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# NHS Continuing Healthcare

## Information for people with or affected by motor neurone disease

If you have health needs that are severe, difficult to manage or are changing quickly, you may be entitled to NHS Continuing Healthcare. This care is funded by the NHS and you will not have to pay towards nursing care and other support. Your primary need must be health-related to qualify. This will be decided by an assessment.

The assessment for NHS Continuing Healthcare is detailed and can be quite challenging. This information sheet explains what this funding is for, the assessment process and the options available.

This information sheet covers the following sections:

- 1. What is NHS Continuing Healthcare?**
- 2. How do I get assessed?**
- 3. What happens if my application is approved?**
- 4. What can I do if my application is refused?**
- 5. What is NHS-funded nursing care?**
- 6. How do I find out more?**

 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.



The MND Association has been certified as a producer of reliable health and social care information.

[www.england.nhs.uk/tis](http://www.england.nhs.uk/tis)

# 1: What is NHS Continuing Healthcare?

If you have health needs that are severe, difficult to manage or are changing quickly, you may qualify for NHS Continuing Healthcare.

This care is arranged and paid for by the NHS. It can be similar to a support package from adult social care services (often called social services), but includes nursing or clinical care.

You do not have to pay towards this as it is entirely funded by the NHS. The care can be provided to you at home or in a care home. For more information about how your care can be provided, see section 3: *What happens if my application is approved?*

## Where does this apply?

This information sheet applies to England. In Wales, local health boards are responsible for local health services and many of the rules for Continuing Healthcare that apply in England also apply in Wales, although there are some differences. Contact Health in Wales (NHS Wales) for more information. See section 6: *How do I find out more?*

In Northern Ireland, there is no guidance on NHS Continuing Healthcare. However, health services in Northern Ireland often follow NHS guidance, so a similar package of care may be offered. Contact your local Health and Social Care Trust for specific advice about what is available.

If you live in Scotland, please contact MND Scotland for advice on NHS services. See *Useful organisations* in section 6: *How do I find out more?* for contact details.

## Who can get NHS Continuing Healthcare?

Everyone has the right to ask for an assessment for NHS Continuing Healthcare, but you need to be referred to your local Clinical Commissioning Group (CCG) by a health or social care professional. CCGs are NHS organisations that organise the delivery of NHS services in England.

You may be able to get NHS Continuing Healthcare if:

- you have complex health issues and a high level of skill is needed to manage your care and treatment
- you require a lot of care and ongoing support
- your condition is changing quickly and this is causing challenges in managing your care.

See section 2: *How do I get assessed?* for information about which health needs are considered during the assessment.



*"I managed to get in touch with the right person after a few calls and we were given a little care. We struggled to get more, but had no problem with NHS Continuing Healthcare once it was established...this information sheet would have helped."*

## **Will NHS Continuing Healthcare affect my benefits?**

If you are living at home and you receive Attendance Allowance (AA), Personal Independence Payment (PIP) or Disability Living Allowance (DLA) and receive NHS Continuing Healthcare, your benefits will not be affected.

If you are living in a care home or go into hospital, your AA, PIP or DLA will stop on the 29th day after your NHS Continuing Healthcare starts.

Your state pension will not be affected.



For further information about benefits, see:  
Information Sheet 10A – *Benefits and entitlements*

## **2: How do I get assessed for NHS Continuing Healthcare?**

If you think you should be getting NHS Continuing Healthcare, ask your GP or health and social care team if they think you should be assessed. See heading *What happens during the screening process?* below.

Beacon Continuing Healthcare are able to provide people in England with up to 90 minutes of free advice on NHS continuing healthcare. This service is funded by NHS England. Trained advisers can give you information over the phone or in writing, at any stage of the process. You could ask for more detail, or for guidance if your application has been refused. They can also help you find out if you are likely to qualify for NHS continuing healthcare and how to navigate the assessment and appeal processes, if needed. More than one phone call can be made, or more than one letter written, up to the 90 minutes of the adviser's time.

For more information about Beacon, see section 6: How do I find out more?

## **How will I be assessed for NHS Continuing Healthcare?**

To give a full picture of how your condition affects you and the support you need, the assessment should:

- be focused on your individual needs
- take your views into account
- include your family and carers in the assessment, if you choose
- involve all the professionals involved in your care.

It is better to wait until you think you meet the criteria than to apply too early. If you are refused for NHS Continuing Healthcare, the CCG may not give the same level of priority to another assessment.

An application for NHS Continuing Healthcare is usually done in two stages. The first stage is a screening checklist completed by a health or social care professional. This is used to decide if the second stage, a full assessment, should be completed.

It is worth noting that all local authorities follow the same framework for their assessments, but they may interpret the guidance slightly differently.

