



# Factsheet

Continuing Healthcare: Should the NHS be paying for your care?

This factsheet explains when it is the duty of the NHS to pay for your care.

It covers:

- what NHS Continuing Healthcare is
- who qualifies
- how the assessment process works
- what you can do if you're unhappy with the outcome of an assessment.



Call free on **0800 319 6789** Visit **independentage.org** 



### **About Independent Age**

At Independent Age, we want more people in the UK to live a happy, connected and purposeful later life. That's why we support people aged over 65 to get involved in things they enjoy. We also campaign and give advice on the issues that matter most: health and care, money and housing.

For information or advice – we can arrange a free, impartial chat with an adviser – call us on freephone **0800 319 6789** (Monday to Friday, 8.30am to 5.30pm) or email us at **advice@independentage.org**.

You can also support this work by volunteering with us, joining our campaigns to improve life for older people experiencing hardship, donating to us or remembering us in your will.

For more information, visit **independentage.org** or call us on **0800 319 6789**.

In this factsheet, you'll find reference to our other free publications. You can order them by calling **0800 319 6789** or by visiting **independentage.org/publications**.



### Contents

1.	What is NHS Continuing Healthcare?	4
2.	Who can get NHS Continuing Healthcare?	6
3.	The NHS Continuing Healthcare Assessment	7
	Stage one: The screening assessment	9
	Stage two: The full assessment	12
	Getting a fast-tracked assessment	17
4.	If your application is successful	18
5.	If your application isn't successful	23
6.	NHS-funded Nursing Care	31
7.	Summary checklist	32



# 1. What is NHS Continuing Healthcare?

NHS Continuing Healthcare is a package of ongoing care that is arranged and paid for by the NHS. It is given to people with a high level of physical and/or mental health needs that are caused by a disability, accident or illness. Having a particular diagnosis, such as dementia or Parkinson's, does not mean you'll automatically qualify.

In England, NHS Continuing Healthcare is arranged and paid for by your local Integrated Care Board. In Wales, your Local Health Board is responsible.

NHS Continuing Healthcare isn't means-tested. If you qualify, the funding will cover the full cost of the services you're assessed as needing.



### Good to know

Care funded by NHS Continuing Healthcare can be provided anywhere – including in a hospice, a care home or in your home.

Throughout this factsheet, we will refer to the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. This sets out who qualifies for NHS Continuing Healthcare, how the assessment process should work and what you can do if your application is not successful.

You can download the National Framework for England from Gov.uk at gov.uk/government/publications/national-framework-for-nhscontinuing-healthcare-and-nhs-funded-nursing-care. If you live in Wales, visit gov.wales/national-framework-continuing-nhs-healthcare.



### If you live in Scotland

NHS Continuing Healthcare is no longer available in Scotland. It has been replaced by Hospital Based Complex Clinical Care. You will only qualify for this if your care needs must be met in a hospital.

To find out more, contact Care Information Scotland (0800 011 3200, careinfoscotland.scot/topics/how-to-get-care-services/hospital-based-complex-clinical-care).



# 2. Who can get NHS Continuing Healthcare?

To qualify for NHS Continuing Healthcare, you must be assessed as having a primary health need.

### What is a primary health need?

You have a primary health need if your main need for care is health related and the care you need is more than what a local council could be expected to provide.

The NHS will look at your needs as a whole to work out if you have a primary health need. They will focus on four key characteristics.

- Nature of your needs: what your needs are like and how they affect your overall health and wellbeing. An assessment could look at the type of help you need and whether your needs will increase or decrease.
- Intensity of your needs: how many different health needs you have, how severe they are and how long you might have these needs for. An assessment might look at needs that require a certain type or level of care to manage.
- **Complexity of your needs**: if your needs are difficult to manage or if you have a combination of symptoms or conditions that make it harder to meet your needs. Complexity can also mean how much treatment you need for a condition, or if you require specialist or urgent care and treatment.
- Unpredictability of your needs: how much and how often your needs change, and the risk to your health if you do not get the right care at the right time. Your condition may need careful monitoring – for example, if it changes a lot, is unstable or is quickly getting worse.



