

The diagnosis of dementia for people living in care homes

Frequently Asked Questions by GPs

A discussion document jointly prepared by Maggie Keeble, GP with special interest in palliative care and older people, Worcester, Dr Nick Cartmell GP lead for dementia, South Devon and Torbay CCG and Alistair Burns, National Clinical Director for Dementia, NHS England.

Q1. I suspect that a lot of my patients in care homes have dementia but as a GP am I able to diagnose, given the NICE guidance 2006 states;

‘Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia’

Any clinician with the proper skills and access to all the relevant information should be able to make a diagnosis of dementia. There is no specific reason why this should exclude colleagues in Primary Care who feel willing, able and supported to make the diagnosis.

While NICE guidance suggests that memory clinics should be the single point of referral, it may not be necessary to refer somebody for the diagnosis of ‘dementia syndrome’. There will be patients where it is inappropriate to refer for example due to frailty or patients who clearly have dementia syndrome but refuse referral.

In April 2013 NICE commissioning guidance¹ clarified that people who present with later stage dementia may not require referral to a specialist dementia diagnosis service however advised that ‘commissioners need to ensure that people are able to receive the same quality of post-diagnosis information and care as those diagnosed in a specialist dementia diagnosis service’.

In terms of brain scanning, the NICE Dementia Guideline states “Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear.” This may particularly apply to older and frailer patients with established dementia.

If a GP makes a diagnosis of dementia they should probably assume it is Alzheimer’s type unless proven otherwise. Vascular dementia ought to require either a history of stroke (not just TIA) or a CT scan showing definite infarction. The other subtypes should probably not be diagnosed by a GP and may require a more specialised opinion.

A supportive and innovative relationship between primary and secondary care can certainly help to make diagnosis feasible in primary care.

Q.2 What is the benefit to patients in care homes of a dementia diagnosis and subsequent coding?

A diagnosis of dementia allows advanced care planning to be arranged and prompt discussion with family and carer about escalation planning to help prevent inappropriate admissions. It is well documented that hospital admissions for patients with dementia can be highly distressing for them and their families and can also be very challenging for acute hospital units. Length of stay tends to be longer and readmission rates are higher in patients with dementia.

It is also really important that we diagnose and code patients with dementia so that their risk of delirium may be understood should they do need to go into hospital. A diagnosis can also explain some behaviour’s and may help moderate use of antipsychotic drugs.

¹ NICE Support for Commissioning Dementia Care. Commissioning Guide (CMG48) April 2013. P.39

Most trusts are using the Dementia CQUIN and therefore should have dementia pathways in place to improve care and speed up timely discharge.

It allows for an assessment of mental capacity with, if indicated, a best interests meeting and Deprivation of Liberty safeguards (DoLS) consideration.

If someone has a diagnosis of dementia there is no reason for that not to be recorded on the clinical record. Firstly it is good practice to have accurate clinical records and secondly other agencies who come into contact with the person such as secondary care, ambulance or out of hours services will then know the person they are dealing with has dementia and will treat them accordingly.

Finally if care homes understand exactly how many residents they have with dementia they are more likely to upskill staff, create suitable environments and manage challenging behaviours better as a result.

It should be noted that there may be some unintended consequences of confirming a diagnosis of dementia. Firstly that care homes might expect to charge more for care or it may prompt a need to find alternative provision if that particular residential home was not registered for people with dementia. Local authorities have a duty to assess the needs of people with dementia and can help arrange transfer to facilities more suited to the needs of people with dementia if required.

Q3 Where there is an established diagnosis of dementia for a care home resident, what is the case for use of dementia medication (as opposed to antipsychotic medications) and what are the benefits?

The specific anti dementia medications are for Alzheimer's disease so that diagnosis would have to be made. One would have to be very clear as to what symptoms were being targeted by prescribing medication and what improvements might be expected. There is certainly no justification for the blanket prescription of these medications in care homes once a diagnosis is made. A joint protocol here between primary and secondary care may be helpful.

