Dementia guidance for NHS continuing healthcare (CHC) assessors
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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 and their needs.

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 is a progressive, disabling condition that requires increasing levels of support over time. The progression will vary from person to person, with each having their own individual experiences. 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.

People typically associate dementia with memory loss, but this is just one of a number of symptoms that co-exist and can make everyday life progressively more challenging. These include communication difficulties, changes in personality, mood disorders, visual-spatial impairments, impaired gross and fine motor skills, sleep problems, hallucinations and incontinence – alongside 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.

You can read more about some of the symptoms of dementia at dementiauk.org/about-dementia/types-of-dementia/ or see Appendix 2 for direct links to information on the most common types. However, it’s important to be aware that dementia symptoms vary significantly between individuals, and that 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 very nature of dementia often makes the individual’s needs complex and highly unpredictable. The person may have good days, where, for example, they are calm and present 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. They may need to be restrained, which could lead to injury to the person themself and their carers.

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, leading to frailty and falls, impaired skin integrity (pressure ulcers), and potential problems with continence

- If they have difficulty swallowing, they may be at RISK of choking, plus all of the possible problems listed above

- If they cannot administer their own medication, they may forget to take it and be at RISK of worsening symptoms, or at RISK of accidental overdose
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 are often primary carers and become highly skilled in caring for the person with dementia 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 are supported by professional carers who are experienced in managing their healthcare 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. See Engaging with health and social care professionals on p9 for more information.
Example

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.

**Behaviour**: the person becomes distressed when leaving the home and often hits or pushes their carer.

**Cognition**: the person has memory problems that mean they forget where they live and have difficulty finding their way home, meaning they cannot go out unaccompanied. They may forget to turn the hob off after cooking, causing a fire hazard.

**Psychological and emotional needs**: when distressed, the person self-harms by banging their head against the wall.

**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.

**Mobility**: the person has difficulties with visual perception and spatial awareness, putting them at risk of falls.

**Nutrition**: the person has difficulty swallowing and is at risk of choking or malnutrition.

**Continence**: the person experiences incontinence and becomes distressed and combative when carers need to change their protection.

**Skin**: the person spends most of their time in a chair or in bed and is at risk of pressure ulcers.

**Breathing**: dementia does not impact on someone’s breathing until the dying stages. 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, leading to a worsening of symptoms.
Completing the Decision Support Tool (DST)

The DST can come across as weighted towards physical health needs, so it’s 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’s important to form a balanced picture of their needs – not just a snapshot.

If they still live at home, assessing their needs in that environment is desirable, especially if they wish to remain at home. This can help you gain a greater insight into their behavioural, cognitive, 

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 their medication, 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.
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, kicking, punching or destroying property?
- Does their behaviour put them at risk of harm – for example, do they leave home alone when it’s not safe for them, display inappropriate sexual behaviour, scratch or pick their skin repeatedly, try to eat raw food etc?
- Are there particular triggers for the behaviour of concern, 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 didn’t take this medication?
- How is their behaviour currently being managed – for example, can they be distracted, or do they need to be restrained or given sedative medication?
- What would be the result if the techniques currently used to manage the behaviour of concern were not available?
- How frequently do carers need to intervene in their behaviour?
- Are there any specialists involved in managing the person’s behaviour, such as a mental health nurse?
Dementia is a complex condition, meaning that every person living with the diagnosis has their own individual 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 the needs of a person living with dementia, such as:

- Psychiatrists
- Speech and Language Therapists
- Physiotherapists
- Occupational Therapists
- Dieticians

Involving multiple professionals – particularly those who are directly involved with the person’s care – can give a more rounded picture of how the needs in one domain impact on others to create additional complexity, intensity or unpredictability.

Engaging with health and social care professionals

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Involving multiple professionals – particularly those who are directly involved with the person’s care – can give a more rounded picture of how the 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 may be 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, and if so, consulting them during the assessment process – and involving them in the MDT – can be particularly beneficial. Admiral Nurses have expert knowledge and experience of dementia and how it affects someone’s health and social care needs. People whose care involves an Admiral Nurse are typically living with multiple complex needs associated with their dementia; their Admiral 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 to speak to an Admiral Nurse who has specialist knowledge of dementia and the CHC process. Please call 0800 888 6678 (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org.

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 CCG will then make the final decision.

“A good number of teams offered to write statements – this included the specialist nurse, the Speech and Language Team, the Dietician 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
Consulting a dementia specialist Admiral Nurse can be highly beneficial in the CHC process.
Without guidance, family carers might be unsure what information will be helpful and support their case.
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 – CHC can be an emotionally charged process. 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 them 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, remembering that it may be beneficial to talk to family separately from the person being assessed to encourage them to talk freely

• Ask for supporting documentation, such as Care Plans, Needs Assessment report, incident logs or a diary/daily record sheet kept by family members/carers – without guidance, family carers may be unsure what will be helpful and 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
Co-morbidities

The All Party Parliamentary group (APPG) report 2016 suggested almost seven in 10 people with dementia also have one or more other health condition, such as:

- hypertension
- depression
- coronary heart disease
- stroke (TIA) or transient ischaemic attack
- diabetes
- Parkinson’s disease
- chronic obstructive pulmonary disease (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).

