

NHS continuing healthcare (CHC) funding for people with dementia – guidance on using the Decision Support Tool (DST)

CHC: an overview

NHS continuing healthcare (CHC) is a package of care that is fully paid for by the NHS. It is for adults with long-term, complex health needs. These needs may be the result of illness, disability or an accident. Normal NHS healthcare – for example, from a GP, district nurse or in hospital – is free, but CHC covers other costs, such as home carers or care home fees.

CHC may be awarded if the person is assessed as having a ‘primary health need’ – in other words, a health need that requires more support than social services would usually provide. It is based on the person’s individual needs, rather than a particular diagnosis, but many people with dementia will have needs that are severe enough to qualify for CHC.

The assessment for CHC involves two stages: a ‘checklist’ to establish whether the person may be eligible for CHC, and a ‘full assessment of need’ which assesses their needs in detail to decide whether or not they should receive CHC.

The Decision Support Tool

A key element of the full assessment of need is the Decision Support Tool (DST). This lists 12 separate areas of health needs, called ‘domains’; the person’s needs in each will be assessed and recorded.

The 12 domains are:

- breathing
- nutrition
- continence
- skin integrity
- mobility
- communication
- psychological/emotional needs
- cognition
- behaviour
- drug therapies and medication
- altered states of consciousness
- other significant care needs to be taken into consideration

In each domain, the assessor will look at:

- the **nature** of the person's needs, the overall impact on their life, and the type and level of interventions and support needed to manage them
- the **intensity** of their needs – their extent (how many/how often), severity and the support needed to manage them
- the **complexity** of their needs – how they present and interact with each other, and the level of skill needed to monitor, manage and treat the person's symptoms and/or manage their care
- the **unpredictability** of their needs – how they fluctuate (including how rapidly they are deteriorating), which can create additional challenges in managing them

The person with dementia will be given a 'rating' in each domain of the DST:

N – no needs

L – low needs

M – moderate needs

H – high needs

S – severe needs

P – priority needs

P ratings can only be given in the following domains: breathing, behaviour, drug therapies and altered states of consciousness. A priority need in one of these is a good indicator that the person will be eligible for CHC, regardless of their ratings in other domains, so pay particular attention to these areas when preparing for the assessment.

If the person's needs are rated S in two or more domains, it is also likely that they will be awarded CHC, so it is important not to downplay their needs. S ratings may be given in any domain except continence, communication, and psychological and emotional needs.

How to use this guide

The information and evidence that you provide during the full assessment of need, along with that of other people involved in the care of the person with dementia, are very important to ensure their needs are assessed accurately. We have written this guide to help you think about the person's needs, looking at each domain separately. You can then make notes for each domain to show the CHC assessors.

You should use this guide alongside our leaflet on CHC to give you a clear understanding of the CHC application and assessment process. You can find this at dementiauk.org/guide-to-continuing-healthcare-funding

Under each domain, we have explained some of the possible effects that dementia may have on the person, followed by some questions to consider. These are not exhaustive but will help you understand the type of information that is used to make a decision around CHC funding.

- Focus on describing the person's needs on a bad day, not a good or average day or the day of the assessment
- It is helpful to familiarise yourself with the DST form as you prepare your information. You can read this at assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1112535/NHS-continuing-healthcare-decision-support-tool-referral-form.pdf
- It is a good idea to keep a diary of the person's needs, with specific examples of how they present, when, and what support is needed

- Keep records of contacts with health or social care professionals including GP appointments, test results, assessment reports, hospital admissions etc
- The assessor should not ignore or underestimate the person's needs just because they are being well managed by you and/or other carers, so make sure you communicate what would happen if the person was not receiving their current level of support

If you would like advice and support with the CHC process, you can speak to a dementia specialist Admiral Nurse on our free Helpline – call 0800 888 6678 (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

If you prefer, you can book a phone or video call appointment with an Admiral Nurse in our virtual clinics at dementiauk.org/book-an-appointment

1. Breathing

Dementia does not directly affect a person's breathing until the advanced stages, typically in the last weeks or days of life. However, if they have other health conditions alongside, such as asthma or chronic obstructive pulmonary disease (COPD), they may not recognise the need for their medication or be able to take it without support. This could affect their breathing.

If the person has swallowing difficulties, they may be at risk of food or drink 'going down the wrong way' which can cause chest infections or aspiration pneumonia (where food or fluids are breathed into the airways or lungs).

Likewise, poor oral health, which is common in people with dementia, can increase the risk of chest infections and pneumonia.

