Hospitals and care homes

Increasing access to a dementia diagnosis

Alzheimer's Society
United Against Dementia

Acknowledgements

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For a full list of thanks see the Appendix.

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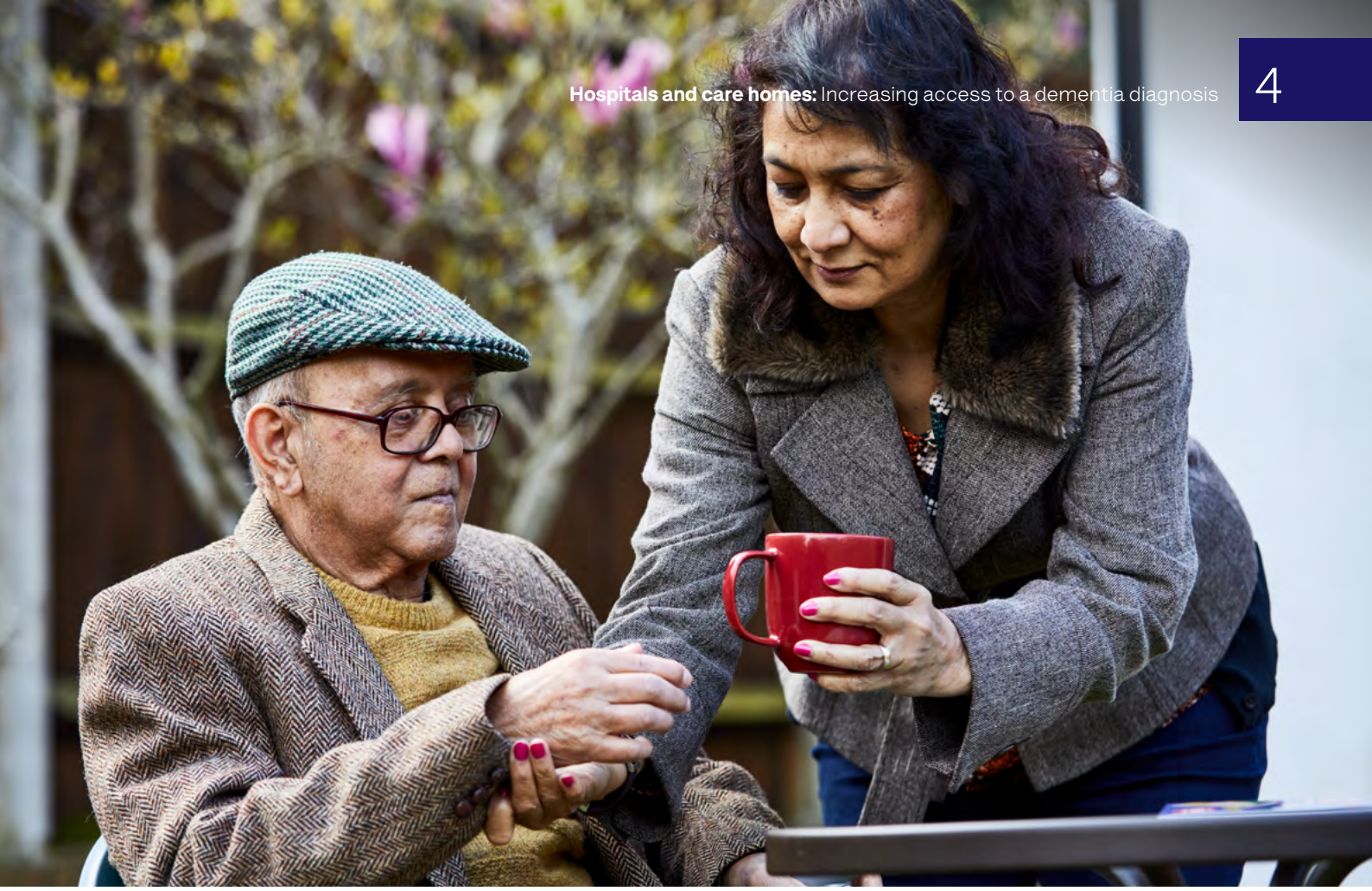


Executive summary

In 2020, Alzheimer's Society published a report on the dementia pathway, 'From diagnosis to end of life: The lived experiences of dementia care and support'. Grounded in the voices of people affected by dementia, it looked at four stages of NHS England's Dementia Well pathway:

Diagnosing Well **Supporting Well** **Living Well** **Dying Well**

It explored in detail what national guidance and government say people in England should be receiving at each stage, and therefore the care and support they say will enable people to live well with the condition. We benchmarked this against the experiences of people affected by dementia. A key finding of the report was a sense of disjointed, fragmented care.

The report laid the groundwork for deeper explorations into the dementia pathway. As part of a short series of reports into diagnosis, this report seeks to identify and address the barriers to diagnosis within a hospital and care home setting.

Many people who are worried about symptoms of possible dementia will contact their GP. However, the condition can often be identified in people in care settings such as hospitals and care homes.

Sadly, hospitalisations are common for people with dementia. Hospitals are often unsuitable environments for those living with the condition. While it is not appropriate to diagnose dementia in this setting in most cases, an admission to hospital is a good opportunity to identify and assess symptoms of possible dementia and provide people with an onward referral to a specialist memory assessment.

However, this report finds many issues with identifying and assessing dementia in hospital. Distinguishing between dementia and delirium is a significant challenge for clinicians.

Clinicians' ability to identify and assess the condition is often affected by a lack of:

Time **Skill** **Confidence** **Screening tools** **Access to patient information**

