



peoplehub
personal health budgets network

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NHS
Continuing
Healthcare
Assessment:
What is it?

INFORMATION PACK ONE OF THREE

Who has written this and why?

This information is written by people who have been through the NHS Continuing Healthcare assessment process, with input from health professionals and other specialists. We were asked to consider what might improve people's experience of the NHS Continuing Healthcare process for everyone aged 18+.

We thought about what would have helped us most, when we were faced with the assessment, and we wanted to share the answers to three main sets of questions.

This pack focuses on the first of these sets of questions, including:

- What kind of needs may be eligible to be funded by NHS Continuing Healthcare?
- How are these needs assessed?
- What happens if I am not eligible or if I become ineligible at a later stage?

Pack two focus on the second set of questions: What can I expect and how can I prepare?

Pack three focus on the third set of questions: What follows if I am eligible and what choices do I have about a personal health budget?

We know that sometimes we can all feel there isn't time to read lots of documents but it's important that you know that there are several NHS documents which contain in-depth information about NHS Continuing Healthcare. We've listed those at the end. This information pack is not to replace the NHS info. It's to help you feel a bit more in control and a bit less powerless, through having a better understanding of how the process works, what you can contribute and what to expect.

The NHS Continuing Healthcare process is first and foremost an assessment of need. A full consideration of how best to meet those needs should follow, regardless of whether you are eligible for NHS Continuing Healthcare funding or not. The assessment does not provide a plan to meet the needs. The plan should follow, wherever the funding comes from.



How does this connect with me?

These are just a few of the things we shared about our own questions and experiences when we started to create this information:

- *“What does this mean?”*
- *“Who will decide?”*
- *“What will change?”*
- *“How are decisions made?”*
- *“Why isn’t my need seen as a primary health need?”*
- *“What happens next?”*
- *“I felt there was so much riding on it.”*
- *“I’m so exhausted right now – it’s hard to think straight.”*
- *“It’s been an emotional rollercoaster recently.”*
- *“It’s great that this funding exists – thank goodness.”*
- *“We’ve been able to feel really listened to and understood.”*
- *“I felt ignored and patronised.”*

We know how scary and complicated this NHS process can be, even when it is done really well, and that we are often asked to go through the assessment at a time of major stress in our lives.

You or someone you care for in your family may have had a fall or a health crisis and be in hospital, or you may have had a major accident, or perhaps you have an ongoing permanent complex health condition or a degenerating illness. Where you are right now is likely to mean you have different questions and concerns as you start the process. But everyone will benefit from knowing what kinds of needs may be eligible.

**DON'T BE MISLED BY THE WORDS
“PRIMARY HEALTH NEED”**



What kinds of needs may be eligible for NHS Continuing Healthcare funding?

NHS Continuing Healthcare is a complete package of health and social care that is paid for by the NHS. NHS Continuing Healthcare funding is available when someone has what the NHS call a “primary health need”.

This is not at all as straightforward as it might sound and is at the absolute heart of the process. If you can get a better understanding of how the NHS defines what a primary health need is and how it’s assessed, you will be in a much better position to take part in the process and to know what is the most relevant information to put forward for consideration.

It is not about just a diagnosis or how many things you feel you need help with. It is based on an assessment of your overall needs which is carried out using a National Decision Support Tool.

This is intended to paint a picture of your needs across a range of headings or ‘domains’ (e.g. mobility, breathing, continence), giving each domain a score or ‘weighting’ (for example, low, moderate, high, severe).

The decision support tool is not a decision making tool. The decision about whether you have a ‘primary health need’ will always be made by professional judgement, interpreting all the information gathered together. So it is not simply the number of high, severe or moderate needs which determine eligibility. It is using those scores to consider the nature, intensity, complexity and unpredictability of those needs.

In these guides we will give some practical examples and descriptions from real life experiences.

Whether or not you have a ‘primary health need’ depends on consideration of **all of your needs across the 12 domains in the Decision Support Tool**. The domains used in the tool are not divided into ‘health’ and ‘social care’ needs – for example needs under the domains of ‘continence’ and ‘mobility’ might be regarded as either health or social care needs depending on the individual circumstances.



However, once all the needs have been identified using the Decision Support Tool, the multi-disciplinary team doing the assessment will take an overview as to whether or not the needs are mainly 'health' needs rather than 'social care' needs. **This is a question of judgement, weighing up the whole picture and taking account of the nature, intensity, unpredictability and complexity of the needs.** Any one of these four factors, on its own or in combination, might mean that the individual is judged to have a 'primary health need'.

In order for the multi-disciplinary team to make a decision it will need to **consider the whole picture**, including needs which require decision-making "in the moment" and will need to have an understanding of all the subtle but important aspects of someone's health.