## **What happens during the screening process?**

The screening tool, known as the checklist, looks at your needs using 11 headings, known as domains.

The domains are:

- behaviour\*
- cognition (thinking and reasoning)
- psychological and emotional needs
- communication
- mobility
- nutrition
- continence
- skin
- breathing\*
- drug therapies and medication (symptom control)\*
- altered state of consciousness (conditions that affect consciousness such as seizures).\*

Your needs will be scored in each domain as either being A, B or C, with A being for the highest level of needs. You will need a full assessment for NHS Continuing Healthcare if you score:

- two As
- five Bs
- one A and four Bs
- an A in one of the categories marked with \* above.

Passing the checklist stage does not necessarily mean that you qualify for NHS Continuing Healthcare. It shows whether you need the full assessment, which will determine whether you qualify.

Make sure that the person completing the checklist records everything in detail. For example, rather than stating that you have swallowing problems, describe how these affect you in as much detail as possible. This might include how much weight you have lost, any episodes of choking or recurring chest infections.

Make sure they do not overlook the domain for psychological and emotional needs. Ensure they are aware of the emotional impact of MND, for example anxiety about breathing difficulties or choking. Your communication needs should also be described in detail, such as needing someone to set up your equipment or to support you when communicating.

If you are in hospital, the checklist should only be completed when you are ready to be discharged and your needs are clear.

## **What happens during the full assessment?**

The full assessment works in a similar way to the screening, but goes into more detail. The person completing the screening will contact your CCG if you need a full assessment. They will arrange for two or more health or social care professionals who are involved in your care to carry out the assessment.

The full assessment uses the same domains as the screening tool, as well as any other needs. Give as much detail as possible. If you have symptoms that are being well-managed, these should still be recorded in the assessment.

The assessment should involve a range of professionals involved in your healthcare. You will need to give permission for them to share information about you.

At the end of the assessment, the health professionals will make a recommendation about whether or not your primary need is health-related and whether you should get NHS Continuing Healthcare.

It can take up to 12 weeks for a decision to be made. If your health starts getting worse during that period, it is possible to switch to a fast track application at any time. See next heading *Is there a fast track system?*

## **Is there a fast track system?**

Yes. If your condition is getting worse very quickly and there is a concern that you may be reaching the end of your life, the Fast Track Pathway Tool should be completed. There is not a strict definition of what counts as the end of life stage. It is the responsibility of the professional referring you to base their decision on the facts of your case and your healthcare needs at the time.

The Fast Track Pathway Tool will be completed by a doctor or a registered nurse and should be accepted by the CCG without delay. They may not agree it straight away if there is not enough detail, so get your referral from a professional who has good understanding of your needs, as they may be able to give a higher level of detail. Once agreed, your care package will be arranged as quickly as possible.



*"This information sheet helped me to engage with professionals, secure the fast track option and enable a better outcome for my stepson, who also had special needs."*

### **3: What happens if my application is approved?**

If you get NHS Continuing Healthcare, the funding will start from the date that it was agreed.

After your assessment, you will be supported by a worker (sometimes called a care manager or care coordinator) to plan your care. Although your needs must be health related to qualify, your care plan should cover all your assessed nursing, healthcare and personal care needs.

#### **What will happen to my care from adult social care services?**

If you are getting support from adult social care services (often called social services), this will now be included and managed as part of your NHS Continuing Healthcare.

If you do not qualify for NHS Continuing Healthcare, you might require a joint package of health and social care. This is where the NHS and your local adult social care services both contribute towards your care.

Support from adult social care services is means tested, so you may have to pay towards that part of your care package, depending on your income, savings and expenses. You will not have to pay towards health or social care provided under NHS Continuing Healthcare.

#### **Where will my care be provided?**

NHS Continuing Healthcare can be provided in any setting, including your own home, a nursing care home or a hospice. If your care needs are very high, it may not always be possible to provide care in your own home.

If the care is to be provided in a nursing care home, your preferences should be taken into account. However, you do not have the right to choose any home or location when it is being provided by the state. You may be offered a choice from a limited range of care homes. The amount of choice will vary depending on each CCG.

If you currently live in a care home, you will need to ask your CCG if you can stay there. If the cost of your care home is more than the amount of money that has been agreed, you will not be able to pay extra money yourself. This means you may have to move to a new nursing care home, though most CCGs try to avoid this.

## **What is a personal health budget?**

You can get your NHS Continuing Healthcare through a personal health budget. This is a regular amount paid to you by the NHS to for you to select and manage your own healthcare services.

This is instead of the NHS arranging your services for you, and is designed to give you more choice over how your needs are met.

