DementiaUK
Helping families face dementia

Dementia guidance for NHS continuing healthcare (CHC) assessors

Many people with dementia have significant needs that make them eligible for NHS continuing healthcare (CHC) funding. However, the complexity of the condition and the variability in how it presents can make it particularly difficult to assess.

While the recommendation for CHC is not based on any particular condition or disease, it may be useful to understand some of the specific ways in which dementia can affect the individual. This guidance is designed to support you in completing a comprehensive and robust assessment of a person with dementia. As well as ensuring their needs are assessed fairly and accurately, it can help to minimise challenges from the panel and/or family carers, appeals and complaints.

Dementia: an overview

Dementia is a progressive, disabling condition that requires increasing levels of support over time. The progression will vary from person to person, but all forms of dementia require palliative care, and as there is currently no cure, everyone with the diagnosis will die from or with the condition.

Dementia is most common in people over the age of 65, but can also affect people under 65, when it is known as 'young onset dementia'.

People typically associate dementia with memory loss, but this is just one of a number of symptoms that can co-exist and make everyday life progressively more challenging. These include:

- communication difficulties
- changes in personality
- mood disorders
- visual-spatial impairments

- impaired gross and fine motor skills
- mobility issues
- sleep problems
- hallucinations
- incontinence

People with dementia also have a tenfold increase in the likelihood of developing delirium, and many other possible symptoms.

In advanced dementia, people experience life-limiting neurological damage which affects essential systems including hunger and thirst, swallowing, regulation of body temperature, sleep, consciousness, breathing and heartbeat, and eventually leads to death.

Dementia symptoms vary significantly between individuals, so every person applying for CHC funding must be assessed in their own right, avoiding preconceptions about how the condition manifests.

"Dementia is a one-way street; it is not going to get better."
Family carer

Assessing complex needs relating to dementia

The needs of a person with dementia are often complex and highly unpredictable. The person may have good days, where, for example, they are calm and show few behaviours of concern, but also bad days, where they are extremely agitated and distressed. Triggers for bad days are often not always obvious, making it hard to predict the person's needs.

Their needs can be very intense – for instance, if the person becomes distressed, they may display physically aggressive behaviour that puts them and the people around them at risk. Many people with dementia need one-to-one care such as checks every 15 minutes to ensure they are safe and their needs are met.

It is important to consider the risks that the person's health and care needs might present. In the case of someone with dementia, for example:

- If their cognition is affected, they may no longer be able to judge the speed of traffic, putting them at risk if they try to cross a road alone
- If they need assistance with eating and this assistance is not available, they will be at risk of malnutrition and weight loss, potentially leading to frailty and falls, impaired skin integrity (pressure ulcers), and problems with continence
- If they have difficulty swallowing, they may be at risk of choking and aspiration
- If they cannot administer their own medication, they may forget

to take it and be at risk of worsening symptoms (including of co-morbid conditions), or be at risk of accidental overdose

How dementia symptoms interact

The vast and varied symptoms and consequences of dementia mean that there is often a lot of interaction between the person's needs in the different domains. An individual with cognitive impairment will have a weighting in the cognition domain, and as a result, may have associated needs in other domains – for example, they may have difficulty expressing their needs (communication domain), leading to frustration and distress (behaviour domain) and anxiety or depression (psychological/emotional needs domain).

Or if the person's fine motor skills are impaired, they may have difficulty with buttons, which could lead to incontinence as a result

of being unable to undo their clothes in time (continence domain), and in turn to moisture lesions if they struggle to practise good hygiene (skin domain).

When a person with dementia presents for assessment, it is not always easy to recognise the true extent of their needs, as often, they are already being well met. Family members may have become highly skilled in caring for the person and meeting their health needs – to the point that their caring duties become routine, and they rarely reflect on the amount of support they are providing.

Equally, people who are in residential care settings are supported by professional carers who are experienced in managing their healthcare needs, which may make these needs less obvious.

However, as clearly stated in the National Framework for NHS continuing healthcare, "The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs." For this reason, it is important to consult as many people as possible who are involved in caring for the person with dementia. This will help you establish needs that may not be obvious as they are already being met, but that would have serious implications without their current level of care and support.

Examples

These are some very simple and abridged examples of how dementia may affect someone's health needs in each domain of the Decision Support Tool (DST). They are purely illustrative, and every single domain will require careful assessment of the person's individual – and often multiple – needs.

