

NHS CONTINUING HEALTHCARE FUNDING

If you have PSP or CBD there may come a time when you need the assistance of paid carers to help you with your everyday activities. If you have social care needs then care will be provided via your local social services. A full assessment of your needs will establish how much care you require, as well as any equipment needed to help you with your activities of daily living. Social care is means tested, so you may find that you have to make a contribution towards the costs, or pay in full.

If your needs become more health related in nature then you may be eligible for NHS Continuing Healthcare. This information sheet aims to provide you with an understanding of NHS Continuing Healthcare.

NHS Continuing Healthcare in Wales, Scotland and Northern Ireland

Wales - Local Health Boards (LHB) are responsible for local health services and many of the rules that apply in England also apply in Wales, although there are some differences.

Scotland - In 2015 CHC funding in Scotland was replaced by Hospital Based Complex Clinical Care (HBCCC) For more information contact careinfoscotland.scot or call 0800 011 3200.

Northern Ireland - there is no guidance on NHS Continuing Healthcare.

What is NHS Continuing Healthcare?

NHS Continuing Healthcare is the name given to a package of care that is arranged and solely funded by the NHS for individuals who are not in hospital, but who have complex, ongoing healthcare needs. It is only available for those that meet specific eligibility criteria. NHS Continuing Healthcare can be provided in any setting, including your own home, or a care home. If you stay at home then it will cover the costs of your assessed health and personal care needs. If you live in a care home then NHS Continuing Healthcare covers the cost of your assessed health and personal care needs, as well as your accommodation and board costs.

NHS Continuing Healthcare is only available for those that meet specific eligibility criteria, and are considered to have a 'primary health need'. Not everyone with a disability or a long-term condition (such as PSP or CBD) will be eligible, as the assessment is based on the nature, complexity, unpredictability and intensity of identified health needs, rather than a specific diagnosis.

Who arranges and funds NHS Continuing Healthcare?

Your Integrated Care Board (ICB) is responsible for funding NHS Continuing Healthcare. Your GP practice will be a member of an ICB. If accepted for NHS Continuing Healthcare, it is the responsibility of the ICB to fund, manage and review your care package.

When should an application for NHS Continuing Healthcare take place?

Your needs and eligibility for NHS Continuing Healthcare should be assessed at the following times:

- Following, or just prior to, discharge from hospital, or from a rehabilitation or intermediate care setting
- If your physical or mental health needs change and it becomes clear that current care is not adequate
- As part of an annual community care review – whether you reside at home or in a care home
- If you are approaching the end of your life.

If you feel that you should be receiving NHS Continuing Healthcare but have not been assessed, please speak with your GP, member of your healthcare team, or social worker.

Giving consent

In order to carry out the assessment process, it will be necessary for your personal information to be shared between individuals and organisations involved in your care. Therefore, staff should seek your informed consent, and be clear on whether you are being asked to give your consent for the full process or for a particular stage of the process, as well as the range of individuals and organisations likely to be involved.

If there is a concern about your ability to give consent, then this should be determined according to the Mental Capacity Act 2005. If you lack capacity to give consent then a 'best interest' decision will be made by the person leading the process. If you have a Lasting Power of Attorney (for welfare) or a Court Appointed Deputy (for welfare) then information must be shared with this person.

Eligibility for NHS Continuing Healthcare

To be eligible for NHS Continuing Healthcare your primary need must relate to your health, and must require a high level of care or nursing support. The assessment required to apply for NHS Continuing Healthcare is very detailed, and will entail written evidence from key health and social care professionals involved in your care, as well as information from you and your family.

Several tools are used by health and social care professionals to help decide whether you are eligible. These are the Checklist Tool, the Decision Support Tool and the Fast Track Pathway Tool (*more about Fast Track Pathway Tool can be found on page 6*). These tools can only be used by health and social care professionals, who have been trained in how to complete them.

Applying for NHS Continuing Healthcare – A two-step process

There are two stages to applying for NHS Continuing Healthcare - an initial screening process followed by a full assessment. Both stages assess your needs through the 12 areas of care (domains) that an individual may need. The domains are:

- Behaviour (*considered a priority aspect of care*)
- Cognition
- Psychological and emotional needs
- Communication
- Mobility
- Nutrition – food and drink
- Continence

- Skin including tissue viability
- Breathing (*considered a priority aspect of care*)
- Drug therapies and medication: symptom control (*considered a priority aspect of care*)
- Altered states of consciousness (*considered a priority aspect of care*)
- Other significant care needs to be taken into consideration.