### 3. The NHS Continuing Healthcare Assessment

The professionals involved in your care must follow the National Framework guidance when deciding if you qualify for NHS Continuing Healthcare. The guidance says that only the following three forms can be used in this process.

- **Checklist Tool**: This is used for screening people who have applied for a full NHS Continuing Healthcare assessment.
- **Decision Support Tool**: This is used during a full NHS Continuing Healthcare assessment by a multidisciplinary team (MDT). This is a team made up of two or more different health and care professionals.
- Fast Track Pathway Tool: This is used when someone needs NHS Continuing Healthcare immediately because their condition is quickly getting worse. In most cases, the person will need end-of-life care.

### **Requesting an assessment**

Your Integrated Care Board (ICB) or Local Health Board (LHB) must make sure you're assessed if you seem to need NHS Continuing Healthcare.

If you think you should have an NHS Continuing Healthcare assessment, you can ask a nurse, doctor, GP or social worker to arrange one. If the health or care professional you approach is unable to carry out an assessment, you can ask them to contact someone who can. You can also contact the NHS Continuing Healthcare team at your local ICB or LHB yourself to ask for an assessment. You can find their details at:

- nhs.uk/nhs-services/find-your-local-integrated-care-board in England
- gov.wales/continuing-nhs-healthcare-chc-contact-details-html in Wales.

If you've tried to ask for an assessment and are unhappy with your experience, you could consider making a formal complaint to the relevant organisation. See our factsheet **Complaints about health services** to find out more.



# The 12 care domains considered in your assessment

To help decide whether you have a primary health need, the Checklist Tool and Decision Support Tool (DST) forms tell assessors to look at the nature, intensity, complexity and unpredictability of your needs in 11 to 12 general areas. These are called care domains and include:

- 1. Breathing\* can you breathe independently or with support?
- 2. Nutrition do you need care so you get enough to eat and drink?
- 3. Continence your control of your bladder and bowel
- 4. Skin integrity the condition of your skin: poor skin integrity can include pressure sores, wounds or infection
- 5. Mobility your ability to safely walk or move about without support
- 6. Communication your ability to express or explain your needs
- Psychological and emotional needs such as anxiety, mood disturbances, hallucinations or distress
- 8. Cognition does your disability or disease cause confusion, memory issues, disorientation or an inability to judge risk?
- 9. Behaviour\* is your behaviour a risk to yourself, others or property? Can it be anticipated or minimised?
- **10. Drug therapies and medication\*** is your medication or pain difficult to manage safely?
- **11. Altered states of consciousness\*** when your mind is aware but not fully in control, putting you at risk of harm (for example, if you have epilepsy)

### 12. Any other significant needs.

The needs marked with an asterisk (\*) are considered the most important. We'll return to this list later in this chapter, when we explain how the assessment collects and uses information about these different care domains to see if you have a primary health need.



### Good to know

The first step of the NHS Continuing Healthcare assessment process will usually be a screening assessment using the Checklist Tool. However, the Checklist Tool may be skipped if it's clear you qualify for a full assessment by a multidisciplinary team using the Decision Support Tool.

### Stage one: The screening assessment

You may have a screening assessment with a professional using the Checklist Tool. This works out whether you need to have a full assessment.

The Checklist Tool can be used by any health or care professional who is trained to use it. This could be a nurse, social worker, GP or other doctor, for instance. They should also be familiar with the National Framework and the DST (the next stage of the assessment).

When the Checklist Tool is used in Wales, it must be completed by at least two professionals, including one from the local council.

If you're being considered for NHS Continuing Healthcare, you should be given an information booklet. You can download a copy at:

- gov.uk/government/publications/nhs-continuing-healthcareand-nhs-funded-nursing-care-public-information-leaflet/publicinformation-leaflet-nhs-continuing-healthcare-and-nhs-fundednursing-care--2
- gov.wales/continuing-nhs-healthcare-chc-information-bookletindividuals-families-and-carers.



### Good to know

You should be fully involved in the process. You can have a representative with you when the assessment is taking place, to make sure that your views are taken into account. This could be a family member, friend, carer or advocate.

#### How it works

The Checklist Tool has three statements for each of the care domains listed on **page 8**. The assessor will pick the statement that best describes the level of your needs. Each statement has a score of 'A' (high), 'B' (moderate) or 'C' (no or low-level need).