Consider:

- Does the person have shortness of breath?
- Are they prescribed any medications for respiratory conditions? Do they accept these and what effect does it have on their breathing if they refuse or forget to take them?
- Do they require oxygen to manage a respiratory condition, and are they able to use it as prescribed? If not, what effect does this have on their condition? For example, a lack of oxygen may increase confusion
- Is there a history of repeated chest infections/pneumonia? List their frequency, the treatment required, any difficulties in getting the person to accept this treatment, and any hospital admissions (with dates and duration of stay)

2. Nutrition – food and drink

People with dementia may no longer recognise hunger or thirst, which may make them reluctant to accept food and drink. They may require significant prompting and encouragement to eat and drink, and be at risk of malnutrition, dehydration and weight loss, despite their carers' best efforts.

Conversely, they may not realise they have already had a meal and insist on eating again, leading to weight gain and related health issues like heart disease and type two diabetes.

Some people try to eat non-food items or food that has gone off as they have difficulty distinguishing what is and is not edible. They may experience changes in taste that make it difficult for them to accept a varied and nutritious diet.

If the person with dementia is supposed to follow a special diet, for example due to diabetes, they may no longer recognise the need for this, which could impact on their health.

In the later stages of dementia, they may have swallowing difficulties and be at risk of choking. They may require a modified diet (eg pureed food) and need to be fed their meals.

Reduced nutrition and dehydration are both risk factors for delirium and can cause the person to become acutely confused and affect how they behave.

Consider:

- Does the person lack interest in eating and drinking? What kind of support do they need to eat and drink sufficiently?
- Do they overeat or eat inedible items if not supervised? How do they respond if you try to moderate their eating?
- How much time does eating and drinking take throughout the day – for example, how long do you spend encouraging them?
- How does the person respond to this encouragement? Do they become upset or frustrated?
- Are they losing/gaining weight? Keep records of their weight if possible. You can also use a change in clothes size or photographs of the person to demonstrate any weight loss/gain
- Does the person have swallowing difficulties? Do they need to eat modified food (eg pureed food) and do they accept this diet?
- Do you need to feed the person? How long does it take? Do they accept being fed – and does it depend on who is trying to help them? Some people may accept food from someone they know well but not from paid carers
- Does the person cough/choke during meals, or pouch food in their mouth and not swallow? How is this managed?
- Have there been any hospital admissions associated with the person not eating or drinking, for example with dehydration?
- Has the person experienced any episodes of delirium (acute confusion) because of a lack of nutrition and hydration?

If necessary, you can ask the person's GP or specialist to refer them to a dietitian and/or speech therapist and ask for reports from them.

3. Continence

People with dementia may no longer recognise the sensation of needing to pass urine or have a bowel movement. They may have difficulties finding the toilet in time, which can cause incontinence. They may become stressed or agitated when they need the toilet but be unable to communicate this.

The person may not recognise or accept that they have problems with incontinence and refuse to wear continence protection. They may not realise if they are wet or soiled. They may not understand why their carer needs to help change their clothing or continence products – possibly viewing this as an assault – and so resist their help.

They may be at increased risk of urinary tract infections (UTIs) and constipation, which increase the risk of delirium.

If the person has a urinary catheter or stoma, they may no longer be able to manage this or recognise the need for it, and may try to remove the catheter or stoma bag.

Consider:

- Does the person have bladder or bowel incontinence and how is this managed?
- How able are they to cooperate with continence care? Do they become distressed, agitated or combative?
- Are there times when they will not tolerate changing their continence protection, which may put their skin integrity at risk (for example, causing sores and rashes)?
- Is there an increased risk of UTIs caused by poor personal hygiene?
- Do they have frequent UTIs? How does this affect them? How have they responded to treatment? Have they needed a hospital admission?
- Does the person have problems with constipation, which may be linked to poor diet or reluctance to take medication?
- Does the person experience recurrent diarrhoea, perhaps associated with other health conditions such as inflammatory bowel disease? How is this managed, and how do they tolerate being helped?
- Does the person have a catheter or stoma? Do they attempt to remove the catheter or stoma bag? How often does this happen and what are the consequences?

4. Skin (includes tissue viability)

A person with dementia may not be as aware of the need to move or be unwilling/unable to reposition themselves in a chair or bed, putting them at greater risk of pressure damage to the skin (eg bed sores). They may not be able to understand why people are trying to reposition them and feel threatened by this.

Some people with dementia pick or scratch their skin causing multiple wounds which may be difficult to heal. They may be unable to recognise the need for treatments for other skin conditions, such as creams and lotions, and resist applying them or having them applied.

Dementia may lead to poor personal hygiene which puts the person's skin at increased risk of damage and infection, especially if they also have problems with incontinence.

