of developing dementia than younger people (Livingston et al 2020).

Dementia is a life-limiting, progressive condition for which there is no known cure (Sampson and Harrison Denning 2021). Therefore, every person living with dementia will die with the condition, and often as a consequence of it (Sampson 2010, Sleeman et al 2014). In 2017 dementia was the fourth most common cause of death globally in people aged over 75 years, behind cardiovascular disease, cancer and respiratory disease (Ritchie et al 2018). In June 2022, dementia and Alzheimer's disease were the leading cause of death in England, accounting for 10.8% of all registered deaths (ONS 2022).

Comorbidities

The length of time between the diagnosis of dementia and death has been suggested to range between three and ten years (Wattmo et al 2014). The progression of dementia depends on the type of dementia and any comorbid conditions. Guthrie et al (2012) suggested that, on average, older people living with dementia have 4.6 chronic conditions alongside dementia, while other studies have indicated that 61% of people living with dementia have at least three comorbid conditions (Scrutton and Urzi Brancati 2016, Timmons et al 2016). Comorbidities in people with dementia include chronic obstructive pulmonary disease, chronic cardiac failure, hypertension, diabetes mellitus, sensory impairment, vascular or heart disease, musculoskeletal disorders and depression (Bunn et al 2016, Browne et al 2017, Denning and Milne 2021). Dementia and comorbidities can interact with one another, complicating treatment and/or accelerating or exacerbating one or more of the conditions (Fox et al 2014, Bunn et al 2016, Page et al 2018).

Advanced dementia

Of the 944,000 older people currently estimated to live with dementia in the UK, it has been suggested that approximately 593,200 live with advanced dementia (Wittenberg et al 2019). As dementia progresses to the advanced stages, people experience significant cognitive

and physical impairment (Moyle and O'Dwyer 2012). They are likely to be unable to verbally communicate, to be incontinent of urine and faeces, and to require support with all activities of daily living (Gage et al 2012, Kupeli et al 2018). They will therefore have significant care needs and it may not be possible to address those needs in a community setting, which increases the likelihood of admission to a care home (Sleeman et al 2014).

Diagnosis

A formal diagnosis of dementia, even in the advanced stages, can improve understanding of the condition and its effects, which in turn can enable healthcare staff to predict people's care needs and plan to address these appropriately (OECD 2015, Aldridge et al 2020). In its guideline on dementia assessment, management and support, the National Institute for Health and Care Excellence (NICE) (2018) recommends that people suspected of having dementia should receive timely access to an assessment, with benefits such as access to treatment and to specialist support and advice. However, in many instances this is still not the case and some healthcare professionals still question whether there is any value in diagnosing dementia (OECD 2018, Woods et al 2019).

Palliative care

The palliative care approach regards dying as a normal process and aims to provide the best possible quality of life until death for people with a progressive and life-limiting condition, their families and informal carers (Gamondi et al 2013, World Health Organization (WHO) 2020). This is achieved through early assessment, management and treatment of pain and any other physical, psychosocial and spiritual symptoms (WHO 2020). In dementia, NICE (2018) recommends a palliative care approach starting at the point of diagnosis all the way through to the end of life by offering 'flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be'. However, there is still a lack of recognition that the diseases causing dementia are progressive and life-limiting, which is a barrier to a palliative care approach in dementia care (Sampson and Harrison Denning 2021).

End of life care for people living with advanced dementia can be suboptimal and fragmented, which increases the risk of negative outcomes such as unnecessary hospital admissions, burdensome treatments, suboptimal identification and management of

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FURTHER RESOURCES

DiADeM Tool
www.yhscn.nhs.uk/media/PDFs/mhndn/Dementia/Dementia%20Diagnosis/2016/DiADeM/DiADeM%20Tool%20Final%2002092016.pdf
 DiADeM website
diadem.apperta.org/

pain, and death in hospital when this may not have been the person's preference (Goddard et al 2013, Dixon et al 2018, Kupeli et al 2018, Sampson et al 2018, Chu et al 2020). The absence of a dementia diagnosis makes it harder for healthcare staff to prevent, or reduce the incidence of, such negative outcomes.

Diagnosing Advanced Dementia Mandate (DiADeM) tool

The DiADeM tool was developed in 2015 by the Yorkshire and Humber Dementia Strategic Clinical Network. It was originally designed to support GPs in diagnosing dementia in care home residents living with advanced symptoms of undiagnosed dementia, in recognition of the fact that being seen in memory assessment services can be distressing and burdensome for this patient group (Yorkshire and Humber Strategic Clinical Network 2015, Alzheimer's Society 2023).