Breathing: dementia does not impact on someone's breathing until the end of life stage. However, if they have a co-morbid condition like asthma or chronic obstructive pulmonary disease (COPD), they may be unable to take their medication without support or refuse to take it, leading to a worsening of symptoms.

Nutrition: the person has difficulty swallowing and is at risk of choking or malnutrition. They may no longer identify hunger or thirst so may be reluctant to eat, putting them at risk of malnutrition and dehydration. Their caregiver may spend

significant time encouraging them to eat and drink throughout the day, still resulting in a reduced intake.

Continence: the person experiences incontinence and becomes distressed and combative when carers need to change their protection. There may be times when continence care cannot be carried out which increases the risk to their skin integrity.

Skin: the person spends most of their time in a chair or in bed and is at risk of pressure ulcers. The person may scratch or pick at their skin repeatedly, causing multiple wounds that are difficult to heal.

Mobility: the person has difficulties with visual perception and spatial awareness, putting them at risk of falls. They may not be able to follow guidance to use walking aids which increases this risk.

Communication: the person struggles to communicate basic needs, and as a result, is unable to express that they are in severe pain. This may mean that a serious underlying health condition is overlooked. The person may also struggle to understand explanations so misunderstand others' intentions, leading to anxiety and distress.

Psychological and emotional needs: the person experiences delusions or hallucinations that frighten and distress them. When this happens, they do not respond to reassurances from their caregivers and may place themselves at risk by trying to flee.

Cognition: the person falsely believes they are caring for themselves well when actually, they are neglecting their own care and require their carers to ensure their needs are met and maintain their health and safety.

Behaviour: the person becomes distressed in the evening (known as 'sundowning') and may misidentify their caregiver, hitting or pushing them in an attempt to get them to leave.

Drug therapies and symptom control: the person cannot manage their medication independently, and if it were not administered by a carer, would be at risk of accidental overdose or forgetting to take it, leading to a deterioration in their health. Diabetes is a common co-morbidity, and the consequences of medication being taken incorrectly can be rapid and severe.

Altered states of consciousness (ASC): the person has seizures linked to a build-up of proteins in the brain that are typical of some forms of dementia. They may experience transient ischaemic attacks (TIAs), which are common in vascular dementia.

Other significant care needs: these are too variable to provide an example and will need to be considered on a case-by-case basis. For this reason, it is essential to speak to the person's carers and, if possible, a dementia specialist about their individual needs.

Completing the DST

The DST can come across as weighted towards physical health needs, so it is important to remember that although dementia is a neurological condition, the impact on a person's life is often no less severe than if they had a physical health condition alone. All forms of dementia are likely to have an impact on every domain in the later stages.

If possible, best practice is to conduct the assessment over several visits, spending time with the person at different times of day, in a familiar setting, and while they are engaged in different activities. This is because characteristics like mood, alertness and understanding may fluctuate in dementia, so it is important to form a balanced picture of their needs – not just a snapshot.

If the person still lives at home, it is good practice to assess their needs in that environment, especially if they wish to remain at home. This can help you gain insight into their behavioural, cognitive, psychological and emotional needs, how they affect their ability to live at home, and the care needed to mitigate against harm or injury.

However, in practice, multiple visits may be unfeasible. This makes the role of the assessing multidisciplinary team (MDT) particularly important, as every member is likely to be able to provide written or verbal evidence of what they have seen while caring for the person with dementia.

Some people with primary health needs related to dementia will still have the cognitive and communication skills to be involved in their assessment, although this ability typically reduces as their condition deteriorates. Those who are able to contribute may find it easier to explain their views if the assessment is carried out as a conversation, rather than working through the DST in a checklist fashion.

However, be aware that the person with dementia may not have accurate insight into their own abilities. They should also be supported by a representative – usually a family member – who should be given the chance to make known their own views of the person's needs.

Example

As an example, in the behaviour domain – in which a person with dementia might have significant needs – you might consider:

- Does the person display verbally aggressive behaviours like shouting, swearing or screaming?
- Are they physically aggressive or destructive, for example slapping, pushing or damaging property?
- Does their behaviour put them at risk of harm – for example, do they leave home alone when it is not safe for them; display inappropriate sexual behaviour; scratch or pick their skin repeatedly; try to eat raw food?
- Are there particular triggers for the behaviour such as a certain environment or carer?
- Does the person take any medication that helps reduce behaviour of concern and the risk of harm? What would happen if they did not take it?
- How is their behaviour currently being managed – for example, can they be distracted, or do they sometimes need to be restrained or given sedative medication?
- What would be the consequence if the techniques currently used to manage the behaviour of concern were not available?
- How frequently do carers need to intervene in the person's behaviour?
- Are there any specialists involved in managing their behaviour, such as a mental health nurse?