You will qualify for a full NHS Continuing Healthcare assessment if you have:

- two or more care domains rated as A, or
- five or more care domains rated as B, or
- one care domain rated as A and four as B, or
- one care domain marked with an asterisk (\*) rated as A these are considered priority needs.

However, the assessor can still refer you for a full assessment even if you do not receive one of these scores. Once the assessor has completed the Checklist Tool, they will need to send it to your ICB or LHB, along with any evidence to support their recommendation.

You can download a copy of the Checklist Tool from the Department of Health website at **gov.uk/government/ publications/nhs-continuing-healthcare-checklist**. You can also find the Checklist Tool in the National Framework for Wales at **gov.wales/national-framework-continuing-nhs-healthcare**.





### To do

Before your assessment, you might want to consider:

- what score you think you should get in the different care domains
- what evidence of these needs you could provide.

### After the Checklist Tool has been completed

There are two possible outcomes:

- a positive Checklist this means that the screening assessment shows you may have a primary health need, and the ICB or LHB must arrange a full MDT assessment using the DST
- a negative Checklist this means that the screening assessment finds you do not meet the criteria for a full assessment, so you do not qualify for NHS Continuing Healthcare.



A positive Checklist only shows that you are entitled to a full assessment. It's important to be aware that most people who have a positive Checklist do not qualify for NHS Continuing Healthcare after the full assessment.

The ICB or LHB must write to you or your representative about why they have or haven't decided to carry out a full NHS Continuing Healthcare assessment. You should also be given a copy of the completed Checklist Tool.

If you do not qualify, you have a right to ask your ICB or LHB to reconsider their decision. See **chapter 5** for more information.



### Stage two: The full assessment

Once your ICB or LHB receive your Checklist Tool showing that you might qualify for NHS Continuing Healthcare, they will arrange your full assessment.

This will be carried out by an MDT of two or more people. This team must contain at least two assessors from different health professions, or one healthcare professional and one social care professional. This could include a:

- medical consultant or doctor
- ward nurse or specialist nurse
- psychiatric nurse
- speech and language or behavioural therapist
- occupational therapist
- social worker or other social care professional.

You can have someone with you to help represent your views during the assessment, such as a relative, friend or an advocate.

The MDT should fully involve you and your representative in the assessment where your needs are discussed. They should record and take into account your views about your healthcare needs and your wishes for your future care.

You and your representative should also be given advice to help you understand the process.



### To do

For more information about independent advocacy, and when you may qualify for it or find it useful, see our factsheet Helping you get your voice heard: Independent advocacy.



#### How the assessment works

The MDT must use the DST to help them decide whether you qualify for NHS Continuing Healthcare. The DST is organised by the different care domains. Each one has a number of statements that describe different levels of need (see **page 8**). Using the descriptions and a range of evidence, the team should decide whether your needs for each domain are none, low, moderate or high.

For some of the care domains, your needs can also be categorised as severe or priority. The only care domains where your needs can be considered 'priority' are the ones marked with an asterisk (\*).

The team should also weigh up the overall risk to you from your condition or need, or the risk to others.

They will recommend to the ICB or LHB that you should be seen as having a primary health need – meaning you would qualify for NHS Continuing Healthcare – if you have:

- a 'priority' level score in one care domain
- two 'severe' needs across all care domains that have this level.

The MDT may also say you have a primary health need, and recommend you for NHS Continuing Healthcare, if you have:

- one domain recorded as severe, together with needs in a number of other domains
- a number of domains with high and/or moderate needs.



### Deciding whether you have a primary health need

Deciding whether someone has a primary health need can be complicated. If your needs do not fit easily into the first 11 care domains, the team should still consider the extent and type of needs you have. They should record this in the 12th care domain section of the DST called 'Other significant care needs'.

The MDT should not ignore any needs that are currently well managed, unless they are sure that the need is permanently reduced or is no longer a need.

If members of the MDT disagree about whether your needs are low, moderate, high, severe or priority, they must select the higher level and give a reason for doing so.

The MDT will make a decision about whether they think you should qualify for NHS Continuing Healthcare using evidence from the completed DST as well as the team's clinical judgement. The team must then make a written recommendation for NHS Continuing Healthcare at the end of the DST form before sending it to your ICB or LHB.

