



peoplehub
personal health budgets network

2

NHS
Continuing
Healthcare
Assessment:
**What can I
expect and
how can
I prepare?**

INFORMATION PACK TWO 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 second of these sets of questions, including:

- What should I be able to expect of a good assessment?
- How can I best prepare for the assessment?
- What information should I gather and how?

Pack one focus on the first set of questions: NHS Continuing Healthcare Assessment: What is it? Including questions regarding eligibility.

We would recommend you read pack one as it is intended to help with understanding this second pack.

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?

The third pack explores what happens if you are eligible for NHS Continuing Healthcare funding, and so you have a legal right to have that funding as a personal health budget. It considers how you might weigh up how much choice and control you wish to take.

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’s involved in the assessment process?”*
- *“Who can support me?”*
- *“Can I expect the person who understands my needs most to be there and support me?”*
- *“What evidence do I need?”*
- *“What IS evidence?”*
- *“Who can be involved?”*
- *“Who has to be involved?”*
- *“Who is the professional who understands my needs most?”*
- *“What influence can I have on the people and the process?”*
- *“What will the assessments be about?”*
- *“What are the criteria?”*
- *“Who makes the decision?”*
- *“How can I prepare? What areas of my health will be assessed?”*

- *“We have to run ourselves or our loved one down – that’s what it can feel like when describing all the needs. The person themselves with all their strengths and character can seem lost in the process. It can feel hard and emotionally painful to describe needs in depth. I guess knowing that’s what it can feel like can help us get prepared and find support too.”*

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 gaining some knowledge about what to expect from the assessment process and thinking about how best to prepare for it.



What can I expect from the assessment process?

How do people arrive at having a full Continuing Health Care assessment?

The process is this: 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.

NOTE: The person doing the “Checklist” should have had training to do this – so you can request this. Preferably it should also be someone involved in your care. It can be empowering to have reference to the legislation or best practice guidance on any of these points so these are included, so that you can feel you can argue for that best practice. The Checklist should be done with the person present if they have capacity, or with their representative.

If the Checklist process decides that you are not to be referred for a full assessment, there is no formal appeals process for this stage, only the local complaints procedure.

If you disagree with the decision not to go ahead to the full assessment you can ask the Clinical Commissioning Group (CCG) to reconsider it. This should include a review of the original Checklist and any new information available, and might include the completion of a second Checklist. If you remain dissatisfied there is no formal appeal process, so you’d need to use the local complaints process.



The Continuing Health Care full assessment must bring together a multidisciplinary team with a minimum of two different professionals (this could be a registered nurse and a mental health nurse for example).

The aim is not to have only the minimum two professionals but rather everyone who is making assessments and recommendations about aspects of care. It could include specialist nurses, district nurses, speech and language therapists and others involved in your care.

The person leading the assessment needs to bring together the information from all the relevant people and invite them to the multidisciplinary meeting (which you might hear called the “MDT”).

The policy is also clear that 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.

THESE ARE SOME USEFUL THINGS TO KNOW AND DO:

- Eligibility for NHS Continuing Healthcare is not based on a specific condition or diagnosis. It is assessed using the “Decision Support Tool for NHS Continuing Healthcare”. We have described what this Tool looks at and outlined how to prepare for the assessment and what information to gather, after this section.
- Nursing needs are NOT the same as what is called a “primary health need”. Information pack one describes how a primary health need is defined and assessed using the NHS Continuing Healthcare Decision Support Tool. (There is a link to this tool at the end. It is sometimes called by staff the “DST”).
- It is supposed to be a 28 day process and the people involved should be the people involved in all aspects of your care.
- The first step then for anyone being assessed is to identify the key health professionals currently involved in your care and get any up to date reports. Flag up to the assessor who the key professionals are in your life and who should be inputting. Don't assume that the assessor will know everyone involved. Make your list of the key professionals who know you, in advance.
- The Continuing Healthcare assessor is not allowed to send out to you any health reports they gather in from professionals involved in your care. You have to request these reports directly from those professionals yourself.
- It's worthwhile checking that all reports being included in the assessment are the most up to date. You can do this by requesting the reports from the relevant professionals yourself and checking them.
- The assessor then sets up the meeting in conjunction with the multidisciplinary team. This can be ward staff or community staff and the assessor coordinates everyone's input. If some staff are on leave the process still has to go ahead.
- The person leading the assessment must bring together information from all the relevant people involved in your care and treatment.
- Be aware that you, or your representative **SHOULD** be at the multidisciplinary meeting (often abbreviated to MDT meeting).
- Know that you are allowed to bring someone you want to support you.