Consider:

- Does the person have any damage to their skin caused by pressure? Are they able to cooperate with repositioning? For example, some people roll back onto their 'preferred' side if they are repositioned on the other side
- If the person scratches or picks their skin, what damage does this cause?
- Are district nurses or tissue viability nurses involved in treating or managing any wounds? If you have evidence, eg wound assessments or measurements, it is useful to show this to the CHC assessors
- Does the person have any skin conditions, and if so, are they getting better or worse? How easy is it to apply their treatments? Does this affect their behaviour towards their carer?
- Do they have any moisture lesions caused by incontinence? How are these managed?
- If the person has skin damage, does this cause them discomfort? This may be displayed in their behaviour, eg through increased irritability or agitation

5. Mobility

A person with dementia is likely to experience a deterioration in their mobility as their condition progresses. They may have issues with their visual perception and spatial awareness, increasing their risk of falls. They may be unable to weight-bear or follow instructions to use mobility aids but still attempt to stand/walk because their perception of their ability is altered.

Some people need to be moved using a hoist or other assistive living equipment. They may find this experience frightening and become distressed, agitated or combative.

Some conditions that are linked to dementia, such as Parkinson's, can cause specific mobility issues such as tremors or uneven gait.

Consider:

- Does the person have difficulty mobilising safely?
- Are there problems with their gait, for example taking smaller steps, or their balance, for example falling when overstretching?
- Do they attempt to sit down but misjudge where the chair is?
- Have they been assessed by an occupational therapist, physiotherapist or specialist nurse? If you have any reports, show these to the CHC assessor
- Have they had any falls? Include dates and outcomes eg a trip to A&E, hospital admission, broken bones
- Has the person had a falls risk assessment and/or been referred to the Falls Team?
- If the person is unable to mobilise, how do they respond? Do they become frustrated, agitated or upset?
- If the person needs to use equipment such as a hoist, how do they respond? Do they become tearful, agitated or lash out? What intervention is necessary to reassure them?

6. Communication

A person with dementia may struggle to understand what other people say to them and may therefore misunderstand their intentions, leading to anxiety and distress. This may be displayed as combative behaviour.

They may struggle to express themselves and may not be able to explain if they have a problem such as pain. Often, behavioural changes can indicate an unmet need that they cannot communicate, but their carers may need an in-depth knowledge of the person to be able to work out what is wrong.

Some people with dementia cannot tolerate wearing hearing aids and/or glasses, further complicating communication.

If the person speaks English as a second language, they may revert to their original language, increasing communication difficulties.

Consider:

- How reliable is the content of what the person is saying?
- Do they rely on 'social chit-chat' rather than communicating with meaning?
- Do they mirror what other people say without understanding what it means?
- How easily can you understand the person? How easily would a person they do not know be able to understand them?

- Do their communication difficulties cause them to feel frustrated, upset or angry?
- Can you give examples of times when communication has been difficult, eg if the person was unwell and could not explain what was wrong?

7. Psychological and emotional needs

A person with dementia may become distressed and anxious because of their confusion and the changes they are experiencing in their lives. Changes in roles and relationships, including feeling increasingly isolated, can impact their sense of purpose and worth and lead to low mood.

The person with dementia may have difficulty expressing how they are feeling, making it difficult for others to reassure and support them. They may not be able to respond to carers when they are experiencing heightened anxiety and may put themselves at risk by trying to flee or becoming combative in response to their distress.

Some people experience delusional thoughts or hallucinations which can be frightening and confusing.

Consider:

- Does the person experience mood disturbances, hallucinations or anxiety symptoms?
- How does this present? What does the person do and how long does it last? Does their behaviour follow a predictable pattern or are there constant changes, meaning you need to revise how to support them?
- During times of distress, is it possible to engage with the person? Who, if anyone, can reassure them, eg specific family members or paid carers? Does this reassurance always work?
- What impact is the person's distress having on their health and/or wellbeing? For example, do they miss meals; constantly pace, being unable to rest and becoming exhausted; endanger themselves by leaving the house?
- Does the person describe wanting to hurt themselves or take their own life? Have other people been informed of this (eg GP, social worker), and are interventions in place to reduce the risk?
- Has there been any input from mental health professionals and if so, are any reports available?

8. Cognition

A person with dementia may lack insight into their own difficulties and may falsely believe they are caring for themselves well when actually, they are neglecting their own needs and rely on other people to ensure their safety, health and wellbeing. This could be due to memory issues and difficulties with thinking and reasoning. They may have an impaired ability to assess risks to themselves and may be impulsive in their actions.

The person may be disorientated in time and place and may misidentify or not recognise other people. They may be at risk of exploitation by others, for example giving away money or possessions.

Consider:

- Does the person have an awareness of their own needs? Are they reliant on others to recognise and attend to these needs?
- Do they have short-term memory problems which impair their ability to recognise and respond to their own needs?