The multi-disciplinary team will also have to understand the interrelationship of the different needs you, or the person you love and care for has. Importantly, **they need to understand the risks that may arise, even when all the appropriate care and treatment is in place.**

You can help support the team to gain this full understanding by thinking about how the needs interact, in order that you can describe that interaction to the assessing team.

The judgement as to whether someone has a 'primary health need' is about the individual's actual day to day needs.

The decision making process should take account of needs which are currently being well-managed as well as needs which may not yet have been properly addressed. The needs might be so complex and unpredictable that a carer has to make judgements in the moment, on the basis of the presenting situation, and have sufficient skills and competence to do all of this.

Many family carers hold all this knowledge but may be almost unaware of how much they are constantly weighing up and considering, because their knowledge has grown deeper over a long period of time.



What does this mean in real life?

For example, if someone has dementia, then carrying out what might otherwise be a routine procedure for someone else, such as personal care, might require a different approach each time.

This could be because of the level of anxiety and unpredictable behaviours which the person has when anyone touches them. Or, if the normally routine procedure of replacing a catheter can lead in one individual to a pain reaction which can then interrupt their breathing or send their blood pressure too high, then the potential impact of the procedure needs to be closely monitored and addressed each time it is carried out.

Completing health care tasks to meet needs like these successfully depends on judgements being made about the best way to do them because there are a range of inter related issues to take into account. So doing the task might involve far more than simply bypassing a normal bodily function.

Every person assessed for NHS Continuing Healthcare funding is unique, even if their diagnosis is the same. For example if we considered two people called Jack and Jill. Both have been diagnosed with dementia and both have live-in carers from an agency.

The following table examines each situation and who is most eligible:



JACK	JILL
Jack is not able to manage any of his care needs.	Jill is not able to manage any of her care needs either.
He is not able to feed himself but does always eat his meals. He takes lots of medication but he takes them when they are given covertly – in yoghurt.	She is able to feed herself but often only eats a very small portion and is losing weight.
He has a catheter and is incontinent of faeces.	She is able to walk but will not see hazards and does fall.
He is not able to stand so moved in a full body hoist although he can hold on when asked.	Jill usually takes routine medication willingly but also requires medication due to changes in her behaviour. She often can show challenging behaviour with no known trigger.
Jack shows behaviour which staff find challenging but only when washed by a male nurse. He can shout out swear words at this time. He does require oxygen therapy but at the same rate all the time.	Jill is continent but suffers with regular urine infections which impacts on her behaviour.

BOTH HAVE HIGH CARE NEEDS, BUT ONLY JILL MAY BE ELIGIBLE – WHY?

JACK	JILL
✓ High care needs	✓ High care needs
✗ Intense	✓ Intense
✗ Complex	✓ Complex
✗ Unpredictable	✓ Unpredictable

Jill may be eligible but Jack may not, bearing in mind that in some situations it is just the intensity on its own, or the complexity, or the unpredictability of the needs which is sufficient to create a 'primary health need'. There are descriptions of the four 'Key Indicators': Nature, Intensity, Complexity and Unpredictability listed on page 49 of the NHS Decision Support Tool referenced at the end. Each of these characteristics may, in combination or alone, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the individual's needs.

What is important to stress is that any description like this does not mean that if you had all the same needs as Jill you would definitely be eligible. Every one of us is different in the way a health condition affects us, our social and family context and our life history.



How do I get an assessment, and what is a full assessment?

There are two stages to the NHS Continuing Healthcare assessment. The first is a **short “Checklist”** which anyone can ask for. Any health or social care professional can carry out the initial check list.

The “Checklist” should be done with you or with your representative if you are not able to speak for yourself. The “Checklist” is not a gathering together of all your health information; it is a quick ten minute assessment of your needs. Through the “Checklist” being completed a decision is made as to whether you are referred for the full assessment. Only a health or social care professional can refer you for a full assessment, you cannot refer yourself.

The NHS Continuing Healthcare full assessment must bring together a multidisciplinary team with a minimum of two different professionals from different professional backgrounds, at least one of whom must be a healthcare professional.

The person leading the assessment must bring together information from all the relevant people involved in your care and treatment. You **MUST** be invited to be involved. **It is really important that you do contribute and involve yourself fully.** Don't assume that if you fly through the initial “Checklist” you will be eligible and don't need to be involved. This would be a wrong assumption and a mistake. (Our second information pack gives more detail on the assessment and answers the question “How can I prepare for the assessment?”)



What happens if I am not eligible or become ineligible at a later stage?

Firstly it's useful to recognise that **there are still some gaps in the whole health and social care system**. This is tough stuff to share but important to be aware of. There are some needs which may not be met by the NHS nor by social services.

This is uncomfortable and can come as a shock to anyone who has thought that all their needs would always be met in every circumstance. What we can be assured of, is that the NHS does continue to provide an incredible range of services for everyone, even if you are not eligible for Continuing Healthcare. This would include GP services and Accident and Emergency services amongst others.