Step 1 - The Checklist Tool

The Checklist Tool is used to provide the initial screening to establish whether you are eligible for the full assessment. It does not indicate whether you are eligible for NHS Continuing Healthcare funding but indicates whether you require a full assessment of eligibility for NHS Continuing Healthcare funding. It can be completed by any health or social care professional, but only if they have received the proper training on how to do this. If they haven't had the appropriate training, they should approach the ICB on your behalf and ask for them to arrange for someone else to complete the Checklist Tool. You should not have to make these arrangements for yourself.

The Checklist Tool rates each of the 12 care domains as follows:

- Column A – high need
- Column B – moderate need
- Column C – no or low need.

You will be entitled to a full assessment if:

- two domains (or more) are assessed as high need
- five domains or more are assessed as moderate need
- one domain is assessed as a high need, alongside 4 domains assessed as moderate need
- one of the priority level domains is identified as a high need, along with any level of need identified in the other domains.

If the results show that you are entitled to a full assessment, this should be arranged for you by the professional who completed the Checklist Tool.

If the results show that you are not eligible for a full assessment then you can ask the ICB to reconsider its decision based on any extra evidence that you or your healthcare team can provide. However, if you agree with the decision to refuse full assessment, then the next step is for a full review of your health and social care needs to take place to ensure that you have all the support that you need.

Step 2 - The Decision Support Tool (DST)

If the Checklist Tool indicates a need, the full assessment should be carried out by the ICB. The full assessment uses the Decision Support Tool, which works in a similar way to the Checklist Tool, but is more detailed, rating each of the 12 domains as follows;

- no need
- low need
- moderate need
- high need
- severe need (*not available for psychological/emotional needs, communication needs or continence needs*)
- priority need (*only available for following domains: Behaviour, Breathing, Drug therapy/ medication with symptom control and altered states of consciousness*).

At the start of the process the ICB will appoint a coordinator to your case. You can ask for their name and contact details. The completion of the Decision Support Tool requires input from a variety of professionals who are knowledgeable about your individual health and social care needs to ensure the fullest possible application. The coordinator should ensure that all relevant professionals share their views on your health and social care needs. This should always include professionals from both health and social care disciplines. Professionals may include a social worker, speech and language therapist, occupational therapist, dietitian, district nurse, community matron, or psychologist. As a person living with PSP or CBD, or a carer, you should also be invited to share your views. All of the findings are recorded within the assessment and this is passed to the ICB's Continuing Healthcare panel for a decision.

How is funding agreed for NHS Continuing Healthcare?

Funding may be agreed by the panel if:

- you are identified as having a priority need in one of the four domains that are recognised as a priority aspect of care (behaviour, breathing, drug therapies, altered states of consciousness)
- you are identified as having a severe level of need in two or more categories
- you are identified as having a severe level of need in one category with a number of other categories identified as high and/or moderate need.

Certain characteristics of your needs, in combination or alone, may demonstrate a 'primary health need' due to the quantity and/or quality of care needed to manage them. So, to assist in decision making the panel will consider the nature, complexity, intensity and unpredictability of your needs.

- **Nature** – refers to the effect your needs have on you and what needs to be in place for you deal with them

- **Complexity** – refers to how your needs impact on each other, and the effect on your overall care
- **Intensity** – refers to the level of seriousness of your need and will look at how regular the need is and how this impacts on you
- **Unpredictability** – refers to how your condition may deteriorate or change. For example, if unexpected changes in your condition occur that are difficult to manage or that present a challenge to carers, this may affect the provision of suitable and well timed care.

The Fast Track Pathway Tool

The process of applying for NHS Continuing Healthcare via the Checklist Tool and Decision Support Tool can be lengthy and may not be appropriate if your condition is rapidly deteriorating and you may be approaching the end of your life.

Fast Track Pathway Tool provides urgent consideration of your eligibility for NHS Continuing Healthcare, allowing for an appropriate package of care to be arranged for you as quickly as possible.

Fast Track Pathway Tool can be completed by an 'appropriate clinician'. This is usually a doctor or nurse responsible for your diagnosis, treatment or care, or with a specialist role in end-of-life needs, who would have an appropriate level of knowledge or experience to review your current type of needs.

Your ICB should accept and immediately act on a properly completed Fast Track Pathway Tool recommending access to NHS Continuing Healthcare, preferably within 48 hours of receiving it.

Any care delivered should, as far as possible, be in accordance with your end-of-life wishes.

My NHS Continuing Healthcare application has been agreed - what happens next?