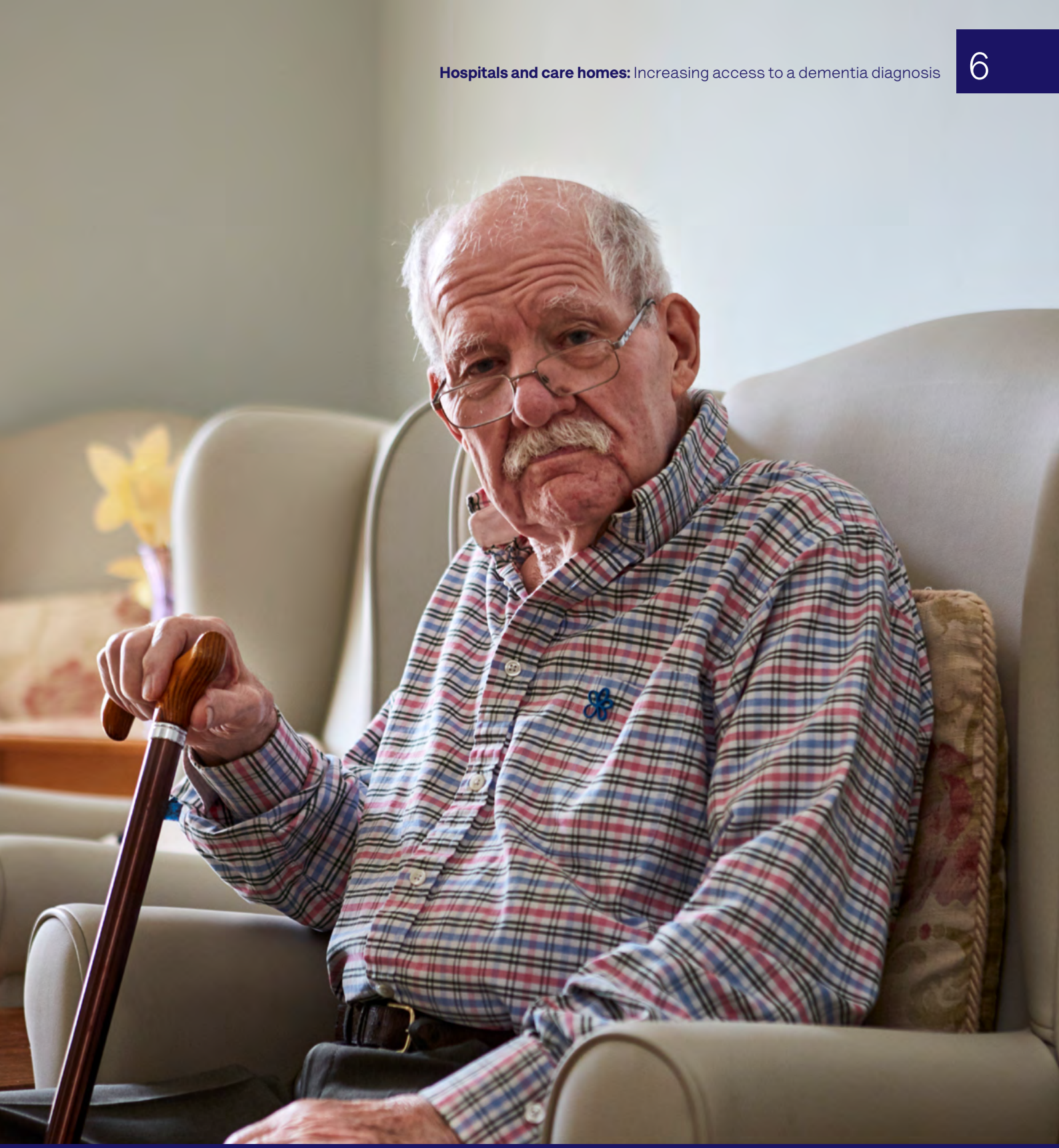
Prioritising the reason for admission and fears over complicating discharge processes may also influence the extent to which dementia is identified and assessed.

This report also finds that even when people with symptoms are identified and assessed in hospital, follow-up to specialist memory assessment does not necessarily happen. This means that people are falling off their diagnostic pathway before it even starts, leaving them and their families to manage their condition without any of the support a diagnosis facilitates.

In care homes, some people with dementia have a diagnosis and while others do not. This means that many people are unable to access effective care and support that would allow them to live well with dementia.

In this setting, identifying dementia can be challenging, particularly if staff have low levels of formal training around dementia. A lack of access to patient information and sufficient tools can impact assessment. An inability to access clinical services to facilitate assessment of dementia can also play a significant role. Lastly, this report finds that care implications resulting from a diagnosis and fears over having to move residency can also mean that both care home staff and families are reluctant to seek a diagnosis.

This report sets out a series of recommendations for improving access to a diagnosis in care homes and hospitals. As dementia is a complex condition, the provision of effective care requires an integrated approach. As such, Integrated Care Systems are ideally placed to undertake these recommendations and provide oversight and accountability for their implementation. This can only be achieved by bringing together all services and professionals involved in diagnosis, and fostering better working arrangements to increase the number and equality of timely diagnoses for people living with dementia.

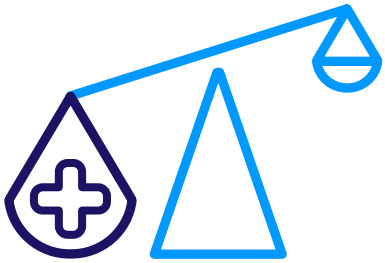


Introduction

Dementia is a progressive neurological condition. It occurs when the brain is damaged by diseases (such as Alzheimer's disease) or by a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function. The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia.

The importance of a dementia diagnosis cannot be overstated. It facilitates access to vital care and support that enables people to live well with the condition. Its significance is outlined in the Dementia Statements, which are grounded in human rights law:

'We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live'.[1]



The decades-long artificial divide between health and social care has meant that **people living with dementia have unequal access to effective healthcare**. This means many people have lived and continue to live without a diagnosis and appropriate support.

Though this report was developed outside of the context of COVID-19, it is important to acknowledge the impact of the pandemic on hospitals and care homes. COVID-19 put immense pressure on hospitals. While the NHS response rightly focused on the care of COVID-19 patients – many of these with dementia – it is likely that dementia identification and assessment took a backseat. For care homes, COVID-19 meant restricting access of carers, families and loved ones, resulting in deterioration of people living with dementia in this setting. Care homes reported being unable to let health and care teams in, limiting the opportunity for residents with suspected dementia to receive a diagnosis.

It is important to recognise that a diagnosis is not done in isolation. The move to Integrated Care Systems is a positive step, setting the footprint for improved health and access to services for care homes. Hospitals are also in need of further integrated health and care to support better identification and assessment of dementia and follow-up.

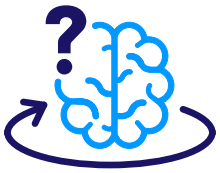
What needs to change?

Hospitals

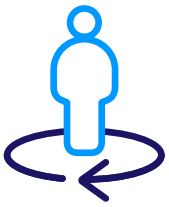
Integrated Care Systems should:

- ensure that acute hospitals' dementia pathways are integrated alongside pathways for common admissions for older people with dementia, such as stroke, delirium, hip fractures and falls, and for other admissions commonly affecting older people, such as influenza, pneumonia and chronic obstructive pulmonary disease
- consider dedicated dementia teams or workforces within acute settings to carry out dementia identification and assessment and support colleagues
- ensure that all acute hospital staff receive mandatory training, appropriate to their role, including:

identification of possible dementia symptoms and the process for assessment



delirium and its relationship to dementia



person-centred care for people affected by dementia

- ensure that, where possible, family and carers are involved in the assessment of dementia in an acute hospital setting
- ensure that sufficient IT and information-sharing processes are in place to support appropriate access to clinical information between primary care, acute and mental health settings
- ensure that acute hospitals review their discharge planning processes so that everyone identified with possible dementia is appropriately assessed. Discharge summaries should include all clinical investigations carried out during a hospital stay as well as clinical reasoning for referral to memory assessment
- consider the provision of a dedicated team or workforce to provide follow-up for patients identified with possible dementia in an acute setting, to facilitate access to memory services
- audit referral rates for people identified with possible dementia in an acute hospital setting to ensure those who are referred to memory assessment access one in a timely way.

Care homes

Integrated Care Systems should:

- ensure that care home staff can access training explicitly designed to improve the identification of cognitive impairment in residents, such as the DeAR-GP tool. Training should ideally be tailored to individual learning needs
- identify GP practices with high care home resident populations and low diagnosis rates, and work with individual GPs to improve the identification of possible dementia
- implement a process for primary care to review all new care home admissions for possible dementia
- review the provision of, and access to, community nursing teams for residential care homes to support better assessment and diagnosis of dementia
- explore a system of direct referrals from care homes to memory assessment. This should be accompanied by sufficient training for care home staff on dementia symptoms
- ensure that Clinical Leads for dementia promote DiADeM as a core part of engagement and training with local GPs
- ensure that care home records are accessible to diagnosing clinicians to support the identification, assessment and diagnosis of dementia
- monitor the implementation of the Enhanced Health in Care Homes model by local Primary Care Networks.


SIEMENS
MAGNETOM Prisma fit
A Tim+Dot System
No patient registered
Home
RADIOGRAPHER

Hospitals

Distinguishing between dementia and delirium

In 2012-13, the Department of Health introduced a mandatory policy ensuring all hospitals across England routinely carry out case finding of dementia – the Commissioning for Quality and Innovation framework (CQUIN).