The DiADeM tool prompts the assessing clinician to (Yorkshire and Humber Strategic Clinical Network 2015):

1. Consider whether the care home resident has functional impairment.
2. Assess the resident for cognitive impairment using the six-item Cognitive Impairment Test (6CIT) (Katzman et al 1983) – or another assessment tool, such as the General Practitioner Assessment of Cognition (GPCOG) (Brodaty et al 2002).
3. Corroborate a possible diagnosis of dementia by determining whether the resident has a history of gradual cognitive decline, checking that history against medical records and the testimonies of care staff and relatives.
4. Conduct tests and investigations – such as blood tests and brain scans – where appropriate.
5. Exclude an acute underlying and potentially treatable cause such as delirium, mood disorder or psychosis.

Background to the project

In 2018, the first author of this article (ZA) piloted the use of an abbreviated memory assessment model based on the DiADeM tool to investigate possible dementia in care home residents. The pilot focused on care home residents considered by staff to have been experiencing signs and symptoms indicative of dementia. This enabled ZA to identify residents who had dementia, but also residents who had other conditions affecting their cognition, such as depression and anxiety, and residents whose cognition was affected by polypharmacy or suboptimal pain management.

The pilot emphasised how complex the needs of care home residents living with dementia (even if undiagnosed) can be, and that there appeared to be a gap in the skills, knowledge, confidence and resources in primary care required to universally adopt an assessment model based on the DiADeM tool. This revealed a need to enhance care home staff's competence and confidence in assessing residents and in engaging with families as part of that process, as well as their understanding of dementia, its effects and the value of diagnosis.

The pilot was considered to be a one-off project designed to increase the rate of dementia diagnoses to 66.7%, the target set by the then prime minister in the Challenge on Dementia 2020 (Department of Health 2015). Therefore, the work stopped once the dementia diagnosis rate in the locality had exceeded 70%. However, in the financial year 2021-22, NHS England made funds available to clinical commissioning groups (CCGs) to encourage healthcare organisations to consider innovative ways of improving their dementia diagnosis rates. This was in response to a significant decrease in the number of people with a recorded diagnosis of dementia and increased waiting lists in memory assessment services as a result of the coronavirus disease 2019 (COVID-19) pandemic (NHS Digital 2022). Residents and staff in care homes in West Norfolk, as in other areas of the country, had been negatively affected by the pandemic, notably through increased mortality (Gordon et al 2020), and care home residents were less likely than before the pandemic to receive a diagnosis of dementia (NHS England 2021).

NHS funding was applied for and obtained by Norfolk and Waveney Integrated Care Board to develop a model that would support care home residents to receive an appropriate assessment if they had signs and symptoms of cognitive impairment – a model that would be informed by the lessons learned from the 2018 pilot. The original approach needed to be adapted and the benefits of diagnosing dementia better communicated to ensure that this would be seen as a quality improvement project, as opposed to a tick-box exercise in meeting a dementia diagnosis target.

Aims of the project

The quality improvement project aimed to:

- » Increase awareness of the prevalence and effects of dementia in care homes.
- » Emphasise the importance of diagnosing dementia for care home residents living with undiagnosed advanced dementia, their families and professional and informal carers.

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- » Test an abbreviated memory assessment model based on the DiADeM tool for care home residents likely to have undiagnosed dementia.
- » Increase the identification of advanced dementia and of its differential diagnoses in care homes in West Norfolk.
- » Reduce waiting times for memory assessment and increase capacity in the local memory assessment and treatment service (MATS).
- » Consider creative solutions to improve care home staff's competence and confidence in investigating possible dementia.

Implementing the project

Acknowledging the need for skilled staff to support the project, Norfolk and Waveney CCG worked in partnership with Norfolk and Suffolk NHS Foundation Trust, which provides memory assessment services for the CCG. The collaborative relationship between healthcare professionals at the CCG and at the trust enabled the creation of a shared vision, clear communication regarding the aims of the project and the engagement of stakeholders.

Primary care professionals in West Norfolk were asked to share lists of their patients living in care homes who did not have a coded diagnosis of dementia (subject to appropriate data sharing agreements being put in place). Norfolk and Suffolk NHS Foundation Trust also identified people on the waiting list for its MATS who lived in care homes in the project area.

Once this information had been shared, the third author of this article (AN), a senior community mental health nurse and specialist memory assessor, attended the care homes and, working with staff, went through residents' records to identify those who had signs and symptoms of cognitive impairment. Those residents were assessed by AN using the abbreviated memory assessment model based on the DiADeM tool. This included history taking, assessment of cognition, discussions with families and care staff, and an investigation of comorbid conditions and potential issues with medications.

Once residents had been assessed, their case was discussed at a multidisciplinary team meeting, a diagnosis was reached and a referral made if required. The meetings were attended by, among others, the second and fourth authors of this article (KP and PC), a dementia nurse consultant and advanced nurse practitioner, respectively, who are both independent non-medical prescribers and could therefore review existing medications and recommend new ones. The outcomes

of the assessment, any new diagnosis, recommendations regarding medications and information about referrals were shared with the resident's GP. A letter template had been specially developed to support appropriate coding in primary care and ensure clear communication of any recommended changes to medication regimens and care plans.

