GIG CYMRU NHS WALES

Llywodraeth Cymru
Welsh Government

Continuing NHS Healthcare Information Booklet for Individuals, Families and Carers

What is Continuing NHS Healthcare?
Who should get it?
How is it organised?

This is a public information booklet for anyone who may need Continuing NHS Healthcare, for Individuals, Families and Carers'

April 2022

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About this booklet

This booklet has been written by the Welsh Government in consultation with stakeholders. It is for any adult who has complex needs and as a result might be eligible for Continuing NHS Healthcare, or their family or carers. It is to help you understand:

- what is Continuing NHS Healthcare?
- who is eligible for it?
- how it is assessed
- how it is organised

You can find information on everything to do with Continuing NHS Healthcare on the Welsh Government's webpages at https://gov.wales/national-framework-nhs-continuing-healthcare

Also by contacting: Welsh Government
Cathays Park
Cardiff
CF10 3NQ

Call: 0300 0604400

Email: **customerhelp@gov.wales**

You can find contact information for your local health board (LHB) at **page 27** of this booklet as well as on the **NHS Direct Wales** website: www.nhsdirect.wales.nhs.uk/localservices/localhealthboards

An Easy Read version will also be available on the Welsh Government website. Please contact the Welsh Government if you require this booklet in any other format.

Contents

What is Continuing NHS Healthcare (CHC)?

Continuing NHS Healthcare, also known as CHC, is a package of on-going care that is arranged and paid for by the NHS.

You will be eligible for CHC if your LHB assesses you as having a **primary health need** (this is explained on page 9). This is the only eligibility criteria for CHC. If you are assessed as having a primary health need, it is your **right** to have CHC.

For example, this could include people who have longer term physical and/or mental health support needs because they are disabled or have an illness or had an accident. It can be provided in any setting, including your own home, within a care home, hospice, or in a prison and be delivered by a range of health and care workers.

Who's responsible for funding what?

If you have long term care needs the type of care you need may be the responsibility of either the NHS or your local authority social services or both. Sometimes it will be obvious who will be responsible for your care but if you have complex care needs you may receive a mixture of services from each of these organisations. This booklet is about services funded by the NHS.

NHS

All NHS services are free, so if you are eligible for CHC, the NHS will cover the cost of all of your health care and most of your social care, including residential accommodation (in a care home). Your Local Health Board (LHB) is responsible for organising the assessment process to see if you are eligible and if so it will also plan and deliver the CHC package of care. If you are found to be eligible for CHC, the NHS will pay for:

- ✓ If you live at home the NHS pays for healthcare such as services from a community nurse or specialist therapist and associated social care needs, help with washing and dressing for example. This does not include the cost of accommodation, food or general household support.
- ✓ If you live in a care home, the NHS will contract with the home to pay fees covering your accommodation and assessed health and personal care needs.

Local Authority

Local Authorities (LAs) are responsible for providing Information, Advice and Assistance about care and support. If you do not have a primary health need, your care and support could be provided by your LA, through Social Services. Eligibility for social care is defined in the Social Services and Well-being (Wales) Act 2014. These services are means-tested, meaning that depending on your financial circumstances, you may have to pay towards your care and accommodation.

Do I need to pay towards my care home costs if I am eligible for CHC?

The NHS will pay for your accommodation and assessed health and personal care needs. There may be circumstances where you choose to pay fees to your care home for additional services such as to receive extra sessions of physiotherapy (in addition to those agreed in your care plan). Other examples include a more expensive accommodation type (larger room) or 'extras' such as daily newspapers. These are sometimes referred to as 'top-up' fees and are a separate, private payment arrangement you have with the care home provider. More information on different accommodation types and whether you will need to pay towards them is at pages **19-20.**

Any decision you make to purchase additional services must be through a personal choice of yours and not through a lack of appropriate NHS funding to meet your needs as identified in your CHC care plan.

If you receive a request from your care home provider to fund additional services that you have not agreed to then contact your LHB immediately to resolve this.