#### After the full assessment

The ICB or LHB should follow the team's recommendation except in exceptional circumstances. This could include if:

- there's a lack of evidence to support a recommendation
- a full assessment of your needs has not been carried out
- the DST is not fully completed.

If this happens, the ICB or LHB should ask the team that carried out your assessment to provide more information or evidence. The ICB or LHB's decision not to follow the recommendation shouldn't be influenced by the cost of the care, where the care will be provided or who will deliver the care.

The ICB or LHB must write to you or your representative to tell you their decision about whether or not you qualify, and give reasons for this decision. You should also receive a copy of the completed DST form.



### If you do not qualify

Even if you do not qualify for NHS Continuing Healthcare, the ICB or LHB and the council should always consider whether the assessment has shown you have care needs. If so, they should arrange the right assessment or services for you. This could include NHS-funded Nursing Care (see **chapter 6**).

You can also ask the ICB or LHB to review their decision (see chapter 5).

### Good to know

You can get NHS Continuing Healthcare for needs that arise from a mental health condition (including those caused by dementia), as well as for physical health problems. If you have a mental health condition, your assessment may involve a psychiatrist or other mental health professional.

The Alzheimer's Society (0300 222 1122,

**alzheimers.org.uk**) runs a dementia helpline and has published a factsheet about NHS Continuing Healthcare for people with dementia.

### How long will I have to wait?

In England, you should have a screening assessment using a Checklist Tool within 14 days of asking for one from your ICB. If you need a full assessment using a DST, this should be done and a decision made by the ICB within 28 days of them receiving the completed Checklist Tool, or being told you need a full assessment (whichever happened first).

In Wales, the process for completing a full assessment takes up to eight weeks. If you've been in hospital, you should have any rehabilitation or reablement that you need first.



You or your representative should usually receive the final decision in writing within two working days. This letter should include:

- reasons for the ICB or LHB decision
- details of who to contact if you want more information
- a copy of the completed tool(s)
- information on how to ask for a review if you do not qualify
- if necessary, timescales for requesting a review.



If you live in England and you need help with your application process, Beacon (**0345 548 0300**, **beaconchc.co.uk**) has a free Navigational Toolkit to help you with your assessment or appeal. This is available online, or you can phone to ask for a postal copy.

If you live in Wales and you need advice, contact Age Cymru (029 2043 1555, ageuk.org.uk/cymru).



### **Getting a fast-tracked assessment**

If you have a primary health need because of a condition that is quickly getting worse and may be entering its final stages, some professionals can assess you using the Fast Track Pathway Tool and recommend you for NHS Continuing Healthcare.

This assessment process is quicker and doesn't use the Checklist Tool or DST.

The Fast Track Pathway Tool must be completed by an appropriate clinician, such as a nurse, consultant or GP responsible for your diagnosis, treatment or care. They must have the skills and knowledge about your needs or palliative care to make a clear recommendation about whether you are now approaching the end of your life.

If an appropriate clinician completes the Fast Track Pathway Tool and recommends you should receive NHS Continuing Healthcare, this must be accepted straightaway by your ICB or LHB, unless it's incomplete or does not meet the criteria. In England, the ICB should aim for you to get care within 48 hours. In Wales, you should get urgent care immediately.



### Good to know

The Fast Track Pathway Tool may not be necessary for everyone who is approaching the end of their life. You also do not need to be at the end of your life to be considered for fast tracking.



### 4. If your application is successful

### Planning your care

If you qualify for NHS Continuing Healthcare, your Integrated Care Board (ICB) or Local Health Board (LHB) must arrange the services you need. These services must meet all the health and social care needs identified in your assessment.

You should be involved in developing your care plan. The ICB or LHB should take your preferences and expectations into account, including your views about where you live and receive your care. The ICB or LHB should talk to you about the benefits and risks of care in different places – such as a nursing home or your own home – before deciding where you will receive care.

Once your care plan is agreed and you're getting the services you need, the ICB or LHB will continue to manage your care. They should:

- coordinate all your services and support
- review the quality of your services
- deal with any problems or concerns
- make sure changes in your needs are met.