Engaging with health and social care professionals

Dementia is a complex condition, meaning that every person living with the diagnosis has unique needs. This can make CHC assessments difficult, especially as by the time the person presents for assessment, they often lack the communication skills and mental capacity to articulate their own needs.

To ensure the assessment is as accurate and robust as possible, best practice is to assemble an MDT of professionals who have specialist knowledge and experience of dementia, such as:

- psychiatrists
- speech and language therapists
- physiotherapists
- occupational therapists
- dietitians

Involving multiple professionals – particularly those who are directly involved with the person's care – can give a more rounded picture of how their needs in one domain impact on others to create additional complexity, intensity or unpredictability. This will also help to mitigate against being influenced by subconscious preconceptions about dementia. It is sometimes assumed, for instance, that people in the later stages of dementia do not experience depression or distress, especially if they are unable to communicate this, but this is not the case.

Some families are supported by a dementia specialist Admiral Nurse who has expert knowledge and experience of dementia and how it affects someone's health and social care needs. If so, consulting them prior to the assessment can be particularly beneficial. People whose care involves an Admiral Nurse are typically living with multiple complex needs. Their nurse will have personal insight into the specific difficulties they face, which can be invaluable in completing the assessment.

You may also like to contact Dementia UK's Helpline for guidance from an Admiral Nurse who has specialist knowledge of dementia and the CHC process. Please see our resources on p21 for information.

If, after considering all the relevant evidence, the MDT does not agree on the level of need in each domain, this should be noted, along with details of how each team member believes the domain should be scored. The local integrated care board (ICB) will then make the final decision.

"A good number of teams offered to write statements. These included the specialist nurse, the Speech and Language Team, the dietitian and the Frailty Support Team. However, none of these professionals were present at the DST meeting. Notes were looked at... but were very sparse, and with no clinicians present, there was no one to make the case for my grandfather's needs." Family carer

Engaging with family carers

The National Framework clearly states that the CHC assessment should take into account the views of family carers. This is important in understanding whether the carers consider that the assessment accurately reflects the person's day-to-day needs, especially as the person with dementia is likely to have trouble self-advocating.

When consulting family carers:

- Be aware of their stress and anxiety – the CHC process can be emotionally charged. Family carers may feel that they are being 'judged' for not being able to meet the person's needs
- Aim to conduct the assessment in a conversational style, rather than following the DST in a linear fashion, as this may allow family members to explain their views more clearly

- Listen and look for clues that indicate greater levels of need: family carers may be in denial or feel embarrassed about continence or behavioural changes, for example
- Be aware that family carers may unwittingly downplay the person's needs – they may not want to 'make a fuss', or their caring duties may have become so routine that they rarely reflect on their intensity, complexity and unpredictability
- Be as open, sensitive and transparent as possible. It may be beneficial to speak to family members separately from the person being assessed to encourage them to talk freely
- Ask for supporting documentation, such as care plans, needs assessment reports, incident logs or a diary/daily record sheet kept by family members/carers – without guidance, family carers may be unsure what will be helpful to support their case
- Encourage them to think about the person's needs on a bad day, not a good day, average day or the day of the assessment
- Reflect back what they have said and give them the opportunity to add further comments/evidence, ask for clarification, and express their views if they disagree with your findings

"Because families do not understand what they are being asked, they often play down people's needs. They are looking for the good and they are looking for what people can do, and don't realise that they can sell themselves short... They don't recognise where the complexities come in."
Dementia specialist Admiral Nurse

Co-morbidities

Public Health England's 'Dementia: co-morbidities in patients' data briefing (2019) cites that 77% of people with dementia also have at least one of the following health conditions:

- hypertension
- depression
- coronary heart disease
- stroke or TIA
- diabetes
- Parkinson's
- COPD or asthma

It is important to consider all co-morbidities in the CHC assessment, and the interface between them. For example, if a person with dementia has hypertension, they may lack the cognitive ability to remember to take their medication, which in turn puts them at risk of a cardiac event or cerebrovascular accident (CVA).

Young onset and rarer dementias

People with young onset dementia (where symptoms develop before the age of 65) and rarer dementias may present quite differently from people who have dementia later in life. However, their needs may be just as significant, if not greater, and their condition often deteriorates faster. In addition, younger people are more likely to be diagnosed with a rarer form of dementia.