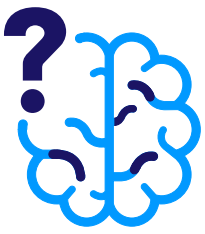
This includes carrying out cognitive tests for all people aged over 75 who have an emergency admission. Those who are identified with possible dementia are assessed and then referred on to specialist assessment.[2] Since many older people in hospital may have undiagnosed dementia, the initiative is intended to identify cognitive impairment earlier and provide a timelier diagnosis.

Pre-existing cognitive impairment for people who are hospitalised is estimated at between 15% and 42%.[1,2,3,4,5,6,7] Many of these patients may not have had a previous diagnosis of dementia.[8,9] Although dementia prevalence is high in a hospital setting, one study suggests that around 56% of patients with dementia in hospital are undiagnosed or their condition is unrecognised by health and care staff.[10]

However, identifying dementia correctly is a significant challenge. The most difficult task is distinguishing between delirium and dementia. Both are disorders of cognitive function, are associated with adverse health outcomes, and are intricately linked.[11]

Delirium is a state of heightened mental confusion which commonly affects older people admitted to hospital, with 96% of cases experienced by older people. When older people with delirium experience a severe illness or trauma, such as a hip fracture, they are at higher risk of delirium.[12]

There are many potential medical causes of delirium, including infections, drug initiation and withdrawal, and stroke. A further difficulty is that around 15% of cases of delirium do not have an adequate medical explanation.[13]



In our survey of professionals working in the hospital setting, **81% reported that distinguishing between dementia and delirium is a particular challenge** in identifying possible dementia in a hospital setting.

Further engagement with Clinical Commissioning Groups (CCGs), memory services and our own support services reported similar difficulties. In older patients with delirium, it is thought that around 36% of those with dementia had a recorded diagnosis of dementia.[14] Delirium is often undetected in hospitals and can increase the likelihood of false positives resulting in misdiagnosis.[15,16]

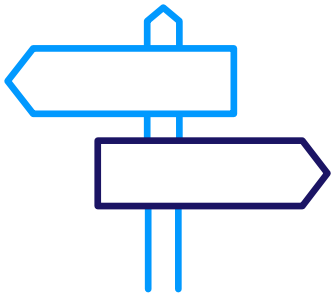
Another challenge is how long delirium lasts. While it gets better in most cases, recovery may be slower in others.

40%
of cases persist at two weeks

33%
of cases persist at one month

25%
of cases persist at three months[17]

Identification of delirium and possible dementia are essential to the care of older people when they are admitted to hospital. However, the 2018-2019 National Audit of Dementia (NAD) found that just 58% of people with dementia were assessed for possible delirium. **Further to this, the audit also found that, excluding those with recorded reasons (such as the patient being too unwell to be assessed), 28% of patient case notes had no record of cognitive testing or of an initial assessment for indicators of delirium during admission.**[18] Symptoms of delirium can fluctuate and change rapidly, so cognitive tests scores may not accurately identify long-term cognitive impairment or dementia.[19]



The NAD found that just 64% of hospitals had an explicit delirium care pathway in place.[20] **It is important there are clear delirium and dementia identification pathways in hospital**, to ensure that those patients who are admitted to an acute setting and who may have dementia can be appropriately assessed.

Prioritising needs and care

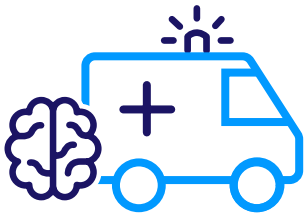
People with dementia are hospitalised for a variety of reasons, but typically in crises. The reasons for admission typically include:

Immobility **73%**

Falls **64%**

Pain **54%**

Breathlessness **23%**



There has been a 27% increase over a four-year period in emergency hospital admissions for people with dementia. Many of these are the result of poor care provision within the community. For these emergency admissions, almost two-thirds (65%) could have been avoided.[22]

Because dementia is more common in older people, frailty is a significant risk factor for hospital admission. Three-quarters of hospitalised patients with dementia have been identified as frail, compared to one-quarter of those without dementia.[23] Other common emergency admissions, particularly for older people, include flu, pneumonia and chronic obstructive pulmonary disease.[24]

Admissions of older and frailer people, particularly those with dementia, are unlikely to have a single pathology through their hospital journey, with many admissions having multiple pathologies. Nurses reported that admissions based on physical impairments are likely to influence the dementia identification and assessment pathway.

The primary aim of hospital clinicians is to provide care for the condition for which a patient has been admitted. Assessing cognitive impairment may be seen as secondary. A 2014 CQC report found that hospital assessments for patients living with dementia too often focused on care of their physical needs, with limited provision of care for emotional, cognitive and psychological needs.[25]

For example, for those admitted to hospital with a hip fracture, the hip fracture pathway is likely to take precedence, and dementia identification and assessment will be secondary. Nurses also reported that older and frailer people are likely to have multiple comorbidities, which can complicate the effective identification and assessment of possible dementia.

This is another reason for the importance of explicit delirium and dementia pathways in hospital. It may be appropriate to integrate these pathways with common admission reasons for older people, such as delirium, stroke, hip fractures or falls.[26] **The NAD found that whilst most hospitals (96%) had a dementia pathway integrated with delirium, this was less likely for stroke (47%) and hip fracture (58%) pathways.**[27] Further integrated pathways for common admissions for older people, such as influenza, pneumonia and chronic obstructive pulmonary disease may also prove beneficial.

Lack of staff time, skill and confidence

Hospital staff have previously reported struggling with managing the needs of people with dementia, which are often complex.[28] During our engagement, clinicians reported that this may still be an issue today.

In our survey, professionals working in the hospital setting are facing particular challenges in identifying dementia:

43%
report a lack of staff time

48%
report a lack of staff skill and expertise

43%
report a lack of staff confidence

Poor understanding or misinterpretation of dementia can hinder examination and investigation.[29] Though it is a basic medical competency, mental state examination is often unfamiliar territory for physicians and is rarely completed sufficiently.[30]

A Care Quality Commission (CQC) report in 2014 found that 56% of hospitals had aspects of variable or poor practice, including where assessments were not comprehensive enough in identifying all a person's care needs. In A&E departments as well as wards, only physical causes for patients displaying symptoms associated with dementia or delirium were investigated.[31]

The report also found screening, as part of the CQUIN, was not always completed, even though a referral was made. This means that many people with undiagnosed dementia who are admitted to hospital and then discharged do not receive a cognitive assessment – their dementia remains undetected and undiagnosed.[32] There may be a resulting impact on specialist memory assessment services too: the lack of cognitive testing can make a referral insufficient and potentially inappropriate.

Dementia is a complex condition and it can be further complicated by a hospital admission. It is important that appropriately skilled clinicians – such as geriatricians, psychologists and psychiatrists – conduct testing on admitted patients who are suspected with dementia or delirium, or both.

In our survey of hospital clinicians, **62% said that specific dementia staff or teams would help facilitate a better identification and assessment process**.

A lack of standardised and structured training in the assessment and diagnosis of cognitive disorders leads to professional under-confidence, which can impact the recognition of possible dementia in a hospital setting.[33] Hospital professionals reported that training can be variable, and that when it is implemented it is often sporadic.