### **Personal Health Budgets**

A Personal Health Budget (PHB) gives you a set amount of money to meet your health and care needs. It can give you greater choice, flexibility and control over your care. PHBs are not available in Wales.

In England, anyone receiving NHS Continuing Healthcare has a right to ask for a PHB. Your ICB should accept requests for PHBs unless they have clear reasons not to – for example, if it would not benefit the person or it would not be a cost-effective or sensible way to provide their care.



You can spend a PHB on a range of services, care and equipment – as long as it meets the needs and outcomes in your care plan. You will put together this care plan with your ICB and a named care coordinator, who will also be responsible for monitoring and reviewing the care plan and PHB. The care plan will need to be approved by the ICB.

A PHB can be managed directly by you, a family member, an independent third party or by the NHS. You can also receive a PHB as a direct payment. This is when the money is given to you directly to buy the services the ICB agrees that you need.

You can find out more about PHBs on the NHS website at **nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget**.

### **Reviewing your care**

Your ICB or LHB should regularly review and update your care plan to make sure it's working well and you're getting the right care. Reviews will also consider if you still qualify for NHS Continuing Healthcare. NHS Continuing Healthcare can stop when your needs change – for example, if a condition improves and you need less support.

You'll have a review no later than three months after you qualify for NHS Continuing Healthcare, and at least once a year after that.

During a review, any previous Decision Support Tool (DST) will usually be looked at again. You and/or your representative should be there for any review.

If your review shows you may no longer qualify for NHS Continuing Healthcare, a full multidisciplinary team assessment using the DST form must be carried out before the final decision is made and any funding stops.



If the ICB or LHB decide you no longer qualify for NHS Continuing Healthcare, they must:

- tell you in writing and explain how to ask for a review
- agree how your care will be paid for in the future with you and/or your local council
- put arrangements in place before they stop paying for your care.

### **Refunds and goodwill payments**

If the decision about whether you qualify for NHS Continuing Healthcare is delayed or disputed, you may qualify for a payment from your ICB or LHB to cover any payments you had to make in the meantime. This payment would make sure that you do not lose out financially because NHS Continuing Healthcare wasn't awarded at the right time – for example, if you paid the local council or a private agency for care services and:

- in England, the ICB took longer than 28 days from the date that they received your completed Checklist Tool assessment to decide that you qualify for NHS Continuing Healthcare, without good reason
- the ICB or LHB decided you didn't qualify for NHS Continuing Healthcare, but then changed their decision following a review
- in Wales, the LHB took longer than eight weeks to put a care package in place once it was decided that you qualified for NHS Continuing Healthcare.



# Can I be asked to pay towards the cost of my care if I receive NHS Continuing Healthcare?

If you qualify, the funding should cover the full cost of the accommodation or care you're assessed as needing. If you live at home, the NHS is not responsible for covering your rent, food and normal utility bills. They will only pay for the costs of your health and personal care.

However, there are some occasions where you might be asked to contribute towards your care or services.

- **1.** If you'd like a service or accommodation that costs more than the ICB or LHB think is necessary to meet your needs. This could be a larger room in a care home, for example.
- 2. If you'd like a new service (or a more frequent service) that the ICB or LHB do not consider essential to meeting your needs.

For example, you might be assessed as needing two sessions of physiotherapy a week, but you would like three. You could arrange and pay for an extra session from a private physiotherapist.

Before the ICB or LHB let you pay for an extra or new service, they need to be sure that it can be provided separately from the services they are responsible for – for example, by making sure that different staff provide the extra service.



### To do

If you're asked to contribute towards your care, or if the ICB or LHB refuse to pay for a particular service for you, contact Independent Age to arrange to speak to an adviser about your options (0800 319 6789, advice@independentage.org).



### How will my benefits be affected if I live at home?

If you receive NHS Continuing Healthcare in your home, you can continue to claim disability benefits such as Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance (AA). If someone claims Carer's Allowance for caring for you, they can also keep this benefit.

# How will my benefits be affected if I live in a care home or hospital?

If you live in a care home or hospital that is paid for by NHS Continuing Healthcare and you receive Bereavement Allowance or Industrial Injuries Disablement Benefit, these will continue.