The ICB should confirm its decision in writing to you, giving clear reasons for the result. The ICB may communicate its decision verbally but it should always be confirmed in writing, giving clear reasons for the decision and accompanied by a copy of the completed Decision Support Tool. The ICB is responsible for ensuring you are told who is responsible for monitoring your care and arranging regular reviews. A decision that you are eligible is not necessarily a permanent one as your condition and needs may change. On-going reviews are built into the process, initially at three months, and then on an annual basis.

If full funding has been agreed then the ICB are responsible for arranging your care package. Funding should be sufficient to meet the needs that have been identified in your care plan.

Where can I receive care?

Your care package can be provided to you in your own home, or in a nursing care home if this is your choice. Please be aware that the choice of nursing care is at the discretion of the

ICB, and if you are already in a nursing care home you may have to move to a different one if the ICB does not have links with them, or if the home does not employ registered nurses. You may find your current care home can meet your NHS Continuing Healthcare needs but is more expensive than the ICB would normally pay to meet needs such as yours. Please note that government guidance states that patients should never be allowed to pay towards NHS services, so it is not possible to top up NHS Continuing Healthcare packages, although this is permissible in legislation regarding social care.

If you decide to stay at home and if you have previously been cared for by local authority carers, it is unlikely that you will be able to keep them. However, if you are eligible for a Personal Health Budget (see below) you may be able to employ your own carers.

Will my welfare benefits be affected if I receive NHS Continuing Healthcare?

If you receive your NHS Continuing Healthcare care package in a care home, and if you are in receipt of either Attendance Allowance (AA), Disability Living Allowance (DLA) or Personal Independence Payment (PIP), then this payment will be stopped after 28 days. However, if you receive NHS Continuing Healthcare in your own home, then you will still be able to claim AA, DLA or PIP, providing you meet the eligibility criteria for these benefits.

What is a joint package of care?

If the ICB decide that you have a mixture of health related needs and social care needs then it may be decided that you require a joint package of care provided by the NHS and the local authority. You will not be charged for anything provided by the NHS, but your local authority may charge you for provision of social care needs.

What are Personal Health Budgets?

Personal Health Budgets give those with long terms conditions or disabilities such as PSP & CBD, greater choice and control over their healthcare and support services.

A Personal Health Budget is an amount of money agreed to support your identified health and wellbeing needs, planned and agreed between you and the ICB. It can be used to buy a range of services such as personal care, equipment, and therapies, giving you more choice and control.

Personal Healthcare Budgets are only available in England.

My application for NHS Continuing Healthcare has been declined – what happens next?

The ICB should provide you with written confirmation of their decision, and full reasons for refusing your application. The letter should contain information on how to make a complaint if you feel that the process was not carried out correctly, as well as information on how to appeal if you do not agree with the decision.

If you are assessed as not being eligible for NHS Continuing Healthcare at any stage of the process, a joint health and social care assessment should take place to identify your needs. Any regular or ad-hoc services provided by the NHS, such as district nursing, speech and language therapy, palliative care or continence advice can be provided if required, and there is no charge for this. However, you will be means tested for services that are the responsibility of social services.

Following a full assessment, if it has been agreed that you are not eligible for NHS Continuing Healthcare, but that a place in a nursing home would best suit your needs, then NHS-funded nursing care may be awarded.

What is NHS-funded nursing care?

The services provided by a qualified nurse are free for everyone, including those who do not qualify for NHS Continuing Healthcare. If you reside in a nursing care home that employs registered nurses, and you have been assessed as requiring their services (including direct nursing tasks, planning, supervision and monitoring of your health needs) then you should receive NHS-funded nursing care. If you are self-funding, then this will provide a small deduction to the amount that you have to pay to the nursing home.

Financial implications

Funding care can be costly. If your application for NHS Continuing Healthcare has been declined, and you are not eligible for social care funding, you may find it beneficial to have a benefits check, to ensure that you are claiming everything that you are entitled to. This, of course, can be carried out at any time, and not just following NHS Continuing Healthcare assessment.

Useful contacts

PSPA Helpline
Tel: 0300 0110 122
helpline@pspassociation.org.uk
www.pspassociation.org.uk

Beacon Continuing Healthcare provide representation for families struggling to navigate the continuing healthcare system. In depth information about CHC can be found on their website: www.beaconchc.co.uk

Telephone: 0345 548 0300

NHS Choices information on NHS Continuing Healthcare Funding www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/NHSContinuingCare.aspx

Age UK Factsheet. Link to NHS Continuing Healthcare Funding and NHS-funded Nursing Care. Also, links to related pages www.ageuk.org.uk/publications/age-uk-information-guides-and-factsheets/

Further information

Other PSPA information available:
NHS Continuing Healthcare Guidance Notes for HSCP's

Acknowledgements

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