This was a quality improvement project, so ethical approval was not required.

Outcomes of the project

Direct outcomes

Over the six-month period between November 2021 and April 2022, AN visited 19 care homes, went through the records of 440 care home residents and identified 114 who had been noted to have signs and symptoms of cognitive impairment. Among those 114 residents, five were found to have a historical diagnosis of dementia – three of whom had received their diagnosis in a different area of the country – and therefore did not require assessment. The other 109 residents were assessed by AN. Following assessment and discussion at a multidisciplinary team meeting, 95 were diagnosed with dementia.

Of the 109 care home residents who were assessed:

- » Eighty were unknown to Norfolk and Suffolk NHS Foundation Trust and 29 were known to the trust, of whom five had a diagnosis of mild cognitive impairment and two had a historical diagnosis of dementia that had not been correctly coded.
- » Thirteen were referred for further assessment and/or support to services such as the community mental health team, the MATS, neurology, speech and language therapy, and the improving access to psychological therapies (IAPT) team.
- » Four received a recommendation to start taking donepezil hydrochloride, an acetylcholinesterase inhibitor commonly used for the treatment of Alzheimer's disease, which while not curative can improve cognition and/or behaviour in some patients (Kumar et al 2021).
- » Three had their existing antidepressant reviewed.
- » Eight had their existing antipsychotic reviewed, of whom five received a recommendation to continue taking it and three received a recommendation to discontinue it.

Indirect outcomes

Informal feedback from care home staff and managers received by AN showed that there

Key points

- A formal diagnosis of dementia can improve understanding of the condition and its effects, which in turn can enable healthcare staff to predict people's care needs
- People in whom dementia is suspected should receive timely access to an assessment, with benefits such as access to treatment and specialist support and advice
- There is a lack of knowledge, skills and resources for diagnosing dementia in primary care and in care homes
- The project described in this article exemplifies how nurses can develop innovative solutions to address system challenges – such as the lack of capacity in memory assessment services

were perceived positive outcomes, such as improved relationships between care homes, primary care services and memory assessment services. Many staff members felt that their knowledge regarding the assessment and management of dementia had improved. Access to appropriate assessments was perceived as supporting decision-making and enhancing residents' quality of life. Furthermore, care home staff and managers said they felt they could approach AN directly for support, advice and assessments in a timely manner, which enabled a more person-centred approach to their care of residents.

Overall, families and informal carers expressed satisfaction with the project. AN received positive verbal feedback from families and informal carers, who said for example that they had been impressed with the information they had received; that the information had helped them make sense of their relative's behaviours and understand how they could better support them; and that having a diagnosis had given them peace of mind and reassured them that their relative would receive appropriate care and support in the event of a hospital admission.

AN was able to offer an abbreviated yet thorough memory assessment to 109 care home residents, some of whom were on the MATS waiting list and were consequently taken off that list, and some of whom would have otherwise been put on the MATS waiting list. The project has therefore taken pressure off the local MATS, which may have increased the local MATS' capacity and enabled its staff to focus on people with a more complex or earlier presentation.

Implications for practice

Nurses with expertise in dementia care and older people's care – and other healthcare professionals with similar expertise, such as psychologists – are well placed to:

- » Raise awareness of the importance of diagnosing dementia at any stage and therefore enable appropriate care and support.
- » Act as an intermediate resource between care homes and memory assessment services to assess residents' cognition.

Nurses with expertise in dementia care and older people's care can also contribute to improving the skills of staff in primary care and in care homes by being role models and through advice and guidance.

There is a need to close the gap in skills, knowledge and resources for diagnosing dementia in primary care and in care homes, as well as a need to promote a less medical model of dementia care (Aldridge and Harrison Denning 2019). This requires a shift in resources and culture. The project described in this article exemplifies how nurses can develop and deliver innovative solutions to address system challenges – such as the lack of capacity in primary care and memory assessment services – and promote best practice.

Norfolk and Waveney Integrated Care Board has committed to providing additional funding to replicate the project across the area as part of a longer-term plan to change the local service model for people living with dementia. Furthermore, NHS England and NHS Improvement, who deemed the pilot a transferable model of good practice, provided £900,000 in 2022 to launch two pilots replicating the project in each of the seven NHS England regions. The authors of this article are also supporting several areas – beyond the areas where the 14 pilots will take place – to adopt the abbreviated memory assessment model.

Conclusion

For residents who have signs and symptoms of cognitive impairment, living in a care home should not constitute a barrier to receiving a timely assessment for dementia from a skilled practitioner. Even in the advanced stages, a diagnosis of dementia enables staff to identify unmet needs, deliver person-centred care, adopt a palliative care approach and discuss advance care planning. This can, in turn, reduce the risk of negative outcomes such as unnecessary hospital admissions, suboptimal pain management and burdensome treatments at the end of life. The quality improvement project detailed in this article was regarded as a transferable model of good practice and is being extended locally and replicated across England.

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