Preparing for your CHC Assessment

The CHC assessment process can be complex. Think about who you would like to support you throughout the process. Many people find there are some things that they don't fully understand; the assessment is about your needs and what is best for you, so please ask questions at any time. It is likely that you will need to talk about things that are sensitive. It is important to have clear and open conversation. A team of health and social care professionals, known as the Multi-Disciplinary Team (MDT) will work with you to assess your needs (**see page 13**).

Advocacy

An advocate is someone who can help you make your views known during the assessment process. The use of an advocate may help you to better and more confidently navigate the CHC process. As well as supporting you to better understand your own role in the CHC process, an advocate can also help you understand the consequences of the choices and decisions you make. You can nominate a person to represent your views or speak on your behalf and this could be a family member, friend, a local advocacy service or someone independent who is willing to undertake an advocacy role for you. The LHB should make you aware of local advocacy services.

It's important to understand the difference between the roles of an advocate and the Care Co-ordinator (**see Page 12**). The Care Co-ordinator will likely work for the health board or the LA and will not be independent. The LHB and LA should make you aware of local advocacy services that could offer you advice and support.

Information on how to contact your LHB, how to complain and other useful contact details, including advocacy support, are included at pages **26-28.**

Consent

You will be asked to give your informed consent to the CHC assessment process. In order to give informed consent, your Care Co-ordinator will meet with you to explain the whole process, and make sure you have enough information to make your decision.

You have the right to refuse a CHC assessment, or later turn down an offer of CHC following an assessment. The LHB and LA will work with you to ensure that the risks are fully understood and mitigated as far as possible. They must inform you of the potential effect this will have on the ability of the LHB or LA to provide appropriate services. The NHS will continue to provide health services for free, for example GP and district nurse services. However, the LHB cannot become responsible for arranging and funding social care services to you that are free, as would be the case under CHC. You are free to change your mind at a later stage.

You may be able to receive a shared/ joint care package from both the LHB, for any health elements, and the LA for any social care elements. The LHB and LA will work with you to co-produce your joint care plan to address any assessed needs you have. More about joint packages of care is included on **page 22.**

If you lack capacity to give consent, staff will check to see if you have an appointed Lasting Power of Attorney (Health and Welfare) to act on your behalf, or if the Court of Protection has appointed someone as a personal welfare deputy. If not, the person leading the assessment at that point will be responsible for making a 'best interests' decision. In these circumstances a decision needs to be made as to whether it would be in the person's best interests to proceed with the assessment and sharing of information or to delay seeking consent until capacity is regained. They will usually consult with family and friends. Where there are no family or friends available an Independent Mental Capacity Advocate will be provided.

Language

Throughout the CHC process, you have the right to use the language/format or method of your choice to communicate and participate fully, as an equal partner, in assessing your needs and arranging your health and social care.

Welsh language requirements are set out in the Welsh Government's strategic Welsh language framework, 'More Than Just Words'. Your request to communicate in Welsh should not delay your CHC eligibility assessment as there are specific Welsh Language Standards in place which require both LAs and LHBs to provide this to you.

The same considerations apply to British Sign Language (BSL) and other languages and formats, e.g. Braille.

Carers

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a friend or family

member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

If you have a carer and it appears to your LA that they may have needs for support, your carer has the right to have their needs assessed by the LA. LHBs and LAs must tell you about this right. Carers could be eligible to receive support to help them with their caring role. It should never be assumed that your carer is able or willing to continue to provide support.

Summary of the CHC Eligibility Process

You are identified as possibly being eligible for NHS CHC. You will be given a **Care-Coordinator (see page 12).** They will oversee the whole process, answer your questions, keep you informed, seek your consent, tell you about advocacy and ensure your language/communication method of choice is used throughout the CHC process.

Your Care -Coordinator will organise a **Multi Disciplinary Team (MDT) (see page 13).** The MDT will collect the evidence needed for your CHC assessment. They may contact you to get the information they need.

An MDT meeting will take place to assess your needs. You and your carer/family or advocate can attend this meeting and be fully involved. The **Decision Support Tool (DST)** will be will be completed to support the process. The MDT will then make a recommendation to your LHB on your eligibility to receive CHC funding. If eligible, your care package should be in place within **2 weeks** from the date of this meeting.