However, if you live in a care home, you will not receive the care component of DLA, or the daily living component of PIP or AA, after 28 days.

If someone supporting you receives Carer's Allowance, this will stop when your payment for DLA, PIP or AA stops.

If you receive Pension Credit, this won't usually be affected during a temporary stay (up to one year) as long as you continue to qualify for Pension Credit. However, the amount you receive may change in some circumstances.

The amount of Pension Credit you receive may also be affected if you move permanently into a care home.

Call our Helpline to arrange to speak to an adviser about how your benefits may be affected (0800 319 6789, advice@independentage.org).



### 5. If your application isn't successful

If you're turned down for NHS Continuing Healthcare, you have a right to ask your Integrated Care Board (ICB) or Local Health Board (LHB) to look again at their decision if you:

- have been screened for NHS Continuing Healthcare with the Checklist Tool but haven't been referred for a full assessment
- had a full assessment using the Decision Support Tool (DST) and have been told you do not qualify.

You can find the contact details for your ICB or LHB at:

- nhs.uk/nhs-services/find-your-local-integrated-care-board in England
- gov.wales/continuing-nhs-healthcare-chc-contact-details-html in Wales.

# Asking for a reconsideration of your screening assessment

If you had a screening assessment using a Checklist Tool but weren't referred for an assessment using the DST, you can write to your ICB or LHB and ask them to reconsider their decision.

If possible, provide more information about your conditions and needs in your letter. For example:

- if you think your score was lower than it should be for any of the care domains (see **page 8**), can you show why this is?
- is there any evidence of your needs such as medical records or care plans – that wasn't considered?

The ICB or LHB should consider your request and write to you with their reconsidered decision. If they still do not think you need a full assessment, you can make a complaint using the NHS complaints procedure. You will usually have 12 months to make this complaint. See our factsheet **Complaints about health services** to find out more.



### Asking for a review of your full assessment

Your ICB or LHB must write to you after your full assessment using the DST to explain whether or not you will receive NHS Continuing Healthcare. They must include the reasons for their decision. You should receive a copy of the completed DST.

If the ICB or LHB do not think you qualify, they must tell you how you can apply for a review. Each ICB or LHB must have a process for reviewing decisions about who qualifies for NHS Continuing Healthcare, and they should make it clear to you what their process is. You have six months from the date of the decision to apply for a review. You will need to explain why you're asking for a review.



### Good to know

In Wales, you must tell your LHB that you intend to appeal within 28 days of the decision date, otherwise your appeal may not be considered. You still have six months to submit your written appeal.

You can request a review if you disagree with:

- the way the assessment was carried out
- how information was used and interpreted by the assessors
- the final decision.



Your assessment may not have been carried out properly if:

- you and your carer weren't involved
- relevant health professionals and other people caring for you weren't invited to contribute
- in England, the full DST assessment wasn't carried out within 28 days of your Checklist Tool assessment
- the team carrying out your assessment did not make a recommendation
- the ICB or LHB changed how you were scored in a care domain, after the assessment.

You may disagree with the way information was gathered and used during the assessment if:

- you think the information recorded in your DST isn't accurate or doesn't fully describe your needs
- you can think of evidence that should have been used during the assessment – such as care plans – that was overlooked.

You may disagree with the final decision if:

- the ICB or LHB did not explain why you do not qualify
- the ICB or LHB did not follow the multidisciplinary team's recommendation
- you feel the ICB or LHB did not properly look at the nature, intensity, complexity or unpredictability of your needs.



### **The Independent Review Panel**

If you disagree with the outcome of the ICB's or LHB's review of their decision, you can ask for the decision to be looked at again through an Independent Review Panel. You have six months after the outcome of the review to apply.

In England, you need to contact your NHS England regional team (0300 311 2233, england.nhs.uk/healthcare). In Wales, contact your LHB – you can find their details by visiting gov.wales/continuing-nhs-healthcare-chc-contact-details-html.

It may be possible for your case to go straight to an Independent Review Panel if using the ICB's or LHB's review process would unfairly delay things for you.

When you apply for an Independent Review Panel, you will be sent a form to complete. You should explain why you disagree with the decision, or why you're unhappy with the process the ICB or LHB followed to make the decision. You must send the form and any supporting evidence back within six weeks from the date the form was sent to you.