To enable better identification and assessment of dementia, 48% of survey respondents felt that improved staff training would be effective. Mandatory training, particularly for older people hospital teams, would help to facilitate improvements in the skill and confidence of staff. **Research suggests that dementia education and training is most effective when it is tailored to roles as well as inclusive of a commitment to person-centred care.**[34]

Difficulty collecting patient information

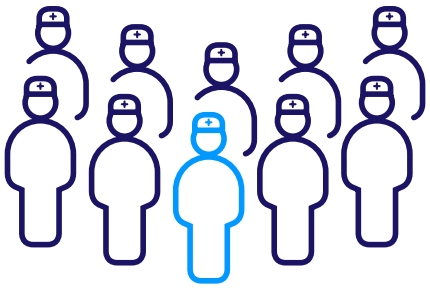
In our survey of hospital professionals, almost 4 in 10 (38%) said the difficulty of collecting patient information and collateral history was a significant barrier to identifying dementia. This is important because cognitive tests alone are not sufficient or reliable enough to identify possible dementia.[35]

Obtaining information about a person's condition, particularly baseline cognition before hospital admission, is critical to ensuring proper identification and assessment of dementia. However, this is sometimes carried out poorly.[36] Hospital clinicians reported that collecting patient history or collateral information is harder with patients who are more advanced in their condition and who live alone or have no family present during their hospital stay.

Other hospital clinicians told us that access to patient information was challenging. They identified the reliance on patient-reported information and symptom history from families and loved ones. But research suggests that engagement with families is poor. **One study found that patients and carers were often unaware that memory assessments had taken place during hospital admissions, or that patients had been assessed alone without a family member or carer present or notified.**[37]

Accessing information can be difficult either between health settings or within the hospital setting itself. Clinicians reported that accessing information to inform the next clinical decision can sometimes take up to four hours and is often reliant on the willingness and ability of staff to seek this information.

Clinicians told us that better engagement with families can support the identification and assessment of people with possible dementia in hospital settings. In the absence of family or carers, closer collaboration between mental health and hospital healthcare services can also improve access to diagnostic information and recognition of possible dementia.[39]



In our survey, **9 in 10 hospital clinicians (90%) reported that improved access to information** – for example, between acute trusts, primary care and mental health trusts – **will enable better assessment of possible dementia in hospital**.

Challenges assessing dementia

The assessment and diagnosis of dementia is complex, so most screening tools are used to identify cognitive impairment. Assessments for identifying dementia, or distinguishing between delirium and dementia, can include blood tests, collateral history and cognitive assessments, including short and long-term memory, language, executive function and attention and concentration.[39]

We heard it is good practice to conduct routine, brief cognitive testing on older patients admitted to hospital. Where test results are abnormal, then follow-up testing, including collateral history, should be carried out. However, mental state examinations can be hindered by hallucinations, delusions, depression and anxiety. An assessment of speech may be easier to carry out, but previous research suggests that conducting this within the context of cognitive impairment is rare.[40]

Cognitive testing, a reliable method for detecting possible dementia in other health and care settings, is ineffective when delirium is present. This is because symptoms of delirium can change and fluctuate rapidly, so tools to detect and identify dementia through measurement of cognitive deficits become less useful.[41] Both delirium and dementia cause confusion, which can become worse in a hospital environment, meaning that it is hard to tell whether a patient has delirium, dementia, or both. Dementia is also the strongest risk factor for developing delirium.[42] **It is thought that delirium on top of dementia accounts for around 65% of all delirium cases in hospital.**[43]

In hospital, limited capacity can mean less time spent with patients. This could hinder the effective assessment of possible dementia, particularly since assessment of people with cognitive impairment takes time and proper attention. Even without dementia or delirium, older patients in acute hospital settings may also perform poorly on cognitive tests due to other factors, including pain, sleep deprivation and medications that can cause drowsiness.[44] Cognitive tests can also be impacted if there are language barriers between the patient and their clinician.

Fear of incorrect diagnosis

In our survey of healthcare professionals, almost 4 in 10 respondents (38%) stated that fear of giving an incorrect diagnosis was a factor in the assessment of possible dementia.

Many clinicians, including geriatricians, may hesitate to diagnose dementia.[45] This can be due to fears of factors such as causing unnecessary anxiety, medication side-effects, stigma, and additional strain on families.[46]

Whilst hospital geriatricians, psychologists, psychiatrists and other clinicians may have sufficient experience and clinical expertise to provide an assessment and diagnosis, it is generally considered best practice to not diagnose in a hospital setting given the likelihood of delirium and comorbidity presentations. **Memory services, CCGs and our own support services told us they had experience of misdiagnoses being given in a hospital setting, which caused frustration and worry for the patient and their families.**

However, while a diagnosis should not be given in a hospital setting in most cases, an admission to an acute setting may provide an opportunity to conduct some of the diagnostic assessment for those identified with possible dementia. Use of cognitive instruments may enable clinicians to understand history and cognitive decline. A hospital setting may be a good opportunity to conduct routine blood testing which could further support future dementia assessment. Brain scanning may be more accessible in acute admissions with possible dementia as opposed to those in the community.[47]

The importance of skilled staff should be considered. Nurses and other clinicians interpret information such as test results and patient- or family-reported history of symptoms, which can help to show a patient's cognitive decline. While a diagnosis should not naturally follow after this, it supports the provision of information passed onto GPs and memory services, potentially reducing the need for further work up by these services.[48]

Complicating the discharge process

Fear of complicating discharge processes was a significant barrier identified by clinicians. Ideally hospitals are best avoided for people with dementia, and professionals may be concerned that dementia identified in hospital may complicate and extend the time patients spend in this setting. Research suggests that a dementia assessment and diagnosis causes hesitancy in hospital clinicians regarding discharge and placement planning.[49]

This may have arisen from NHS England's ambition that discharge planning should happen at the point of admission, with a patient's time viewed as the most important currency in healthcare. A second ambition ensures frail people are discharged immediately once their acute care is complete.[50] These principles could impact sufficient assessment in patients with possible dementia, since guidance requires clinicians to see a frail patient's stay in hospital as the most important.

Whilst this is true, particularly for people with dementia, better discharge planning processes should be in place to ensure that this does not deter clinicians from conducting dementia assessment.

There is a need for a clear referral pathway, particularly from those clinicians trained to deliver this support. This is especially important given the time people with dementia spend in a hospital environment.

Our analysis of the Hospital Episode Statistics dataset found that **over 40,000 people with dementia were in hospital following an emergency admission** between a month and a year in 2017/18 – a 6% rise since 2012/13.[51]

Lack of assessment follow-up post-discharge

During our engagement with CCGs, memory services, hospital clinicians and our own dementia support services, the clearest issue relating to hospital settings was the lack of diagnostic follow-up after a hospital admission.

Research suggests that case finding in hospitals does not necessarily lead to GP follow-up after discharge, or to referral for further investigation by specialist diagnostic services. In fact, few services were initiated because of dementia case finding in hospital.[52] During our engagement with clinicians, we found various reasons for this.

First, feedback loops between hospitals and community mental health teams, where many memory services are located, are impacted by the lack of information sharing. Often, a lack of compatibility between separate IT systems in acute and community settings can worsen a lack of communication and of access to information. Hospital clinicians also reported that they are often unaware of whether a person had a memory assessment after being identified with dementia in hospital. **In some cases, clinicians told us they had identified people with possible dementia, referred them to memory assessment, and later saw them readmitted to hospital still without a diagnosis.**

Second, GPs reported difficulties regarding discharge letters to primary care from acute hospital settings. Sometimes a discharge letter may be insufficient, with a lack of clinical information that would enable GPs to make an appropriate referral to secondary care diagnostic services. Although in most instances, copies of discharge plans and summaries are sent to GPs or primary care teams,[53] GPs reported receiving a mixed bag of information regarding which clinical processes and tests the patient has undergone.