If you are eligible for CHC, your LHB should arrange your package of care within **8 weeks** from any intial indication or assessment e.g. the checklist (**see page 11**), that indicated you may have a primary health need. This includes any time you require for rehabilitation or reablement. This timescale may be extended if you require a longer period of rehabilitation or reablement.

If your need for care is more urgent, e.g. end of life care, the LHB should consider applying a fast track assessment.

The 7 principles of CHC

Everyone involved in your assessment must work to these principles:

1. **People first.** Your best interests must be put first. You should be treated with dignity and respect.
2. **Integrity of decision making.** The Multi-Disciplinary Team **(see Page 13)** must work with integrity. Their expert advice and decisions should be based on clear rationale.
3. **No decisions about me without me.** You are the expert in your own life. You and your carers should be fully involved in the assessment and care planning process.
4. **No delays in meeting your needs due to funding discussions**. You should not experience any delay in having your needs met because health and social services, and any other care provider, are not working well together. They have the responsibility to resolve any disputes or concerns as soon as possible.
5. **Understand diagnosis. Focus on need**. You are not defined by your diagnosis. Your care and support should be tailored to you. It should maximise your independence and focus on what is most important to you and your carers.
6. **Coordinated care and continuity.** Every effort must be made to avoid disruption to existing care arrangements, or to provide a smooth and safe transition where change is required for your best interests.
7. **Communicate.** Professionals must take extra care to communicate with you in your preferred way, and they should try to find out what that is before the assessment begins. This includes: Welsh, British Sign Language, written information in alternative formats such as easy read, or alternative methods of communication for people with severe speech and communication difficulties.

Who is eligible for CHC?

You are eligible for CHC if you are over aged 18 or over and are assessed as having a **primary health need**. Your eligibility for CHC is based only on what your overall day-to-day care needs are and not based on any particular diagnosis or condition.

To determine if your care needs are primarily health related, you will have an assessment. This will look at 4 things:

1. **Nature** – this is about what your needs are, what effect they have on you, and what care and support you need to manage them.
2. **Intensity** – this is about how many needs you have, and how frequently you need support as well as the level of support and regularity of that support e.g. 2 carers may be needed.
3. **Complexity** – this is about all your needs, how they interact with each other and how difficult they are to support or manage. This is also about the training or skills needed by health and social care staff, carers, family members, etc.

to be able to provide your care. The issue here is what your total health and care needs are, and not on who might deliver your care needs.

4. **Unpredictability** – this is about how much your symptoms change and how difficult that makes them to manage. It is also about the risk this poses to your health if the right care isn't given quickly enough.

Each of these characteristics may alone or in combination, demonstrate a primary health need.

What triggers a CHC assessment?

You have the right to a thorough assessment of all your needs. These assessments will help to identify if you have a primary health care need.

LA Adult Social Services teams are responsible for assessing people's need for social care services. Social Services must tell the LHB if they are assessing someone who has needs that may fall under the remit of the NHS, including people they think might need an assessment of eligibility for CHC.

A CHC assessment of eligibility could be triggered because:

- You have recently been admitted to hospital and it is clear that you will have on-going care and support needs once you have been discharged.
- Your current care needs are being reviewed and your needs have changed.
- Your physical or mental health has got worse and the current care and support you receive, at home or in a care home, is no longer enough.
- You are transitioning from Children's services into Adult services.
- You have a condition that is getting rapidly worse and your need for care and support is increasing for example because you may be approaching the end of your life or there may have been a catastrophic event.

If CHC has not been discussed with you, but you think you might be eligible for it, you should talk to the hospital staff involved with your care, social services or your GP. You could also request that a CHC checklist tool is completed.

The Checklist Tool

To help health and social care staff identify if you should move on to having a full CHC assessment, they can use something called the Checklist Tool. They do not have to use this, but it is there to help them to make the right decisions and to help make sure everyone who needs a full CHC assessment has the opportunity to get one.

If you are in a situation where the use of the Checklist Tool has ***not*** been thought necessary and it has been decided that you will not be referred for a full CHC assessment, you could ask the LHB to reconsider the decision. You could also make a complaint if you believe that your needs have not been fully considered.