- Does the person have false memories that could affect their care, such as believing they have already eaten, washed or taken their medication?
- Are there potential risks to the person's safety such as leaving the cooker on; leaving the house in unsuitable clothing; talking to strangers or inviting them into their home; getting lost; difficulty with day-to-day tasks such as meal preparation; problems managing money?
- Do they rely on somebody else to manage these risks? What measures have been put in place?
- If you have reports such as memory clinic assessments, show these to the CHC assessor

9. Behaviour

A person with dementia may show challenging behaviours. For example, they may believe their carer is an intruder and try to force them to leave. They may believe this is a reasonable reaction to the perceived threat, but it may potentially put them or others at risk.

The person may demonstrate impulsive or disinhibited behaviour as they become increasingly unaware of normal social boundaries. They may express themselves in an unrestrained manner (eg using offensive language, exposing themselves) which can increase the risk both to and from others.

The person may find it difficult to rest and show extreme restlessness and agitation. They may leave the home when it is unsafe to do so or attempt tasks that they are no longer capable of, such as home maintenance or driving, putting themselves or others in danger.

The CHC assessor should record how the person's needs in other domains affect their behaviour (for example if communication difficulties lead to frustration and physical aggression).

Talking about challenging behaviour – especially aggression or inappropriate sexual behaviour – can be very difficult but try to be as honest as possible to ensure the assessor can form an accurate view of the situation.

Consider:

- Does the person resist care interventions like support with washing and dressing? Does this result in aggressive behaviour? Try to give examples – for example, did they push you or threaten you? Did you need to seek help and if so, what support was needed?
- Is the person displaying sexualised behaviour which is difficult to manage? Have you needed to seek help around this?
- Does the person pace or show other restless, repetitive behaviours such as emptying drawers?
- Does the person need to follow you everywhere? Do they become distressed if they cannot find you quickly?
- Does the person make repeated noises such as shouting, screaming, whistling, banging?
- Does the person put themselves at risk by being overfamiliar with strangers?
- Has there been intervention from other agencies, eg the Community Mental Health Team or the police?
- Are there plans in place to manage these challenging behaviours? Do these plans always work?

10. Drug therapies and medication: symptom control

A person with dementia may be unable to manage their medication independently. They may be at risk of not taking essential medication or taking too much, leading to a deterioration in their health. Other health conditions (co-morbidities) that the person may have, such as diabetes, may be difficult to control if they do not cooperate with their treatment.

Some medications need to be given regularly and monitored to ensure they are at a therapeutic level, such as insulin, warfarin or thyroxine. This can be hard to achieve if the person with dementia will not reliably accept medication.

Some people with dementia are more sensitive to medications such as opiates (used to manage severe pain) as they can increase the risk of delirium. This can make treating chronic pain conditions more difficult. Pain can be hard to assess in a person with dementia, and this can have an impact on their care or on managing other domains.

Consider:

- Does the person require medication for other health conditions? Are they consistently compliant with this medication?
- Do they rely on other people to administer their medication, and how long does it take to encourage them to take it?
- Is the person at risk of health deterioration or relapse as a result of not taking medication as prescribed? What are the risks involved?
- Are there any examples where failure to take medication correctly has affected the person's health and may have caused hospitalisation?

11. Altered states of consciousness (ASC)

A person with dementia may be at risk of transient ischaemic attacks (TIAs), often referred to as 'mini strokes', which are associated with vascular dementia and can cause fluctuations in their state of consciousness. Some people with dementia have seizures associated with a build-up of proteins in the brain.

People with dementia are at greater risk of delirium – a sudden state of intense confusion. Some people experience impaired consciousness associated with delirium.

Consider:

- Does the person have a history of stroke or TIAs? Have they had any recent episodes? What intervention did this require? If possible, provide dates and details of any need for treatment/hospital admissions
- Does the person have a history of seizures? Keep a record if possible
- Has the person had any episodes of delirium? What did these look like? Were any triggers identified? Did they need intervention such as hospital treatment?

12. Other significant care needs to be taken into consideration

This domain exists so that any other healthcare need which has not been covered in the other domains can be identified and included in the assessment.

It is important to think carefully about any individual needs of the person with dementia that do not fit comfortably into the other domains, for example:

- Does the person's ability to assess risk to themselves fluctuate, making it difficult to predict when and how they might need support to protect them from danger?
- Do they accept care and support from a range of people, or do they depend solely on their main family carer to meet their needs?
- Do environmental factors influence their behaviour and wellbeing? It may be possible to control the home environment to ensure noise, temperature, lighting and the behaviour of others do not impact on the person, but this may not be possible in the community, a hospital or a care home, leading to distress and agitation