### To do

To make sure you have enough time to prepare, you may want to get advice and gather supporting evidence before requesting an Independent Review Panel.

The Independent Review Panel will only look at:

- the procedure your ICB or LHB followed when deciding whether you qualified for NHS Continuing Healthcare, or
- the ICB's or LHB's decision about your eligibility for NHS Continuing Healthcare.



Your Independent Review Panel will collect evidence about your care needs – such as medical and care records – before meeting to discuss your case. You can ask to attend the meeting and you can also ask for a representative, such as a family member, carer or advocate, to attend for support or to speak on your behalf.

The panel may recommend that your case is reconsidered by the ICB or LHB. Or it may recommend you should be seen as qualifying for NHS Continuing Healthcare.

However, the panel could also recommend that you should not be seen as qualifying.

You, and any other people involved, should receive a copy of the panel's record. In England, NHS England must write to you and the ICB to tell you their decision and the reasons for it. In Wales, the LHB must write to you about the outcome. The ICB or LHB must accept the decision except in exceptional circumstances. If they do not accept the decision, they should write to you and the chair of the panel to explain why.

For more information about Independent Review Panels in England, visit england.nhs.uk/publication/nhs-continuing-healthcareindependent-review-process-public-information-guide. In Wales, visit gov.wales/national-framework-continuing-nhs-healthcare.



### To do

You can arrange to speak to an Independent Age adviser for general advice on Continuing Healthcare matters, including the appeals process (0800 319 6789, advice@independentage.org).

In England, you can also call Beacon (**0345 548 0300**, **beaconchc.co.uk**) for up to 90 minutes of free advice with an independent NHS Continuing Healthcare adviser. In Wales, contact Age Cymru (**029 2043 1555**, **ageuk.org.uk/cymru**).



### The Ombudsman

If you're not satisfied with the outcome from the Independent Review Panel, you can ask the relevant Ombudsman to review this decision. The Ombudsman investigates complaints and unfair decisions made by NHS bodies.

- In England, contact the Parliamentary and Health Service Ombudsman (0345 015 4033, ombudsman.org.uk).
- In Wales, contact the Public Services Ombudsman for Wales (0300 790 0203, ombudsman.wales).

You must usually make your complaint within 12 months of the panel's decision.

### If you're unhappy with how the Ombudsman handles your case

If you feel the Ombudsman hasn't fully considered your complaint or they have done something wrong, you can also make a formal complaint about the Ombudsman.

If you're not satisfied with the Ombudsman's decision, you could consider a judicial review. You usually need to do this within three months of the decision you want to challenge.

You should get legal advice first to see if you have a good case – you can find legal specialists through the Law Society (020 7320 5650, solicitors.lawsociety.org.uk).

Read our factsheet **Complaints about health services** for more information about the Ombudsman, judicial reviews and getting legal advice.



### Tips for appealing an NHS Continuing Healthcare decision

### **Getting organised**

- Ask for all the information provided and decisions made by the ICB or LHB in writing.
- Record the dates, times, names and details of conversations every time you speak to the ICB or LHB or another professional about your assessment or appeal.
- Gather all your documents: for example, care needs assessments, health records, completed Checklist Tool/Decision Support Tool/ Fast Track Pathway Tool.
- Try to go to all meetings in person if you can, or ask a family member, friend or advocate to represent you.

### Preparing for a review

- Ask the ICB or LHB to explain in writing how and why they decided you did not qualify for NHS Continuing Healthcare.
- Write a diary of your needs over a 24- or 48-hour period. Record the type and amount of care you require and how your needs are managed. Record how your needs change. Consider any risks to yourself or others if care isn't provided properly.
- Compare what you have recorded to what was written in the tool used to assess you – were your needs accurately recorded? Remember that the tool should have also taken account of any needs you have that are currently well managed.
- Complete a copy of the Checklist Tool/Decision Support Tool/ Fast Track Tool, depending on what stage of the assessment you are appealing. Score yourself against the care domains and think of evidence, people or examples to explain the level of your needs for each one.
- Check that all your medical and social care needs have been accurately recorded on the tool used during your assessment, and highlight anything missed out.



