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NHS Continuing Healthcare funding for people with MSA

This factsheet explains what NHS Continuing Healthcare (CHC) funding is, who might be eligible for it and how needs are assessed. If you have a diagnosis of MSA you may be, or could become, eligible for CHC funding. It is important to know about CHC funding as otherwise you may be paying for care (in your own home or in a care home) which should be free.

What is NHS Continuing Healthcare?

NHS Continuing Healthcare (known as CHC) funding is a package of care. It is arranged and solely funded by the NHS for adults who are not in hospital but who have complex, ongoing health care needs. To be eligible a person must show they have a 'primary healthcare need'. This is different to having social care or personal care needs. Social care or personal care needs are those related to activities of daily living. The needs do not require special skills or training to manage as they are not unduly complex, intense or unpredictable.

CHC funding support is provided free of charge (so there is no means test) and no financial contribution towards the care package is made by the individual or their family.

Care can be provided within a variety of settings including your own home or a care home.

Some people with MSA may find that they qualify for CHC funding, especially at a later stage in their condition. However, having a diagnosis of MSA (or anything else) does not guarantee that you will meet the criteria for CHC funding as eligibility is not based on a person's diagnosis.

A 'fast track' CHC funding assessment may be appropriate if your condition is rapidly deteriorating and you may be approaching the end of your life. For reference you may like to look at the National Framework on CHC –

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/746063/20181001_National_Framework_for_CHC_and_FNC_-_October_2018_Revised.pdf.

In England, Integrated Care Boards (ICBs) are responsible for the funding. Your GP practice will be a member of a local ICB.

The system in Wales is very similar to that in England although there are a few differences. Responsibility for CHC funding lies with Local Health Boards (LHBs) who are advised by the Welsh Government.

NHS Continuing Healthcare in Scotland, Northern Ireland and Eire

Scotland

In June 2015, CHC funding in Scotland was replaced by Hospital Based Complex Clinical Care (HBCCC). People who were assessed under the old system and found eligible for CHC funding continue to receive it for as long as they remain eligible. Assessment for long term complex clinical care is now based on one question 'Can your care needs be properly met in any setting other than a hospital?'. If, following a full assessment the answer is 'yes' the person will be discharged to a community setting such as a care or residential home or their own home (with care support if required). The local councils charging policy then applies and a person may need to contribute to the costs, although personal care is free. The NHS will continue to meet any healthcare needs, free of charge. See www.careinfoscotland.scot for more information or call 0800 011 3200 from 8am-10pm, seven days a week.

Northern Ireland

In Northern Ireland there is no national guidance on CHC funding and no evidence of people receiving CHC funding.

Republic of Ireland

Different arrangements operate in Republic of Ireland and CHC funding does not exist.

When might a CHC assessment be completed?

A CHC assessment should take place if:

- You are moving to a nursing home
- You are being discharged from hospital with more care needs
- You may be approaching the end of your life
- You have had an increase in your care needs

It is not easy to distinguish between a health care need and a social care need but if you find that you are having for example, frequent falls, have significant swallowing difficulties (or have a PEG or other alternative method of feeding fitted) or are struggling to communicate then do ask about having a CHC assessment. These factors alone will not make a person eligible but could be an indication that a person may have a high level of support needs.

You may need to be pro-active in requesting the assessment.

Giving Consent

In order for a CHC funding assessment to be carried out your informed consent must be gained. Having an assessment involves the sharing of your personal information between individuals and other agencies.

If there is a concern about your ability to give consent, this should be assessed in line with the Mental Capacity Act 2005. If the assessment shows that you lack capacity to make this decision, the person leading the process will make a 'best interests' decision. If anyone holds a Lasting Power of Attorney for Health & Welfare for you, they must be consulted, as must any Court Appointed Deputy (for Personal Welfare).

How to apply

Request a CHC funding assessment by contacting your GP, District Nurse, Social Worker or other health or social care professional.

Assessments

There are usually two stages to a CHC funding assessment – an initial screening followed (where the initial screening indicates it) by a full assessment.