All primary healthcare services, such as your GP, community nurses and essential medical treatment will still be provided for you by the NHS.



For full details about personal health budgets, see:  
Information sheet 10B – *Direct payments and personalisation*

## **How often will my care be reviewed?**

If you qualify for NHS Continuing Healthcare, you will have a review after 3 months to make sure your care package is working well and meeting your needs. Your care will then be reviewed yearly or more often if your health needs change.

## **What if my needs change?**

If your care needs increase between reviews, contact the CCG who arranged your care and inform them that your needs have changed and you would like a review.

If your health needs improve or become easier to manage, you may no longer qualify for NHS Continuing Healthcare. In this situation, you may be able to access care from your local adult social care services.

## **4: What can I do if my application is refused?**

After the screening or full assessment, you should receive a clear written response telling you if your application has been successful.

If you are not entitled to NHS Continuing Healthcare, the assessment findings will be shared with social services to see if they will pay for your care package. Support from social services is means tested, so you may need to pay a contribution, depending on your income and savings.

If you do not qualify for NHS Continuing Healthcare but have some health needs, the NHS may still pay in part to help you. They may pay to support certain health needs within a joint package of care with adult social care services. They could do this by providing NHS-funded nursing care (see heading below *What is NHS-funded nursing care?*), other services or money to help meet your needs.

In time, your needs may increase and you may then qualify for NHS Continuing Healthcare. In this case, you should ask for another referral to your local CCG from a health or social care professional. If you have recently been refused NHS Continuing Healthcare, this may affect how much priority is given to your assessment. It is better to wait until you think you meet the criteria than to apply too early.

## **Can I appeal the decision?**

If you disagree with the outcome of the assessment, you can ask your CCG to look at your case again and you can include any extra evidence you feel has been missed. If you are still unhappy with the decision after this, then you can ask NHS England for an independent panel review. This must be done within 6 months.

You should be given details of how to appeal with the letter informing you about your unsuccessful application.

## **5: What is NHS-funded nursing care?**

If you are offered ongoing nursing care by the NHS, in a nursing care home, this is known as NHS-funded nursing care.

Local authorities do not provide registered nursing care. In a nursing care home, registered nurses are usually employed by the care home itself and the NHS makes a payment directly to the care home to pay for them.

If you are funding your placement in the care home yourself, your fees should be reduced by the amount the NHS pay to the care home.

You may be able to get NHS-funded nursing care if all of the following apply:

- you have been assessed as needing the services of a registered nurse
- you cannot get NHS Continuing Healthcare
- you live in, or are moving into a nursing care home.

## **Do I need to have an assessment?**

If you have already been assessed for NHS Continuing Healthcare, this will usually give enough information for a decision to be made about NHS-funded nursing care. If another assessment is needed, your CCG will arrange this.

## Can I appeal the decision?

If you are not happy with the decision made about NHS-funded nursing care, you can ask the CCG for the decision to be reviewed.

## 6: How do I find out more?

### Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

#### Advicenow

Advicenow is an independent, not-for-profit website providing information on rights and legal issues. It provides online information only.

Website: [www.advicenow.org.uk/](http://www.advicenow.org.uk/)

#### AGE UK

Advice and support for people in later life, including information on how to access benefits, health care and social care.

Address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: 0800 169 6565 (advice line)

Email: [contact@ageuk.org.uk](mailto:contact@ageuk.org.uk)  
[enquiries@agecymru.org.uk](mailto:enquiries@agecymru.org.uk) (Wales)  
[info@ageni.org](mailto:info@ageni.org) (Northern Ireland)

Website: [www.ageuk.org.uk](http://www.ageuk.org.uk)

#### Beacon Continuing Healthcare

Provide representation for families struggling to navigate the continuing healthcare system. In depth information about Continuing Healthcare on their website.

Address: Oxford House, 1600 John Smith Drive, Oxford OX4 2JY

Telephone: 0345 548 0300

Email: through the website contact page

Website: [www.beaconCHC.co.uk](http://www.beaconCHC.co.uk).

#### Citizens Advice Bureau (CAB)

Helps resolve legal, money and other problems through free, independent and confidential advice.

Telephone: 08444 111 444 (for England, or contact your local CAB branch)  
0844 477 2020 (for Wales)

Website: [www.citizensadvice.org.uk/](http://www.citizensadvice.org.uk/) (main site)  
[www.adviceguide.org.uk/](http://www.adviceguide.org.uk/) (online help site from CAB)  
[www.citizensadvice.co.uk/](http://www.citizensadvice.co.uk/) (for Northern Ireland)

### Department of Health

The government department producing policy, guidance and publications for our health services.