The Decision Support Tool does not change the fact that health professionals have to weigh all the evidence and make an informed judgment. This is an assessment of need first and foremost and a consideration of how best to meet those needs (regardless of whether someone is eligible for CHC funding or not). The assessment does NOT provide the plan to meet the needs. The plan should follow, however it is funded. It is not about solutions at this assessment stage.

Hopefully it can make the process less terrifying to know that the assessment of need, even if the decision is “no” for NHS Continuing Healthcare, is still a summary of your needs and it should be made clear to you where you go from that point on to meet those needs.

If the outcome is not what you want you can appeal first locally, then to an independent review panel convened by NHS England which has to look at procedural issues as well as the decision. If you decide that you want to appeal about being assessed as ineligible then be aware that appeals can take a long time. We would suggest that you always pay the care agency fees or the nursing home fees whilst you are appealing.

This is because if your appeal is upheld you will be repaid – but if your appeal is not upheld and you had not paid the fees you would face a big debt.



What should you expect and what is helpful to know?

You should expect to be fully involved and that you have had the opportunity to input everything you want to about your needs or the needs of someone you care for in the family.

You should be a part of contributing to the decision making process, although you need to know that once all the information has been gathered it is the multidisciplinary team which will make the decision about whether you are eligible, based on professional judgement and interpretation of all the information gathered.

What is very helpful to know, is that there is a set of statements through which the quality of the process can be judged. These have been written from the perspective of someone going through the process. They are contained in this document: [“NHS England Operating Model for NHS Continuing Healthcare”](#) which is all about HOW the process should be done. It has statements at the end about what anyone should expect from the process, referred to as “I statements”.

These include statements such as:

- *“I felt the assessment focused on me as an individual and helped me live the best life I can.”*
- *“I felt that my needs were thoroughly and accurately identified and considered within the assessment.”*
- *“I felt that the assessment process included all the relevant professionals, as well as my family, and captured all relevant information.”*
- *“I felt the assessment focused on my needs and not my financial circumstances.”*
- *“I was confident that the professionals wanted to reach the correct decision, not the cheapest or more convenient one.”*
- *“I was assessed in a way that captured the full impact of my condition and not just a snapshot on a ‘good day’.”*

If you take a glimpse at all of the “I statements” which are on pages 36 to 40 of the “Operating Model” document you will be equipped to know what you should expect if good practice is being followed. And it may be very useful to let the staff who are responsible for the assessment know that you are aware of these national quality indicators.



What information should you gather and how?

It can feel quite daunting to consider what information to prepare, at what is frequently a very stressful point of upheaval in your life. We have thought long and hard about ways to make this gathering of information as simple and relatively short as possible. We describe some questions you might use, after we have outlined the way that the assessors will approach thinking about your needs.

What will the assessors consider?

The assessor has to use the “Decision Support Tool for NHS Continuing Healthcare” and this considers your needs across 12 areas, known as “domains”:

- Behaviour.
- Cognition.
- Psychological and emotional needs.
- Communication.
- Mobility.
- Nutrition.
- Continence.
- Skin integrity.

- Breathing.
- Drug therapies and medication.
- Altered states of consciousness.
- Any other significant care needs.
Consideration is given to the nature, intensity, complexity and unpredictability of your needs.