Both stages assess your needs in different areas (known as 'domains'). These domains are:

- Breathing (Priority level domain)
- Nutrition
- Continence
- Skin and Tissue Viability
- Mobility
- Communication
- Psychological and Emotional Needs
- Cognition
- Behaviour (Priority level domain)
- Drug Therapies and Medication: Symptom Control (Priority level domain)
- Altered States of Consciousness (Priority level domain)
- Other Significant Care Needs (not assessed when using the Checklist Tool at the initial screening stage)

Stage 1 – The Checklist Tool

The Checklist Tool is used by a health or social care professional and is designed to assess whether your needs are sufficient to require a full CHC funding assessment. At this stage needs in each domain are rated as High, Moderate or Low. A full assessment is indicated if:

- One priority level domain (as indicated in the above domain list) is assessed as high plus any level of need in other domains
- Two or more domains are assessed as high need
- Five or more domains are assessed as moderate need
- One domain is assessed as high need plus four or more domains assessed as moderate need.

Not everyone who proceeds to a full assessment will be awarded CHC funding as the thresholds for the Checklist Tool are set low to ensure that those who should be fully assessed are.

Stage 2 – The Decision Support Tool

The second stage involves a full assessment by a multidisciplinary team, led by a coordinator. This team usually includes professionals in health and social care who already know you – for example, the District Nurse, Hospice Nurse, Social Worker, Therapists and GP. It is important that somebody with specialist knowledge of MSA (such as one of our MSA Health Care Specialists or your Parkinson Nurse Specialist) is consulted, so ensure this is requested ahead of time. You, your family and your carer(s) should be fully involved in the assessment meeting and actively contribute to the assessment.

The domains are again looked at and needs in each domain are assessed as:

- 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 the following domains: behaviour, breathing, drug therapy/medication with symptom control and altered states of consciousness).

Four key indicators are considered in making the assessment of a 'primary healthcare need'. These are:

- Nature – the type of needs (physical, mental or psychological) and the quality of support needed to manage these needs
- Intensity – the quantity of your needs and the degree of support required to meet those needs
- Complexity – this considers the skills required to manage your needs. The complexity could be due to the existence of multiple conditions or symptom management requirements or the interaction between these factors
- Unpredictability – the degree to which unexpected changes in your condition mean that your needs fluctuate and can be challenging to meet. This indicator looks at the risk to you or others unless you receive adequate and skilled care.

CHC funding may be agreed if:

- You are assessed as having a priority need in one or more of the four relevant domains
- You are assessed as having a severe level of need in two or more domains
- You are assessed as having a severe level of need in one domain plus high/moderate needs in other domains
- A number of domains with high/moderate needs

How to prepare for an assessment

- Know the domains and how your care needs might fit into these. With a complex condition such as MSA it is important to highlight the impact that the diverse range of symptoms may have on each other. For example, fluctuating blood pressure and impaired mobility may increase the likelihood of falls; continence issues may impact on the condition of your skin and various medications may affect your functional abilities.
- Stress the variability of any symptoms you have from hour to hour, day to day and how things like fatigue and infection may impact your abilities. Try to detail the kind of support you need and the level of skill required by the person assisting you. For example, when being assisted at mealtimes the carer may need to know how to prevent or deal with a choking incident. People with MSA can develop infections without showing the common signs of an infection. Infections may go unnoticed if the carer is not alert to this and able to recognise subtle signs such as changes in your behaviour or abilities.
- Provide the assessor with a list of your medications and of the professionals involved in your care. The CHC assessor should gather reports from all the professionals, but it is very helpful if you provide copies of reports you have too.
- Evidence must be specific to you and not just a general description of MSA. Evidence should ideally be recent but should show your changing needs. For example, it can be helpful to record weight changes or changes to your diet over a period of several weeks. Records of the time taken to eat meals, of any falls, of fainting or dizzy spells or any loss of consciousness, and of infections are useful.
- Remember that it is an assessment of all your care needs – whether or not these are due to MSA is irrelevant - so include needs related to any other conditions you may have too.
- Ask family/carers to be at the assessment with you. They often know you best and may add a different perspective. A carer's diary can be very useful, even if it only covers a few days in detail.
- If communicating in a group setting may be challenging for you consider preparing notes in advance. Doing this will also help ensure that points that you want to make don't get missed. You should always be asked to contribute and given time to do so using a communication aid if necessary.
- Advise the coordinator of any specific needs you may have (for example, you may use an aid to communicate).