Address: Richmond House, 79 Whitehall, London SW1A 2NL  
Telephone: 0207 210 4850  
Email: through the Department of Health website contact page  
Website: [www.dh.gov.uk/en/index.htm](http://www.dh.gov.uk/en/index.htm)

### DIAL UK

Provide guidance on all aspects of living with a disability, including welfare benefits.

Address: St Catherine's, Tickhill Road, Doncaster, South Yorkshire DN4 8QN  
Telephone: 0808 800 3333 (helpline)  
Email: [helpline@scope.org.uk](mailto:helpline@scope.org.uk)  
Website: [www.scope.org.uk/support/disabled-people/local-advice](http://www.scope.org.uk/support/disabled-people/local-advice)

### GOV.UK

The main government online information service, including help about benefits and government support schemes.

Email: different contacts are given on the website for various subjects  
Website: [www.gov.uk](http://www.gov.uk) (England and Wales)  
[www.nidirect.gov.uk](http://www.nidirect.gov.uk) (Northern Ireland)

### Disability Law Service

Contact the DLS for assistance on disability law.

Address: 39-45 Cavell Street, London, E1 2BP  
Telephone: 020 7791 9800  
Email: [advice@dls.org.uk](mailto:advice@dls.org.uk)  
Website: [www.dls.org.uk/](http://www.dls.org.uk/)

### Health in Wales (NHS Wales)

Online information on NHS services in Wales. (See also NHS Direct Wales).

Email: through the website contact page  
Website: [www.wales.nhs.uk](http://www.wales.nhs.uk)

### Local Authority Welfare Rights Officers

Can advise and assist in matters relating to social care and benefits. You may find the GOV.UK online contacts for local councils useful:

Website: <https://www.gov.uk/find-your-local-council>

### MND Scotland

Provides care, information and research funding for people affected by motor neurone disease in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA  
Telephone: 0141 332 3903  
Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)  
Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

### **NHS 111 Service**

Online/telephone help and support service, available whenever you need health advice and information. This service operates in England only.

Telephone: 111  
Email: through the website contact page  
Website: **[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)**

### **NHS Choices**

The main online reference for the NHS, including information on continuing healthcare.

Address: Richmond House, 79 Whitehall, London SW1A 2NL  
Telephone: 0207 210 4850  
Website: **[www.nhs.uk/carersdirect/guide/practicalsupport/pages/nhscontinuingcare.aspx](http://www.nhs.uk/carersdirect/guide/practicalsupport/pages/nhscontinuingcare.aspx)** (for NHS Choices on continuing healthcare)

### **NHS Direct Wales**

Similar to NHS 111 Service, but for Wales.

Telephone: 0845 46 47  
Website: **[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

### **NHS Northern Ireland**

Information on NHS services in Northern Ireland. This is an online service.

Email: through the website contact page  
Website: **[www.hscni.net](http://www.hscni.net)**

### **NI Direct**

The equivalent of GOV.UK for Northern Ireland, providing government information on a variety of welfare subjects, including health services and support for disability.

Email: through the website contact page  
Website: **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

### **Adult social care services (often called social services)**

Contact details for your local adult social care services can be found through your local authority, local council or local telephone directory.

You may also find the following online information from GOV.UK useful:

Website: **<https://www.gov.uk/find-your-local-council>**

For Northern Ireland, search for Health and Social Care Trusts at **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

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Nicky Perkins, Clinical Lead Continuing Healthcare, NHS Barnet CCG

The information contained in this information sheet has also been checked against the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care November 2012 (Revised).

## References

References used to support this document are available on request from:

Email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

## Further information

If you have any questions about the information on this sheet, please contact the MND Connect team.

You may find the following related information sheets useful:

Information sheet 10A – *Benefits and entitlements*

Information sheet 10B – *Direct payments and personalisation*

Information sheet 10C – *Disabled Facilities Grants*

Information sheet 10E – *Work and motor neurone disease*

You can also refer to our main guides:

*Living with motor neurone disease* – our guide to MND and how to manage its impact, including guidance about your finances

*Caring and MND: support for you* – comprehensive information for family carers, who are supporting someone living with MND

*Caring and MND: quick guide* – the summary version of our information for carers

*End of Life*: a guide for people with motor neurone disease – open and honest information about end of life care.

You can download most of our publications from our website at: **www.mndassociation.org/publications** or order in print from the MND Connect team, who can provide additional information and support.



**MND Connect**

Telephone: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

MND Association, PO Box 246, Northampton NN1 2PR

**MND Association website and online forum**

Website: **www.mndassociation.org**

Online forum: **<http://forum.mndassociation.org/>** or through the website

## **We welcome your views**

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/s/infosheets\_1-25**

You can request a paper version of the form or provide direct feedback by email: **[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)**

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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