It is well worthwhile taking a look at this tool and seeing the descriptions it contains of how levels of need are evaluated. [The tool can be viewed here.](#)

How you can collect relevant information for the assessment?

You don't have to try and describe your needs under those “domain” headings, since none of us tend to think about our lives in separate boxes like that. We've included the “domains” so that you are best informed about how the assessors will approach their assessment.

We are aware that needs can impact on one another and don't neatly divide up. And so we suggest that for the information you gather, what is vital is to explain to the assessor all the important things you have to do and to consider throughout each day and night.



What the assessor needs to understand is how your particular health condition or conditions affect you as a unique individual in your own unique circumstances and with your particular life history. So gather information for a few days about what happens through that time.

Think about it in terms of tasks as well as time. We've given some questions to support your thinking this through. Don't feel you have to answer all of these, they are given as examples:

- What has to happen for me to get up and be ready for the day?
- What help do I need to wash and dress and eat?
- What support do I need to go out of my home?
- What help do I need to sleep well?
- How are my health needs met through the day and night?
- What medication do I need, how often and how do I take that?

- Is there medication which is not taken routinely but in response to health needs that happen sometimes which need to have a response?
- Do I need help to be moved and to assist with toileting?
- How am I able to breathe easily and have enough food and drinks?
- How am I able to feel emotionally well, physically comfortable and not in pain?
- What is the most difficult thing I have to deal with?
- For each task, who has to be involved and what skills and knowledge are needed?

Another way to gather the information is to consider:

- How do you prepare for each day?
- What has to be recorded or monitored?
- What information do you need to have?
- What do you have to do to prepare to carry out an everyday health related task well?

- What would someone else have to know and be skilled at if they had to do that task?
- What do any care staff have to do to keep you or your family member safe?
- What records inform your day to day decision – making about your care?

Once you've gathered this everyday information, think about things which can happen, and have happened "out of the blue". Ask yourself:

- What are the kinds of needs that require a moment by moment monitoring, and can't be met by planned interventions?
- What kinds of things happen that require decision making in the moment depending on the presenting situation?

A "well-managed need" is still a need. Well managed needs can be considered if you state – what would happen (and what may have happened in the past) if it were not continuously well managed; AND what would happen, even when the task is done well, that is, what might arise in spite of all the input and tasks being done well – **this is key**.



You need to describe what has happened without adequate skilled support and what still happens even with adequate skilled support.

EXAMPLE

Someone might not have had any skin problems for several months because a whole process of care to prevent skin problems has been put into place. The process was put in place following patches of skin breaking down. The process needs to be very clearly described and include what has to be continuously observed/ looked out for, even with the new process being carried out well, to prompt urgent further action to keep skin intact. The focus is on actual risk rather than only potential risk – things that have happened (e.g. my skin broke down and became an infected wound previously.)

The level of risk needs to be considered in relation to the quality of the interventions needed and the quantity of that input. You need to pay attention to what has to be thought about to take care of the need, this is key. Be as clear and specific as you can. For example think about the timing and frequency of input and be aware for example that “constant input needed” is different from “daily input needed”.

Over time, individuals and family members can become so familiar and skilled at health care tasks that you have to sit back and really consider everything you are regularly “doing on autopilot”. You have to make the things you do and what you weigh up explicit, so that the assessor can see the amount of thinking and decision- making that you have to do and appreciate fully any complexity or risk.

The Decision Support Tool states that: “Completion of the Decision Support Tool should be organised so that the person understands the process, and receives advice and information to enable them to participate in informed decisions about their future care and support. The reasons for any decisions should be transparent and clearly documented.”

If the assessment process follows the policy in this way, so that you can take an active informed part, then the final decision will not be unexpected or shocking, and you are far more likely to feel that you have been fairly treated. We hope the summary information in this pack help support your participation in the assessment, and how it feels as a process.



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.](#)