GPs must therefore extract and piece together disjointed information to make an appropriate referral. We also heard of GPs having to phone patients to ask about their time in hospital to gather the right information. Time and capacity at primary care level may also impede an onward referral process.

Discharge plans should contain up-to-date information to support onward care. This is particularly important where possible dementia is identified in a hospital setting and therefore requires other care settings – primary and secondary mental health – to support access to a diagnosis.

However, an audit of hospitals found that, **of those who had symptoms of delirium during admission, just under half of patients (47%) had their symptoms summarised for discharge.**[54]

Third, clinicians told us that, given the strong possibility of delirium in hospital for people with dementia, it is appropriate that the patient is given a 'period of stability' to allow them to return to a normal baseline. This is to ensure any presentations caused by a hospital admission have receded and a valid assessment of their cognition can be carried out in better conditions. Around one-quarter of delirium cases (25%) last up to around three months,[53] so an effective assessment for possible dementia should not occur before this.

However, we found two issues with this. Memory services told us that GPs will sometimes not wait for the period of stability to end, and directly refer to specialist diagnostic services. As a result, a referral to a diagnostic service may not be appropriate because the patient has not returned to a suitable baseline with which to carry out a valid assessment. Another issue is that extended time without clinical intervention can result in people falling off the diagnostic pathway. **GPs, memory services and hospital clinicians described referrals being lost due to workload pressures.**

Nurses reported that the extent of follow-up depends on the condition of the patient. If a patient has been identified with possible dementia in hospital but memory or cognitive impairment is not as advanced, and they have a support network around them, this can help facilitate access back to a memory assessment. However, for patients who have been identified with possible dementia and are advanced in their condition, with little support network around them, it is much harder for them to reach back for referral into a memory assessment.

To avoid this, we heard it is good practice to have an explicit team or named clinician to provide outreach to patients who have been identified with possible dementia. They can facilitate access back into the diagnostic pathway via the patient's GP or memory service. This service could be delivered by a community or district nurse or social prescriber. This may be supported by the move to Primary Care Networks and the provision of more community-based care. Audits of referral rates for people identified with possible dementia from an acute setting to specialist assessment may also show where improvements can be made.

What is best practice?

Doncaster Acute Hospital Liaison Service

The Acute Hospital Liaison Service, as part of the broader Doncaster Older People's Mental Health Liaison Service, facilitates the assessment and treatment of older people with mental health needs while in hospital. It also provides support by guiding, educating and developing the skills of acute hospital and hospice staff.

To improve patient outcomes and experience, the team provides a seamless service for older people while they are in acute wards. It ensures a smooth transition between wards, departments and services focusing on the individual, supporting a timely discharge and reducing delays.

It also liaises with acute hospital management and staff, and helps increase the confidence and skills of staff, enabling them to effectively manage the range of mental health conditions encountered in an acute environment. This includes assisting in developing and delivering appropriate education packages and advice to hospital staff based on best practice and individual needs.

The service is made up of mental health nurses and mental health physiotherapists, and clinical work is managed by the team's nurse. The team also has input from a Consultant Psychiatrist and admin support.

The team will respond to local hospital ward referrals for assessment, advice and support regarding patients in an acute environment with a recognised mental health condition or suspected mental health needs. A Nurse Consultant will provide expertise, supervision and consultation whilst managing a caseload of patients independently. The service accepts referrals for people with both delirium and dementia, as well as other mental health needs such as anxiety or depression.

Cumbria's 'REACH Out' Delirium Service

Cumbria's 'REACH Out' (Reduce, Educate, Assess & Care with Hope) Delirium Service had been co-produced by mental health specialists and clinicians from across the North Cumbria Health and Care System, with input from patients and their carers. Key elements of the service include prevention, effective screening, support, treatment, liaising with other services to support discharge and education.

The service actively seeks out patients at risk of delirium following a hospital admission, including those with new or suspected dementia. This includes screening all over-65s using the Hospital Patient Information systems, as well as anyone known to memory services, and case finding patients who are at higher risk of delirium.

Referrals are also accepted from any health professional within the hospital where delirium is suspected or identified, or where the patient has dementia or other high-risk factors. The service also provides interventions for those who develop delirium while in hospital. It is hoped this will reduce length of stay for those patients by an average of two days.

In addition, the service provides twice-daily social and mental stimulation to those at high risk of delirium, support hospital staff in their management, and work closely with families and carers. The service also provides education and practical support to other hospital staff to improve awareness and recognition of delirium.

Care homes

Identifying dementia

Staff capacity

People with dementia living in a long-term care facility have a right to the same care and support as those living in their own property. Care homes are places that many people call their home.

In a survey to care home and health professionals, almost one-quarter (23%) reported difficulty spotting symptoms and staff capacity as significant barriers to identifying possible dementia in a care home setting.

Care staff reported concerns around workforce capacity. With a vacancy rate of 7.3% among social care staff at any one time in 2019/20, equivalent to 112,000 vacancies,[56] many staff fear they do not have the capacity to engage in the time-intensive clinical process of identifying symptoms of dementia.

Getting to know residents is a challenge for care home staff for many reasons, especially when residents are admitted in the later stages of dementia. They may have limited verbal communication skills, or may have outlived family and friends, meaning little background information is available.[57] This can make it difficult to spot progressive cognitive changes that would help identify possible dementia. Difficulty accessing residents' medical information may also be a barrier, with one study finding that some GP surgeries were reluctant to provide such information to care homes.[58]

But as the professionals most likely to engage with residents and to know them and their baseline status the best, it is key that they should be supported to identify dementia effectively.

Access to nursing teams

Access to nursing teams may be particularly important for those with possible dementia in residential care homes, which may lack routine access to registered clinicians.

Nurses reported that in this setting, the onus on care workers to recognise cognitive impairment is greater than that in a nursing care home setting where there may be better access to clinical input.

Professionals also reported that care homes may have access to community or district nursing teams, but this usually requires recognition of a physical health need. This is challenging because memory or cognitive impairment is not generally recognised as a physical health need. Research suggests that care home staff's confusion over the role of community or district nursing teams, and district nursing teams' poor understanding of the skill set of care home staff, were barriers to effective care.[59]

Generally, a lack of clinical expertise and awareness within this setting can be a barrier to the identification of cognitive changes. It may be important for local areas to consider the challenges residential care homes experience accessing community nursing teams to ensure that staff can access clinical expertise to support the assessment and diagnosis of dementia.

Staff skill and training

Health and care professionals also recognised the importance of upskilling staff within the care sector to improve the identification of possible dementia.

Research suggests that if care staff have high levels of confidence and skill, this can facilitate better working relationships with GPs, which may support the overall quality of care delivered to residents.[60]

Both GPs and care home staff reported that care for residents was affected by inadequate training as well as insufficient time.[61] Research finds that care home staff struggle to access the training needed for their role, and that the cost of training is a barrier for some care homes.[62]

In terms of quality of training, previous research suggests that training has a variable impact on a range of resident and staff outcomes.[63] Researchers reviewing 170 training manuals for person-centred care in dementia found that only four showed evidence of success when tested in a research setting.[64]

National clinical guidance states that care home staff should be competent in recognising when older people need a referral for assessment and management of a mental health condition.[65] Even more importantly, staff and professionals should be aware that older people in care homes have the same right to access healthcare as people living independently in the community, as stated in the NHS Constitution.[66]

To support this aim, any training delivered to care home staff should be tailored to their educational needs. While many training programmes may be general, because of the high prevalence of dementia in care homes care home staff should have access to specific training on identifying possible dementia.