Health and social care staff must get your permission before they complete your CHC Decision Support Tool checklist.

You should be given reasonable notice of the intention to undertake your checklist and you should normally be given the opportunity to be present on its completion, together with any family/carer or advocate you may have. The completion of the Checklist tool should be in the language or communication method of your choice.

The Checklist is based on the same 12 'domains' or 'areas of need' as the Decision Support Tool (DST) (**see page 14**).

The 12 domains are:

- Breathing
- Nutrition
- Continence
- Skin Integrity
- Mobility
- Communication
- Psychological & Emotional Needs
- Cognition
- Behaviour
- Drug Therapies and Medication
- Altered States of Consciousness
- Other Significant Care Needs

It is important to note that this initial checklist does not decide if you are eligible for CHC funding. It identifies whether you should progress to a full CHC assessment using the DST.

The outcomes of the checklist assessment would either be:

- Yes - the level of your needs suggest you may be eligible for CHC so a full assessment should take place; or
- No – your level of needs to have a full assessment for CHC are not met; instead, a decision needs to be made on whether other LA or NHS services could meet your needs

The outcome of the Checklist tool should be explained clearly to you, your family/carer or advocate and also be given to you in writing as soon as possible following the checklist assessment. The correspondence sent to you should be in the language of your choice and should include the reasons why the Checklist outcome

was reached and normally include a copy of your completed checklist for your information.

You should not be left without appropriate health and social care support while you wait for the outcome of your CHC assessment

If the outcome of your Checklist means you will not progress to a full CHC assessment, you may ask the LHB to reconsider this outcome. The LHB should consider your request, taking account of all the information available, and/or including additional information from you.

The LHB does not have to undertake a further Checklist. It should provide you with a written response which includes details of your rights under the NHS Complaints Procedure if you remain unhappy about this decision, contact details for NHS Wales complaints and concerns: Putting Things Right, are on **page 29.**

How is CHC eligibility assessed?

When will my CHC assessment take place?

Your needs assessment and following that consideration of eligibility should take place in the right place and the right time for you.

It should normally take place when you are in a community setting such as a community hospital, your home or your care home. It should only take place in an acute hospital setting in exceptional circumstances.

If you have spent time in hospital, you should have any rehabilitation or reablement you may require, before you have your CHC assessment. You should be supported to recover before your CHC assessment takes place so that you can regain the ability to look after yourself independently as much as possible.

Care Co-ordinator

When it has been identified that you might have on-going healthcare needs, your LHB becomes responsible for carrying out your CHC assessment, and it will assign you a care co-ordinator, sometimes called a Lead Professional.

In keeping with a person-centred approach for the CHC eligibility assessment process, it may also be acceptable for a social worker with a long-standing relationship with you and your family to act as your Care Co-ordinator. The LHB and LA would need to agree this approach, with the final decision being with the LHB.

Your Care Co-ordinator is the person responsible for coordinating the whole CHC assessment process. They are your point of contact if you have any questions or concerns. They must keep you informed of what's going on and make sure you are invited to any meetings where decisions are made on your eligibility so that you are fully involved in the discussions and decision making process. You should be given your Care Co-ordinator's name, contact number and email address to ensure swift communication.

Multi-disciplinary team (MDT)

It is the responsibility of the MDT to:

- undertake a robust assessment of your needs;
- provide the LHB with consistent expert advice on your CHC eligibility;
- develop a care plan to meet your needs, and
- make recommendations regarding the setting, and what provision of care staff would be required to most effectively deliver your care plan.

Your CHC eligibility assessment will involve a team of health and social care professionals from different disciplines, working together to decide what your needs are, and how they should be met. This is the multi-disciplinary team, often called the **MDT.**

Your Care-Coordinator will make sure the right professionals, who have **direct knowledge of you and your needs**, are part of the MDT. As a minimum, the MDT must include:

- at least two professionals from different healthcare professions, i.e. nurses, Doctors, Occupational Therapists, other Specialists e.g. Speech and Language / Behavioural Specialists
- Social Worker

And could include the following where required:

- Care home staff
- Domiciliary care staff

They will look at all your physical health, mental health and social care needs, individually and together. This is to get an accurate picture of your needs and to give expert recommendations on how your needs can best be met. They may visit you separately before everyone meets together to get a full picture of your needs. Any meeting you have should be in the language of your choice.