Because families don’t 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.” Admiral Nurse

- Reflect back on 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
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Young onset and rarer dementias

People with young onset dementia (dementia in someone aged 65 or under) and rarer dementias may present quite differently from people who have more common forms of dementia or a diagnosis later in life. However, their needs may be just as significant, 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’s 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 strong – they may be able to dress and feed themselves independently, move around without help, and go to the toilet alone.

However, while their physical needs may be fewer than in older people, they may still have significant mental health/behavioural needs that mean they need a lot of specialist care and support. For example, at some stage, the person with dementia may have to stop driving. If they have forgotten this and try to get in their car and drive off, their life and the lives of others may be at risk.

Aggression and anger can be a feature of dementia, and in a younger person, who may be much stronger than an older, frailer person, this may put them, their carers or others at risk of injury. They may display behaviour that not only challenges the family but can also lead to issues within their local community eg risky or antisocial behaviour.

In the case of rarer dementias, symptoms 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 – problems with sight are common, and this can have an impact on many areas of life, such as putting them at risk of falls or burns.

If you are assessing a person with young onset dementia or a rare
The health and care needs of a person with dementia will not reduce between assessments, and may worsen significantly in a short space of time.
dementia, it is strongly advised that you consult someone with relevant specialist knowledge and experience of the condition to ensure their needs – and the impact on their daily life – are recognised. Admiral Nurses can support you with this – see p19 for details of Dementia UK’s Helpline and remote clinic appointments.

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.

Whether the person has dementia alone or a co-morbid condition, their trajectory is always downward. Their symptoms may fluctuate, but ultimately, there is no cure, and the person will eventually die with or from the condition.

This means their health and care needs will not reduce between assessments, and can in fact worsen significantly in a short space of time, so their need for CHC funding 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
Types of dementia

For information on the symptoms of some of the most common types of dementia, please see Dementia UK’s guides, below.

If you would like to discuss the symptoms of these or any other forms of dementia and how they might affect the health needs of the person being assessed, please contact our Admiral Nurse Dementia Helpline or book a Closer to Home remote clinic appointment using the details opposite.

Alzheimer’s disease
dementiauk.org/about-dementia/types-of-dementia/alzheimers-disease/

Alcohol related brain damage
dementiauk.org/about-dementia/types-of-dementia/alcohol-related-brain-damage/

Vascular dementia
dementiauk.org/about-dementia/types-of-dementia/vascular-dementia/

Posterior cortical atrophy
dementiauk.org/about-dementia/types-of-dementia/posterior-cortical-atrophy/

Frontotemporal dementia
dementiauk.org/about-dementia/types-of-dementia/frontotemporal-dementia/

Huntington’s disease
dementiauk.org/about-dementia/types-of-dementia/huntingtons-disease/

Mixed dementia
dementiauk.org/about-dementia/types-of-dementia/mixed-dementia/

Parkinson’s disease
dementiauk.org/about-dementia/types-of-dementia/parkinsons-disease/

Lewy body dementia
dementiauk.org/about-dementia/types-of-dementia/dementia-with-lewy-bodies/
Resources

National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, October 2018 (revised)

Admiral Nurse Dementia Helpline
0800 888 6678 (Monday–Friday 9am–9pm, Saturday and Sunday 9am–5pm)
helpline@dementiauk.org

Closer to Home Admiral Nurse clinics
Visit dementiauk.org/get-support/closer-to-home/ to book an appointment by phone or video call, indicating that you would like to speak about assessing someone for CHC.

Dementia UK Guide to continuing healthcare (CHC) funding (for the public)
dementiauk.org/get-support/legal-and-financial-information/guide-to-continuing-healthcare-funding/

Dementia UK information on types of dementia
dementiauk.org/about-dementia/types-of-dementia/
The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

If you would like any further information, or have any questions about dementia and the CHC process, call or email our free Dementia Helpline for specialist support and advice.

Call **0800 888 6678** or email **helpline@dementiauk.org**

Monday–Friday, 9am–9pm
Saturday and Sunday, 9am–5pm

Alternatively you can pre-book an appointment with an Admiral Nurse in our virtual Closer to Home clinics. Please visit [dementiauk.org/get-support/closer-to-home/](http://dementiauk.org/get-support/closer-to-home/) and indicate on the booking form that you would like to speak about CHC.