Identification tools

The use of identification tools by care home staff may bring about further diagnosis or referral to memory assessment in care home settings. The DeAR-GP (Dementia Assessment and Referral to GP) is a simple paper-based case-finding tool for use by care workers to identify people who are showing symptoms of dementia.[67]

A study of its implementation was carried out in three care homes in South London. This involved care staff using the tool to identify symptoms such as confusion or memory problems which have persisted over three months. Where concerns were identified, these were reported to the GP or other clinician by completing the tool. In a total of 23 uses of the tool for case-finding, 20 residents identified by care staff as having possible dementia were subsequently diagnosed with dementia or referred to memory services when reviewed by a clinician, or it was found that the care home staff were unaware of an existing dementia diagnosis beforehand.[68]

However, despite its effectiveness, little is known about the provision and use of the tool by care home staff locally. It may be appropriate that local health and care systems work together to understand where the tool is used and, where it is not, to provide resource and training to care homes to improve uptake of the tool.

To achieve this and diagnose people in care homes with dementia most effectively, it may be necessary to identify where there are large care home resident populations. Despite a high prevalence of dementia in care homes, diagnosis rates can be relatively low.[69] These populations may be identified through primary care registers and local areas may identify where there are practices with high care home resident populations within their catchment area. This will be particularly important for practices with a low dementia diagnosis rate.

To support this aim, it must be recognised locally that **every person with dementia has a right to a diagnosis, regardless of where they live, to enable them to access the right care and support and to live well with the condition**.

Assessing dementia

Difficulty accessing GP services and poor working between primary care and care homes

In our survey of care home and health professionals, almost six in 10 (57%) identified the difficulty of accessing a GP and poor working relationships between primary care and care homes as barriers to the assessment of possible dementia in care home residents.

Our 2014 report '**Fix Dementia Care: NHS and care homes**' found that people with dementia had poor access to primary care. Care home managers reported that the health service did not provide residents with dementia with adequate and timely access to GP services.[70] Further research identifies a lack of health support for care homes, particularly regarding GP services, but also geriatric and psychiatry services.[71]

Ideally, GPs should have a close working relationship with their local care home. It is considered best practice to have one GP per care home with regular visits scheduled.[72] However, our engagement with health professionals found that this happens variably.

Care home staff told us that the relationship between GPs and care homes can often be ad hoc and transactional, rather than the proactive and continuous contact needed for consistent identification of possible dementia. This supports previous research that primary care is not organised to deliver effective healthcare to care home residents. Its provision is often reactive and poorly placed to anticipate gradual or acute deterioration, impacting effective management of dementia.[73]

Nurses, particularly in residential care settings, reported that accessing a primary care service often requires proactive outreach and engagement with GPs, and that this may be hindered by a lack of awareness of locally available services for care home staff. It may also be affected by a lack of understanding of when it is clinically appropriate to reach out to primary care colleagues. Clinicians further reported that dementia in care homes can often go unnoticed, and that engagement and facilitation of health services will only come about when a person's condition progresses and symptoms become more pronounced.

However, there are challenges at primary care level in the delivery of effective care, particularly regarding capacity. Research suggests that high GP workloads within care homes can result from travel, being called out inappropriately and complexities of residents' health and illness.[74] GPs have reported having limited time and capacity to carry out proper evaluation of patients in care homes.[75]

Additionally, research suggests that close working relationships between care homes and primary care are associated with a range of positive outcomes.[76] It's important that time is allocated for primary care professionals to identify possible dementia. **A process between care homes and their local GP in which all new care home residents are reviewed for possible dementia on admission may be especially beneficial.**

Limited capacity at primary care level can affect care homes' access to GPs. However, during our engagement it was suggested that direct referrals for memory assessments from care homes would help residents access a timelier diagnosis. One GP expressed frustration at simply repeating what care home staff have told them about a resident's cognitive impairment, since this could be done from a care home by staff who know the residents best.

Providing and accessing primary care services for care homes for assessment and diagnosis may be a challenge locally. However, people with dementia have a right to a diagnosis and support to help them live well, regardless of where they live.

Assessment tools

Use of standardised assessment tools for people with dementia can be difficult with care home residents, particularly those in the later stages of dementia.

The use of nonstandard assessments and clinical intuition can be beneficial in these circumstances.[77] There are positive examples of this, where standardised assessments were not used for routine care home admissions – instead, a detailed history of cognitive and memory impairment and functional capability was used.[78]

However, there are standardised assessments tools that are effective in supporting the recognition, assessment and diagnosis of dementia. The DiADeM (Diagnosing Advanced Dementia Mandate) tool is designed to be used with people in the later stages of dementia living in a care home who do not have a formal diagnosis. In cases of severe impairment or frailty, a referral to memory services may not be feasible, desirable or appropriate, and is likely to be distressing for the person.[79]

A pilot of a systematic approach to dementia diagnosis in care homes, led by a local GP, used the DiADeM tool effectively. In the assessment of 31 residents, the DiADeM tool was used to support a dementia assessment of people who were thought likely to have dementia by their respective care homes. Of the 31 residents, 23 of these were diagnosed with dementia – 64.5% of all assessed residents.[80]

However, despite the tool's benefit, commissioners reported that GPs' lack of awareness of the tool was a barrier to ensuring that GP-led diagnoses in care homes took place. Commissioners also told us of GPs' reluctance to make diagnoses outside of specialised memory assessment services.

Local areas should work with individual practices to ensure that GPs are aware of the tool's validated use, and to provide additional training and resource to support further use. We heard positive examples of promotion of the tool, particularly where Clinical Leads for dementia promoted it among primary care colleagues when engaging with and training them on diagnosis.

Access to information

Access to information is important in ensuring that clinicians deliver a correct diagnosis. However, poor record-keeping, with unclear, incomplete, out-of-date or inconsistent information, has previously been reported in care homes and may affect the diagnostic process.[81]

We found that many GPs have primary diagnostic responsibility for people living with dementia in care homes. But access to information for primary care professionals may also be problematic. GPs reported that diagnostic work up can be time-consuming. Blood tests and electrocardiograms can take time, as can collecting collateral history from care home staff and family members.

However, basic clinical information – particularly symptom history and cognitive changes – is important to understand whether a dementia diagnosis may be appropriate.[82] It is essential that care homes' records are kept up to date, and that GPs or Community Mental Health Teams can access these.

Recent national strategy to improve data sharing within the social care sector is a positive and much-needed step, ensuring that social care professionals have access to information about the needs of those they care for.[83] But it's important that this new guidance is implemented effectively.

Diagnosing dementia

Accessing secondary care services

Accessing secondary care services to facilitate a dementia diagnosis can be problematic in a care home setting, particularly where patients are frail.

Additionally, the impact of a diagnosis itself, especially its implications for a person's future care and residency may impact the willingness of services, professionals and families to seek a diagnosis.

However, dementia is a progressive condition, and a person's needs will become more complex. A diagnosis will help care homes identify the reasons behind progressive changes and provide a more appropriate level of care for their residents. Four in 10 survey respondents (40%) identified physically moving a person from a care home to a specialist diagnostic service as a barrier to diagnosis.