When assessing someone with young onset dementia or a rare dementia, it is important to be aware of how their needs may be different, and potentially less obvious. For example, a younger

person may be physically fit and active, and less frail than an older person. However, while their physical needs may be fewer, they may still have significant psychological/ behavioural needs requiring specialist care and support.

For instance, they may lack insight into their condition and how it affects them. This may mean they believe they are capable of things they can no longer safely do, putting them at risk. Additionally, the person may have children at home who could be at risk, for example if they have lapses in concentration that affect their ability to carry out their parental responsibilities safely.

Symptoms of young onset and rarer dementias may be quite different from the memory loss and confusion that are often associated with dementia. For example, in posterior cortical atrophy (PCA) – a form of dementia that typically occurs in people aged 50-65 – visual problems are common, and this can have an impact on many areas of life, such as putting them at risk of falls while crossing roads or burns when cooking.

If you are assessing a person with young onset dementia or a rare dementia, it is strongly advised that you consult someone with specialist knowledge and experience of the condition to ensure their needs are recognised. Admiral Nurses can support you with this – see p21 for details.

"Emotional support was provided by my Admiral Nurse... Her knowledge around the system and the deterioration brought on by my husband's illness was invaluable."
Family carer

Reassessment

Reassessing the needs of a person with dementia after three months, and again every 12 months, should focus on their needs and whether they are still being met, rather than their eligibility for CHC. The trajectory of dementia is always downward. Symptoms may fluctuate, but ultimately, there is no cure, and the person will deteriorate and eventually die with or from the condition. This means their needs will not reduce between assessments, and could in fact increase significantly in a short space of time, so their need for CHC is likely to continue or increase.

"I think the reason we got the funding was because [my husband] was put on antipsychotic drugs, which they eventually weaned him off. At that point, you sort of think if he comes off the drugs, does the funding stop? It was a continuous worry as to what the next step was going to be."
Family carer


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Resources

Admiral Nurse Dementia Helpline: guidance from a specialist dementia nurse on any aspect of dementia, including CHC. Call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email **helpline@dementiauk.org**

Virtual clinic appointments: pre-bookable clinics offering 45-minute appointments with an Admiral Nurse by phone or video call. Please indicate when booking that you would like to speak about assessing someone for CHC.
dementiauk.org/book

Types of dementia

Please note that these are the most common forms of dementia. If you would like to speak to an Admiral Nurse about these or rarer types of dementia, please contact our Helpline or virtual clinics.

Alzheimer's disease
dementiauk.org/alzheimers-disease

Vascular dementia
dementiauk.org/vascular-dementia

Frontotemporal dementia
dementiauk.org/frontotemporal-dementia

Mixed dementia
dementiauk.org/mixed-dementia

Lewy body dementia
dementiauk.org/dementia-with-lewy-bodies

Alcohol related brain damage
dementiauk.org/alcohol-related-brain-damage

Posterior cortical atrophy
dementiauk.org/posterior-cortical-atrophy

Huntington's disease
dementiauk.org/huntingtons-disease

Parkinson's
dementiauk.org/parkinsons

Other Dementia UK resources

Continence
dementiauk.org/continence

Delirium
dementiauk.org/delirium

Eating and drinking
dementiauk.org/eating-and-drinking

Falls
dementiauk.org/dementia-and-falls

Fix the funding: Dementia UK campaign on CHC
dementiauk.org/fix-the-funding

Frailty
dementiauk.org/frailty

Guide to continuing healthcare (CHC) funding for carers
dementiauk.org/guide-to-continuing-healthcare-funding

Guide to the CHC Decision Support Tool for carers
dementiauk.org/CHC-decision-support-tool

Stages of dementia
dementiauk.org/stages-of-dementia

Understanding young onset dementia
dementiauk.org/about-young-onset-dementia

Other resources

Beacon: free, independent advice on CHC
beaconchc.co.uk

National Framework for NHS continuing healthcare and NHS-funded nursing care, July 2022 (revised)
gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

NHS continuing healthcare in England: House of Commons research briefing
researchbriefings.files.parliament.uk/documents/SN06128/SN06128.pdf

Rare Dementia Support
raredementiasupport.org

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:
0800 888 6678 or **helpline@dementiauk.org**

Book a virtual appointment:
dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan **the QR code**

Thank you.

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