### **Getting support**

- Find as many people as possible who can support your case and help you show that you have a primary health need. This could include a social worker, GP, consultant, professional care worker or family member.
- If you do not have a family member or friend who can represent you at meetings or help with your appeal, ask your ICB or LHB for information about a local advocacy service. You can also read our factsheet Helping you get your voice heard: Independent advocacy for more information.
- If you think you have a good case, you may need to be patient because the appeal process can take time. Don't give up – many people have successfully appealed an NHS Continuing Healthcare decision.

### Remember

You can call our Helpline on **0800 319 6789** or contact Beacon (**0345 548 0300**, **beaconchc.co.uk**) for help and advice about appealing a decision. If you live in Wales, contact Age Cymru (**029 2043 1555**, **ageuk.org.uk/cymru**).



### 6. NHS-funded Nursing Care

If you do not qualify for NHS Continuing Healthcare, you could get NHS-funded Nursing Care. This is a weekly payment from the NHS for some people who live in a nursing home. In England, it is £219.71 (2023/24 rate) a week and in Wales it is £201.74 (2022/23 rate) a week. The payment will go towards the care you receive from, or under the supervision of, a registered nurse.

It is sometimes called a Registered Nursing Care Contribution, which is the old name for this payment.

NHS-funded Nursing Care is only paid if you're assessed as needing nursing care and you're living in a nursing home. You must be considered for NHS Continuing Healthcare before a decision is reached about the need for NHS-funded Nursing Care.



### If you've already had a full NHS Continuing Healthcare assessment using the Decision Support Tool, this should provide enough information to decide whether you can get NHS-funded Nursing Care. However, you may also be assessed by a registered NHS nurse, who will consider all your nursing needs.

The payment is normally paid by the NHS to the nursing home. If you are paying for your own care, this payment may reduce the overall care home fee (depending on your contract with the home). If your local council is contributing to your care home fees, this payment may reduce the amount they contribute.

For more general information about fees, see our factsheet **Paying care home fees** or call our Helpline on **0800 319 6789**.



## 7. Summary checklist

Here are the key steps you should take both before and after an assessment for NHS Continuing Healthcare.

Ask for an assessment from your health professional or contact your local NHS Integrated Care Board (ICB) or your Local Health Board (LHB) in Wales.

### Prepare well for your assessment

- Read about the 12 care domains that are considered in the assessment (see **page 8**) and think about what you might score in the different care domains.
- Write down how your healthcare needs affect you in your dayto-day life and your wishes for your future care.
- Get written evidence from your GP or health or care professional to show that you have a primary health need (see **page 6**).
- Make sure evidence, such as care plans and daily records, is up to date and includes any important details about your needs.
- Think about whether you'd like someone to support you during the assessment, such as a friend, family member or advocate.
- Make a list of any questions you'd like to ask during your assessment.

### After the assessment

- Get copies of the completed Checklist Tool and/or Decision Support Tool forms after your assessment. Keep any letters you receive from the ICB or LHB.
- If you're told you qualify and you're wondering how this may affect your benefits, call our free Helpline on **0800 319 6789**.
- If you're told you do not qualify, you can ask your ICB or LHB to review their decision (see **chapter 5**). Contact our Helpline on **0800 319 6789**, or Beacon if you live in England on **0345 548 0300**, if you need support with requesting a review.



While we make every reasonable effort to ensure that our information is accurate at the time of publication, information can change over time. Our information should not be used as a substitute for professional advice. Independent Age does not accept any liability for any loss however caused arising from the use of the information within this publication. Please note that the inclusion of other organisations does not constitute an endorsement from us.

The sources used to create this publication are available on request. Contact us using the details below.

### Thank you

Independent Age would like to thank those who shared their experiences as this information was being developed, and those who reviewed the information for us.

### How did we do?

To tell us what you think of our information, contact us using the details below. We will use your feedback to help us plan future changes to our publications.

If you would like to be involved in helping us to develop our information products, you can join our Readers' Panel. For more information, visit **independentage.org/readers-panel** or call us.

### **Other formats**

If you need this information in a different format – such as large print or audio CD – please contact us.

### Contact us

Call 0800 319 6789

Email advice@independentage.org

### Visit independentage.org