Diagnostic responsibility in residential settings varies considerably across the country. **Over 4 in 10 respondents (43%) said that primary care diagnosed people with dementia in a care home, with community nurse teams (10%) and memory assessment services (73%) also diagnosing people in a care home setting.**

Referral to a memory assessment service and having computerized tomography (CT) or magnetic resonance imaging (MRI) scans and further blood tests may be inappropriate for many care home residents, due to their frailty. It is also likely to be distressing for the person.[84] However, this should not deter care homes from seeking a diagnosis of dementia for their residents. In these cases, it may be appropriate for primary care to play an active role in diagnosis. However, this has training and resource implications, and may depend on the willingness, confidence and skill of GPs to diagnose dementia.[85]

Care implications and moving residency

A diagnosis of dementia may prompt a need to find alternative care provision. A care home may be unable to provide quality care for people with the condition if it lacks qualified and competent staff. Therefore, a diagnosis may necessitate a transfer to somewhere better suited to delivering care and support for more complex needs.[86]

This is particularly relevant for people living in residential care homes. These homes usually provide accommodation and personal care, such as help with washing, dressing, and taking medicines. Nursing homes, on the other hand, provide nursing care, usually with one or more qualified nurses on duty to provide this.[87] Because of the higher level of clinical care within nursing homes, they are usually more expensive.

The current state of social care means that many people affected by dementia and their families face huge care costs. **The average annual cost of dementia care is £32,250 per person, with two-thirds of this cost currently being paid by people with dementia and their families**. Much of this pays for private social care.[88]

While it may be clear that a loved one has dementia, the expected increase in cost to moving them to nursing care can deter families from proceeding with the diagnostic process.

Nurses and GPs reported that some professionals may be reluctant to diagnose people living with dementia symptoms in nursing homes, because they feel it will not make any difference. Our own support services reported similar experiences.

This may be due to an assumption that if a person is living in a nursing home, they are already receiving a level of care that would be appropriate for their level of need. While this may be the case in some instances, a diagnosis has important care implications, such as initiating different care and support or advanced care planning.

GPs reported the importance of a diagnosis for future care provision. For example, if a person is diagnosed with dementia in a care home and this is recorded in their patient records, this enables them to be put on a dementia pathway in any future hospital admission. **It is also essential for the person and their family, as they have a right to know they have dementia and to understand their condition.**

Clinicians and care home staff reported that the implementation of the Enhanced Health in Care Homes model, established through Primary Care Networks, with care home access to local Multidisciplinary Teams, is a positive step towards improving dementia diagnosis.

The model prescribes 'a systematic and proactive approach to identifying, diagnosing and recording dementia and cognitive needs in a timely manner, following admission to the care home and upon first presentation of signs and symptoms.' Additionally, 'education, training and professional development should be made available to help ensure that carers, families, and care home staff feel supported and confident in identifying, assessing and managing dementia and cognitive needs in care home residents.[89] **Given the potential of this new model on the delivery of care for people with dementia, it is important that monitoring of its implementation is considered locally.**

What is best practice?

Rotherham Care Home Liaison Team

The Care Home Liaison Team is a multidisciplinary team providing assessments and interventions to support those with a mental health condition – including dementia – living in care homes across the Rotherham Borough. In total, the team supports 44 care homes in the Rotherham area.

For assessment and diagnosis of dementia in care homes, the core functions of the team include:

- providing care homes with direct access to specialist mental health services and, where appropriate, timely assessment of the needs of people living in care homes
- working in partnership with care homes to develop and support implementation of appropriate and effective care plans
- providing advice on the care and services that best meet an individual's physical, mental and emotional needs
- developing and delivering collaborative education and training, supporting improvements in practice, in line with the mental health needs of service users and care home staff
- developing and maintaining effective working relationships with care home managers, care staff and partner organisations.
- The team consists of three band 6 nurses who work as care coordinators, two band 5 monitoring nurses, an occupational therapist, a part-time psychologist and three community support workers.

Where a resident is identified with cognitive or memory impairment, the person's GP will undertake a range of investigations to ensure that treatable physical causes of mental ill health or distress are investigated. Once reversible causes have been ruled out, primary care colleagues are able to refer into the service.

The referral is received via the 'care coordination centre', which is a central hub for referrals in Rotherham. It is passed onto the Care Home Liaison Team and screened by a duty worker who allocates it to the appropriate team member. Referrals are actioned within 14 days. The support worker team will gather information on a range of factors including the resident's life story, function, interests, family and social care provision.

Once information gathering has been completed, a care coordinator will do baseline assessments such as cognitive testing and symptom history. ECG and neuroimaging will be carried out where appropriate. The results will be discussed between the team and a consultant and, where appropriate, a diagnosis will be given. Information about diagnosis and options for medication, if applicable, are provided as well as the opportunity to ask questions.

Bristol Care Home Liaison Service, Bristol Wellbeing Service

The Bristol Dementia Wellbeing Service supports people living in Bristol's care homes through the Care Home Liaison Service. It is a multidisciplinary team of care home practitioners, with each care home in Bristol having a named practitioner who works with the home as a whole, including its GPs. The team will make regular contact with care homes to talk through concerns and offer help and guidance to ensure the delivery of proactive care and support.

The service supports 60 separate residential and nursing homes in Bristol, totalling over 2,000 beds. It aims to help local care homes to deliver the best care for residents, supporting each home's staff and providing bespoke assessment and interventions for residents. Ongoing education and awareness raising is a core component of the Care Home Liaison Service offer. One of its key performance indicators is ensuring that people living in care homes receive a timely and accurate diagnosis.

In Bristol, GPs are commissioned to diagnose dementia as the primary care coordinator. Where the GP requires support with making a diagnosis or identifying a subtype of dementia, they are able to refer to the Dementia Wellbeing Service for diagnostic support.

Where the GP requests support with making a diagnosis, the team receives referrals for diagnostic assessment from care homes' local GPs as well as the local Hospital Liaison Team. The team will carry out a variety of assessments, including collection of collateral history and cognitive testing (such as the Addenbrookes Cognitive Examination III or the blind Montreal Cognitive Assessment if there are significant sensory impairments). They can also carry out a functional assessment where needed. Once all tests have been completed and information has been gathered from the service users, the service will review each case in a diagnostic meeting, agree a diagnosis and inform the resident, their power of attorney if relevant and their GP.

In terms of further identifying possible dementia in care homes, the service works closely with local GP Primary Care networks and can help facilitate identification of people living with dementia on GPs' caseloads.

The team is made up of 12 practitioners, including general nurses, mental health nurses, occupational therapists, social workers and physiotherapists. They work using a tiered model of 'whole home' support, with a flexible toolkit of resources developed to support assessment, formulation, intervention and education. Each care home has a named practitioner, and residents with a diagnosis of dementia or a mental health need are not discharged but are reviewed regularly throughout their time living in the care home. Practitioners use an in-reach and a proactive approach with their homes, to pre-empt staff issues and offer support on an ongoing basis. Before COVID-19, the service ran ongoing education and awareness-raising sessions as a core offer to care homes, as well as information sessions for both primary and social care staff. The named practitioner will work with care homes and conduct 'scenario' development sessions alongside case study discussions – this ensures learning can be embedded into daily practice.

When someone accesses the service, they are never discharged, meaning that once a person has a diagnosis, they stay with the service until the end of their life.

Cumbria's Care Home Education and Support Service (CHESS)

CHESS aims to improve and support the ability of care homes to understand and manage dementia and mental health needs and reduce unnecessary hospital admissions.