IF YOU ARE ASSESSED AS NOT ELIGIBLE AND THINK THAT IS WRONG YOU CAN APPEAL LOCALLY.

If this doesn't work and you believe you should be eligible, you can then ask for an Independent Review Panel convened by NHS England which will look at procedural issues (how was the assessment process done) as well as the decision. All the local processes must have been gone through before NHS England would agree to carry out an Independent Review Panel.



What if I have had social care funding and don't want to be assessed for NHS Continuing Healthcare?

If someone is funded by social services it is possible that their nursing/health needs might become such that social services believe that the needs are no longer within their responsibility or power to meet. The person is then offered an assessment for NHS Continuing Healthcare.

If that person says they don't want to be assessed then the Local Authority responsible for social services will need to understand their reasons and discuss this with the individual. Just because someone says that they do not want to be assessed for NHS Continuing Healthcare it doesn't mean that the Local Authority gains additional powers to meet their needs.

It is possible that the Local Authority might say they can no longer meet the needs and the individual might be faced with having to fund themselves, since social services cannot fund needs they see as beyond their legal power to meet. You need to know this: if you refuse to be assessed there could potentially be these consequences.

There are statutory duties on the NHS even if a person is assessed and found not eligible for NHS Continuing Healthcare funding. (Page 35 of the main policy referenced at the end). It may still be reasonable for the NHS to fund a contribution to care. Joint funding can happen sometimes with social services too.



Can I fall out of NHS Continuing Healthcare funding eligibility?



YES YOU CAN. This is probably the hardest part of the process for any of us to get our heads round. But it's really important to know in advance.

It's important to know if you are assessed as eligible that this may change and how that might happen. Someone's care should be reviewed 3 months after the start of funding by NHS Continuing Healthcare and then at least annually.

Most people with a deteriorating health condition will make the reasonable assumption that they will remain eligible when they become more ill. **But this is not always the case.**

Someone can become ineligible if the level of unpredictable risk reduces through the person perhaps becoming more frail and therefore less mobile, less unpredictable in their behaviour, meaning that they can be cared for more readily and in a more routine way.

The person may become less of a risk to themselves or others AT THE SAME TIME as their life becomes more fragile, but DON'T PANIC: Knowing in advance that this can happen means that you can be prepared to handle any funding changes.

When reassessed it should be made very clear where needs have changed, if they have, and therefore why funding/input is being reduced. If someone's needs and circumstances have not changed substantially then the review should be brief. There are plenty of "grey areas" since the assessment is about professional judgements and interpretation of information. There is a right to appeal any assessment outcome.



When someone is no longer eligible for any health funding then they are assessed for eligibility for social care funding and if not eligible for social care funding then they may have to self-fund some of their own support; but they will still of course have access to all the usual health care services open to everyone like their GP services, and Accident and Emergency services.

Not all end of life care is eligible for health funding even though people think it will be. This feels like harsh information to share but we want to be honest so people can know where they stand.

If someone becomes ineligible and they have staff that they employ through a personal health budget, they need to be sure to have got redundancy insurances, which are available. For example one insurance firm has just brought out a policy specifically for people using a direct payment for a personal health budget to employ staff.

There is no reason why staff would always have to be made redundant if the funding source changes, but if there is less money, then their hours may need to be reduced. This will affect any contracts of employment that are put in place with support staff and all the planning for the future. People need to know that a support plan can and will allow for these kinds of adjustments.



Useful information about NHS Continuing Healthcare...

[Beacon](#) – A national organisation which offers free independent expert advice and information totally focussed on NHS Continuing Healthcare. tel: 0345 548 0300.

[Decision Support Tool for NHS Continuing Healthcare](#) – This is the tool which will be used to do the assessment. It has the “domains” or types of need which will be assessed.

[NHS England Operating Model for NHS Continuing Healthcare](#) – This is all about HOW the process should be done. It has statements at the end about what anyone should expect from the process “I statements”.

[NHS Continuing Healthcare and NHS funded Nursing Care Public Information leaflet.](#)

[The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care](#) – Sets out the full principles and processes.

[NHS Continuing Healthcare Checklist](#) – This is the quick initial checklist used to decide whether you can be referred for a full assessment.

[You can find links to all of the Continuing Healthcare assessment documents and National Framework guidelines here.](#)

[NHS Greenwich CCG](#) – NHS Greenwich CCG has created an animated graphics film to help explain the framework better. The film is about 30 minutes long, and there are 2 versions. The “continuous play” version is the whole film. The “playlist version” is the same film divided into sections, and you can move between the sections by using the menu control. The film uses pictures, audio and text, and there is no spoken information that is not also shown in text.

[The Care Act 2014](#) (came into effect in April 2015).

[The Care Act 2014 easy to read version.](#)

[Carers UK have summarised the Care Act information available.](#)