Q4. If I code these patients they will appear on my QOF register for dementia - I will then be expected to do blood tests and the 15 month review - The blood tests are not likely to affect patients outcome so what is the point in distressing them and taking blood?

One would clearly not want to take blood if inappropriate and if this were the case a patient can be exempted from QOF. Equally if a patient has a historical diagnosis of dementia but was never coded, backdating Read entry will also remove the need for bloods.

However bloods are important to exclude treatable causes of cognitive loss and so should be done if the above does not apply and doing them is not difficult nor is interpreting the result. Once a diagnosis is made no further blood tests are required, although it would be appropriate to check bloods in people known to be at risk of certain other disorders such as vitamin or thyroid deficiency or anaemia.

The 15 month review of cognition, functioning, well-being, medications along with carer views are important, even for people in a care home setting, so annual review exceptions should be very few. This review can be done with colleagues in the Community Mental Health Team (CMHT) particularly Community Psychiatric nurses or suitably qualified care home staff.

Q5. Can I exception code those patients in Care Homes with Dementia as unsuitable for intervention (i.e. blood tests and reviews)?

The GP contract and QOF expects all patients to be treated equally regardless of their residence. You should only exception code if there is very good reason to do so. It is possible to except a patient from the initial blood screening tests but without excepting from the care plan review. Each

is recorded separately and not interconnected. As stated above, the number excepted from both blood test and annual review should be very few.

Q.6 If we then code a high percentage of patients with code 9HD0 code 'unsuitable' it will put up our exception codes which will look bad on our 'dashboards' for the Area Team. How can we avoid being criticised for high 'Exception rates' for patients with Dementia in Care Homes?

Patients cannot be added to the register and then excepted because they live in a care home. Excepting from initial diagnostic tests is more justifiable than excepting from annual review so if GPs do except a lot of patients from the annual review Area Teams would be justified in seeking an explanation from the GPs for why this is the case. This applies to other QOF domains too.

Q7. I have to do a care plan for the unplanned admission DES for all my patients in Care Homes – does review of the Care Plan constitute a Dementia Review?

A diagnosis of dementia will trigger the preparation of a care plan, if not already in place, and ongoing reviews as per QOF requirements. Dementia reviews will inform a person's ongoing care plan and should be undertaken every 15 months or sooner if required or circumstances change. A dementia review will cover many items within the care plan prepared for an unplanned admission such as advance care planning, mental capacity assessment but there would need to be evidence in the case notes that dementia relevant aspects of care were also considered.

In summary a care plan for unplanned admission cannot be substituted for a dementia review as there are additional considerations to be assessed and monitored that are in addition to the 'standard' care plan. Many GPs schedule the dementia review to coincide with annual medicines review as often more relevant to consider both together. In all cases the review should take place face to face rather than by phone

Q8. We are swamped with work at the moment – we haven't time to review all our patients in care homes without a dementia diagnosis to see if they do indeed have dementia. Who will do this work for us?

Only people with a suspicion of dementia should be assessed and whilst this may involve significant number of residents initially it should be relatively straightforward to maintain. Developing close working relationships between primary and secondary care services has helped many teams address this, and develop shared care protocols and ongoing support arrangements.

GPs should have a close working relationship with their local care home, ideally one GP per home, with earmarked time for regular visits to review residents and undertake added value work including dementia reviews and care plans, advanced care planning and medicine reviews. This should help reduce both GP calls from care homes for acute visits and inappropriate hospital admissions.

A financial incentive may help address any significant backlog for assessments and suggest you explore this with your local commissioners and memory service providers. In the longer term it may be feasible to pull back funding from acute hospitals that can be invested back into primary care to enhance the service though appreciate this is often easier said than done!

Q9. When a person has found all the patients with dementia in a care home who is going to put those codes on our computer system and except them if appropriate?