The service has three elements:

- A rolling programme of education about dementia and mental health experiences for care home staff, offered to all care homes free of charge and for up to three staff per care home.
- A practical outreach service to provide mental health assessment, specialist interventions and support.
- Outreach support to ease the transition from inpatient unit to care home.

The care homes currently supported by the service are identified by GPs or the local CCG. Any resident within these identified homes can be referred to the service. Referrals can be received from the GP or care home staff, as well as from families and patients themselves.

The team offers weekly clinics in care homes, telephone advice and support to care home staff. The nurses within the team have clinical assessment skills to diagnose and treat acute ill health in the care home. The nurses will support the care home staff in care planning to reduce, where possible, inappropriate hospital admissions. They will also offer guidance in advanced care planning discussions.

Conclusion

The identification and assessment of possible dementia in hospitals and care homes can help ensure that everyone can access the diagnosis they have a right to. It can also support much-needed increases in local diagnosis rates.

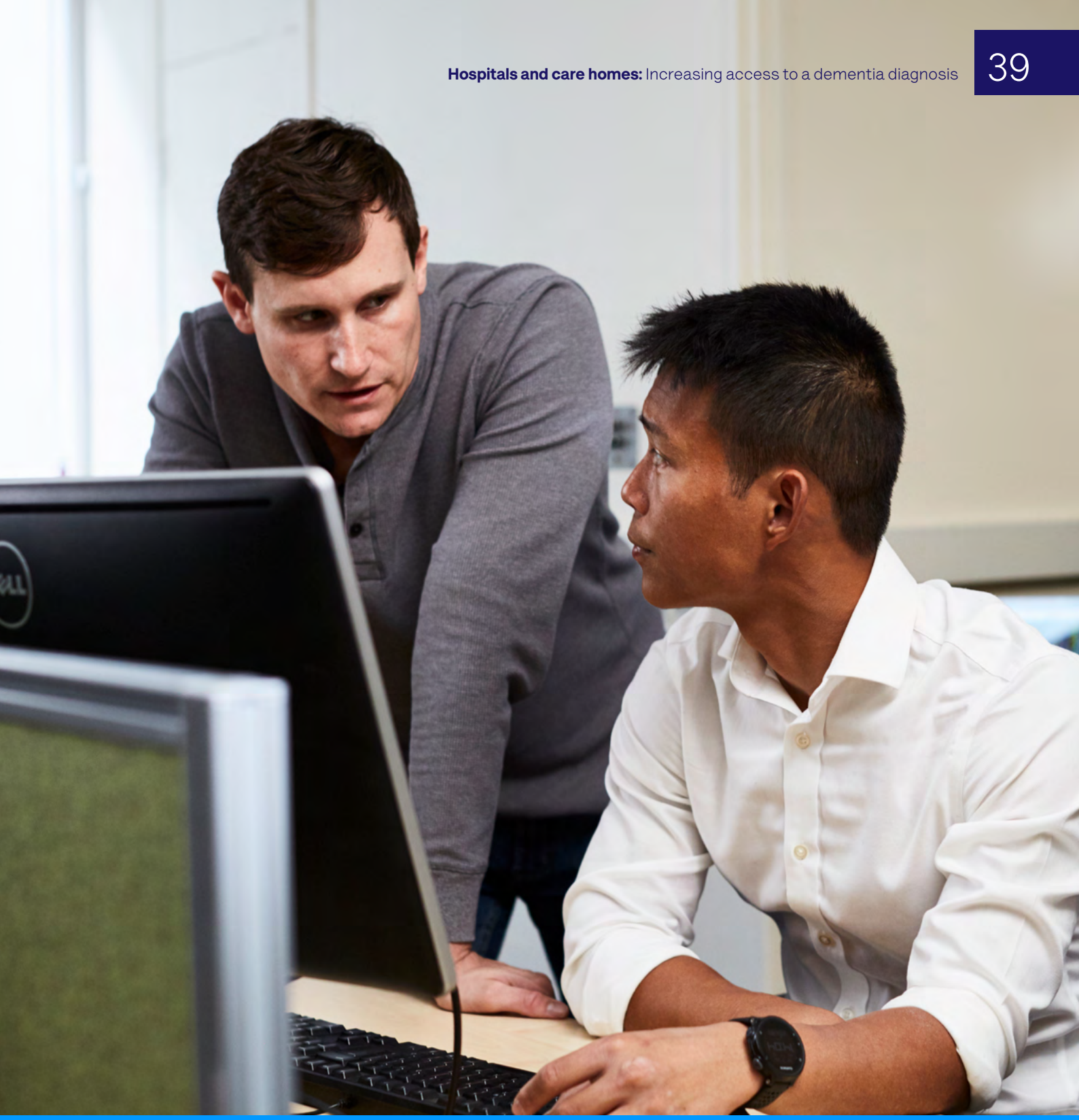
However, there are significant challenges with identifying and assessing dementia in hospitals. It is difficult to distinguish between dementia and delirium symptoms in a hospital setting. Lack of staff time, skill and confidence can impact the identification and assessment of the condition, as can the challenges of collecting patient information and collateral history.

Busy hospitals are not considered the most appropriate environments for people with dementia. Patients' care needs and planning their discharge process tend to be prioritised over identifying cognitive impairment appropriately. Even when people are identified and assessed in hospital, a diagnostic follow-up does not always take place after discharge.

There are similar issues around identification of dementia in a care home setting. Assessment can be affected by poor access to primary care services and insufficient access to information. Concerns over increased charges and care implications can affect the extent to which people with dementia, their families and care homes seek a diagnosis.

An admission to a care home or hospital involves a range of healthcare professionals and services. Historically, the care of people with dementia has been fragmented, and the issues outlined in this report can significantly impact the extent to which a person is diagnosed. A more integrated health and care system is needed to drive forward improvements in diagnosis, care and support.

The recommendations in this report set out a framework to increase diagnosis rates. Integrated Care Systems are ideally placed to undertake these recommendations and provide oversight and accountability of their implementation, so that people living with symptoms are diagnosed with dementia in a timely and equal way. When this is achieved, people with dementia can be provided with vital care and support to enable them to live well.



Appendix: Methodology

Literature review

We carried out a thorough literature review of local diagnostic pathways, datasets and documents relating to dementia diagnosis, care homes and hospitals.

Engagement with health, care and voluntary sector organisations and professionals

To supplement our understanding of dementia diagnosis in care homes and hospitals, we conducted semi-structured interviews with a range of health, care and voluntary sector professionals.

These included commissioners, General Practitioners, psychiatrists, psychologists, geriatricians, nurse consultants, memory service managers, care home managers and staff, Voluntary Sector and Community Organisation staff, researchers working in dementia care, as well as our own support services such as Dementia Advisers/Dementia Support Workers and Dementia Connect Local Service Managers.

Survey to hospital and care home professionals

From 6 April 2021 to 6 June 2021, we ran a series of online surveys for professionals working in care home (31 responses, although not every respondent answered every question) and hospital settings (21 responses, although not every respondent answered every question).

For care home professionals, we asked:

- What is your job role?
- In your local area, who is primarily responsible for diagnosing people with dementia in a care home setting?
- What do you think are the main challenges of identifying, assessing and diagnosing dementia in care homes?
- How do you think the identification, assessment and diagnosis of dementia in care homes may be improved?

For hospital professionals, we asked:

- What is your job role?
- Why do you think identifying possible dementia in a hospital setting is challenging?
- Why do you think it is challenging to assess dementia in a hospital setting?
- What do you think will enable more robust identification for dementia in hospitals?
- What do you think will enable better assessment of possible dementia in hospitals?

List of thanks

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