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NHS Continuing Healthcare Assessment: **What is it?**

INFORMATION PACK ONE OF TWO

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

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.

“124. Establishing whether an individual has a primary health need requires a clear, reasoned decision, based on evidence of needs from a comprehensive range of assessments relating to the individual. A good-quality multidisciplinary assessment of needs that looks at all of the individual’s needs ‘in the round’ – including the ways in which they interact with one another – is crucial both to addressing these needs and to determining eligibility for NHS Continuing Healthcare. The individual and (where appropriate) their representative should be enabled to play a central role in the assessment process.”

(National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care October 2018 (Revised) Published March 2018, Incorporating the NHS Continuing Healthcare Practice Guidance - link provided in resource section at end of pack).

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’. The care domains are:
1) Breathing 2) Nutrition 3) Continence
4) Skin Integrity 5) Mobility 6) Communication
7) Psychological & Emotional needs
8) Cognition 9) Behaviour 10) Drug therapies and medication
11) Altered states of consciousness
12) Other significant care needs.

Each domain is given a score or ‘weighting’. Domain needs are scored in range from “no needs” through to priority, the stepped range is: “no needs”, “low”, “moderate”, “high”, “severe” and at the top end of the spectrum, “priority”. Only some needs are given a score level up to priority.



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 priority 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 four key characteristics of nature, intensity, complexity and unpredictability of needs. These characteristics are described, and their use explained in paragraphs 58 to 66 of the National CHC Framework and Practice Guidance 2018. 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.

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 nature, or the complexity, or the unpredictability of the needs which is sufficient to create a 'primary health need'. 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.

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

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



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. The Checklist can be completed by a variety of health and social care practitioners, so long as they have been trained in its use.

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 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 *“consisting of at least two professionals who are from different healthcare professions, or one professional*

who is from a healthcare profession and one person who is responsible for assessing persons who may have needs for care and support under part 1 of the Care Act 2014. ... The multidisciplinary team should usually include both health and social care professionals, who are knowledgeable about the individual’s health and social care needs and, where possible, have recently been involved in the assessment, treatment or care of the individual.” (para 120 **National Framework and Practice Guidance 2018**).

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 REQUEST A REVIEW LOCALLY.

The CCG should give clear reasons for its decision on whether or not they have assessed you as having a primary health need and set out the basis on which the decision of eligibility was made. You or your representative have the right to request a review of the decision if you disagree with it. This should be addressed through a local resolution procedure.

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. You may potentially receive a joint package of health and social care. *"This is where an individual's care or support package is funded by both the NHS and the local authority. This may apply where specific needs have been identified through the Decision Support Tool assessment, that are beyond the powers of the local authority to meet on its own."* (para 263 National Framework).



Can I fall out of NHS Continuing Healthcare funding eligibility?



YES YOU CAN. *“Eligibility for NHS Continuing Healthcare is not indefinite, as needs could change. This should be made clear to the individual and/or their representatives.”* (para 66 National Framework) 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.

The 2018 revised Framework policy makes clear that: *“reviews should primarily focus on whether the care plan or arrangements remain appropriate to meet the individual’s needs. It is expected that in the majority of cases there will be no need to reassess for eligibility.”* (para 183 National Framework). If there is clear evidence of a change in needs, to such an extent that it might impact on eligibility, then a full reassessment must be carried out involving a multidisciplinary team and using the Decision Support Tool. There is a right to ask for a review of any re-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.

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 is a national organisation which offers free independent expert advice and information totally focussed on NHS Continuing Healthcare tel: 0345 548 0300.

NHS England have produced a summary information film which explains all about NHS continuing Healthcare. It's about 20 minutes long and has helpful images and descriptions about each part of the whole process.

National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care October 2018 (Revised) Published March 2018 Incorporating the NHS Continuing Healthcare Practice Guidance. Easy-read version.

Public Information Leaflet NHS Continuing Healthcare and NHS-funded Nursing Care Supporting the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care Published December 2018.

NHS Continuing Healthcare Decision Support Tool Published December 2018.

NHS Continuing Healthcare Checklist Published December 2018.

NHS Continuing Healthcare: Independent Review Process Public Information Guide.

Factsheet FS20 NHS Continuing Healthcare and NHS-funded nursing care Age UK Published October 2020.

The Care Act 2014 (came into effect in April 2015). Easy-read version.

Care Act Factsheets.

Carers UK have summarised the information about the Care Act and how to get support.