- To better understand the whole process, further information can be found here www.beaconchc.co.uk and talk to the MSA Trust's Social Welfare Specialist (details at end of factsheet).

Fast track assessments

If you have a rapidly deteriorating condition and may be nearing the end of your life a 'Fast Track' assessment of your needs can be made so an urgent care package can be arranged (in a care home or your own home) usually within 48 hours. The Fast Track Tool can be completed by an 'appropriate clinician', usually a doctor or nurse who sees you regularly. The care delivered should, wherever possible, reflect your end of life wishes.

If the CHC application has been approved

If the assessment determines that you meet the criteria for CHC funding this will be confirmed to you in writing. The local Integrated Care Board or, in Wales, the Local Health Board, are then responsible for arranging the full package of care that you require. The care package can be provided in your own home or a care home. With a care home placement, although your wishes should always be considered, the ICB or LHB may not necessarily fund a place in the home of your choice if your needs can be met in a less expensive home within your area. It is not possible for you or your family (or anyone else) to 'top up' CHC funding to meet your care needs. If you have a care package at home the ICB or LHB will identify the most appropriate agency to meet your care needs, which may be a different agency than you have previously used through the local authority.

Personal Health Budgets (England only)

Instead of having their package of care arranged for them some people prefer to have a Personal Health Budget. These are only available in England. A Personal Health Budget is an amount of money that is identified to meet a person's health care needs, as planned and agreed between them and their local ICB. The CHC coordinator can advise you about how this works to enable you to get the care you need. It can cover personal care, equipment and therapies and may allow a person to make choices that are more personal to them and more flexible. It is not extra money; it is money that the NHS would have spent on your needs. If you prefer the ICB to arrange your package of care this option remains open to you.

When your benefits may be affected

Depending on your circumstances some Department of Work and Pensions benefits may be affected by a successful CHC funding application (for example, Attendance Allowance would not usually be paid if you moved to a CHC funded nursing home placement). If you are awarded CHC funding you should advise the Department of Work and Pensions.

If the CHC application is refused

If the assessment determines that you are not eligible for CHC funding this should be conveyed to you in writing and a full copy of the Decision Support Tool made available to you. The letter should also tell you how to complain or appeal. If you are unhappy with the process or the decision you may wish to consider appealing. Taking advice on this can be helpful as it is important to appeal on relevant grounds. Our Social Welfare Specialist will be happy to talk with you about this or you may like to contact Beacon CHC on 0345 548 0300 (www.beaconchc.co.uk).

What is NHS Funded Nursing Care (FNC)?

This is quite different to CHC funding. It is a contribution that is made by the NHS to Nursing Homes to pay for the care delivered by their registered nurses. If you are in a nursing home and responsible for your own fees, any FNC contribution (£209.19 per week in 2022/23 for most residents) should be deducted from your bill. A FNC contribution should only be agreed after an assessment for CHC funding has been made. This is to ensure that you are awarded CHC if applicable.

Further Information

Beacon CHC – www.beaconchc.co.uk

Age UK - https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fcs_guide_index.pdf

NHS England - <https://www.england.nhs.uk/healthcare/>

For Wales -

<http://www.wales.nhs.uk/documents/chc%20communication%20tool%20may%202011%20-%20english%20%282%29%20%20final1372011.pdf>

Key Points to remember:

- With CHC funding, the NHS will pay for your care regardless of any savings or income you may have.
- To be eligible, you must show you have a 'primary healthcare need'.
- Two-part assessment process: (1) The CHC checklist to determine if you are eligible for (2) a full CHC assessment with a multidisciplinary team of health and social care professional.
- Your views are important. You, your family and your carer(s) should be fully involved in the assessment process.
- Contact our Social Welfare Specialist for more information.

MSA Trust contact details

The MSA Trust is happy to offer information and support to people living with a diagnosis of MSA and to their families and carers.

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

If you have questions about benefits, grants, CHC applications or advocacy related issues please contact our Social Welfare Specialist via our main office on 0333 323 4591 or email support@msatrust.org.uk.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

T: 0333 323 4591

E: support@msatrust.org.uk |

W: www.msatrust.org.uk

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