This is likely to be a one off exercise and unlikely to take much administrative time as long as your clinical record of the assessment is clear. Most practices have administration staff trained to add Read Codes to patient records. To help with this, regions are in the process of providing a list of suggested common Read codes for use in primary care. Please contact your local dementia lead for more information.

Administration staff can exception code but really exception coding is a GP decision so they would need to be asked to do so by the GP.

Q10. Are there any benefits to my practice of putting more patients on my Dementia Register?

The provision of better care should be the prime incentive

A practice QOF income depends on two things: first their recorded prevalence of each clinical condition (e.g. bloods done at diagnosis and annual reviews). Thus the more patients' on the dementia register the more £'s per point the practice earns. The prevalence effect on QOF income is more potent than the point's effect so it is actually better to have a larger prevalence and miss some points than keep prevalence low and get all the points.

A diagnosis of dementia triggers the identification of carers who are likely to be registered with the practice. Carers do nearly all the work of caring for patients with dementia so helping them to maintain their health and wellbeing and providing the support and information they need will increase their ability to cope with less reliance on the GP.

By improving patient care and by recognising dementia, developing advanced care plans etc. the number of call outs to care homes in an emergency may well decrease. This will also support the new 2% unplanned admissions enhanced service for GPs.

An innovative relationship with the local memory service could facilitate earlier and better assessments if people develop challenging behaviour.

If a patient has a clinical record of a diagnosis of dementia this is more likely to appear on their death certificate. Dementia is under recorded as a contributory cause of death.

Q11. Why is there such an emphasis on Dementia diagnosis when the provision of Dementia Support Services in Care Homes is already so limited?

This is really a 'cart before the horse' argument. If we increase diagnosis rates this will help drive up provision of better services both in care homes and the community. Once better services are in place diagnosis rates should increase.

We know dementia support services in care homes do vary by area and provider. Guidance is available covering issues around environment and activities and staff training especially around advanced care planning and end of life care.

Care homes are expected to provide a 'regular scheduled programme of activities in order to stimulate and engage people with dementia according to individual needs, wishes and lifestyles'. Several care homes now provide cognitive stimulation therapy and access to other therapies. The voluntary sector and other agencies can play a significant role in providing other types of support in these environments.

A blog on care homes and dementia appears at:

<http://www.england.nhs.uk/category/publications/blogs/alistair-burns/>

Summary Statement

Diagnosing dementia: any appropriately skilled clinician can make the diagnosis and brain scanning not always needed

Dementia is a clinical syndrome and at one level simply implies brain failure (analogous to heart failure or liver failure). The diagnosis is a two stage process.

First, to make a diagnosis of dementia you need to differentiate it from: depression; delirium; the effect of drugs and; the changes in memory expected as part of normal ageing. Two key features for a diagnosis of dementia are that the patient's symptoms should affect daily living activities and be progressive. Second is to determine the cause of condition – the commoner causes are Alzheimer's disease, vascular dementia and Lewy body dementia.

Both stages are based on a comprehensive assessment including a history, including one from someone who knows the patient well, a physical and mental state examination, including a specific assessment of cognitive function, a functional assessment and selected ancillary investigations (Dementia: NICE Clinical Guideline 42, www.NICE.org).

Any clinician who has the appropriate skills can recognise and make a diagnosis of dementia, once it is established. Specialist advice is more likely to be needed in the early stages and in particular clinical situations such as when the presentation or course is atypical, where significant risks are identified where the picture is complicated by behavioural or psychological symptoms and in groups such as people with learning disabilities.

Specialist advice may also be needed to establish the exact cause of the dementia. This may have clinical implications for the prescription of medication such as drugs for Alzheimer's disease, treatment of vascular risk factors in vascular dementia or avoidance of antipsychotics in Lewy body dementia.

In terms of brain scanning, the NICE Dementia Guideline states **“Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear.”** This may particularly apply to older and frailer patients with established dementia.

Post diagnostic support which should be person centred goes hand in hand with the diagnosis (which does not necessarily have to result in the prescription of medication) and is largely independent of the cause of the dementia.