Your own views and what you want your outcomes to be are an important part of the assessment. You are the expert of your own life, and nothing should be decided about you, without you.

This information is then used at an MDT meeting where the **Decision Support Tool (DST)** will be completed. The DST is a tool for recording information to support the assessment process.

The Multi-Disciplinary Team (MDT) meeting

Once the MDT has done a thorough assessment of all the information and evidence gathered, your Care Co-ordinator will organise and invite you and any representative you choose to bring with you, to an MDT meeting. This meeting must be in the language / communication method of your choice.

Your Care Co-ordinator will explain the format of the MDT meeting to you and how you and/or your representative can be fully involved. You should be given sufficient notice of the date of the MDT meeting so that you can make arrangements to attend should you wish to. You should be offered the opportunity to attend in person or virtually. To attend virtually, you would need a computer and an internet connection. The meeting invitation would be sent to you by email and you would need to click on the link in that email to join the meeting.

If you or your representative are not able to attend, your views should be obtained and considered. The DST allows the MDT to bring together and record their assessment of your various needs in 12 'care domains' (**page 11**).

When completing all domains of the DST, the MDT team should use the assessment evidence and professional judgement to select the level that most closely describes your needs, e.g. low need or severe need.

The assessment should result in a comprehensive picture of your needs that captures the nature, complexity, intensity and/or unpredictability of your needs – and whether you have a primary health need. It will also capture the quality and/or quantity (including continuity) of care required to meet your needs.

A clear recommendation of eligibility would be expected if you have:

- priority level of need in any of the three domains with that level, or
- two or more instances of severe needs across all domains, or
- one domain recorded as severe together with needs in a number of other domains, or
- a number of domains with high and/or moderate needs.

Your needs should not be placed between levels. If, after considering all the relevant evidence, it proves difficult to decide or agree on the level, the MDT should choose the higher of the levels under consideration and record the evidence in relation to both the decision and any significant differences of opinion.

Your needs should not be marginalised because they are successfully managed. Well-managed needs are **still** needs and should be recorded appropriately.

If it can reasonably be anticipated that your condition will deteriorate and your needs in certain domains will increase in the near future, this should be recorded and taken into account when the final recommendations are made.

The MDT meeting should be arranged in a way that enables you to give your views on the completed domain levels before you leave the meeting. In the DST there is a section at the end of the domain tables for you or your advocate to give your views that have not already been recorded elsewhere in the document, including whether you agree with the domain levels selected. It also asks for reasons for any disagreement to be recorded.

If you or your representative have concerns about any aspect of the assessment process, the Care Coordinator should discuss this matter with you and seek to resolve your concerns. If your concerns remain unresolved, they should be noted within the DST so that they can be brought to the attention of the LHB making the final CHC eligibility decision.

The Multi-Disciplinary Team's recommendation

Following discussion with you or your representatives and completion of the DST, the MDT members will immediately make their recommendation to the LHB on whether you have a primary health need, based on the four key indicators, as set out on **page 13**.

This recommendation will be made separately from any discussions with you and your representatives but even if you are not present on the day it should be communicated to you as soon as possible.

In the majority of cases, the LHB will accept the MDT's recommendations. In exceptional circumstances, and for clearly set out reasons, the LHB may request additional evidence to support the MDT's recommendations. For example, this might be because the DST is incomplete, or there are significant differences between the evidence in the assessment, the DST and the recommendation being made.

Quality Assurance

LHBs and LAs must have systems in place to make sure the professionals involved in the MDT have the right skills, knowledge and competency to carry out assessments to the standards expected. LHBs must have robust quality assurance mechanisms in place to ensure consistency of decision-making.

Communicating the eligibility decision to you

You will be informed of the outcome of your eligibility assessment in writing as soon as possible (you may also be informed verbally where appropriate). The correspondence sent to you should be in the language / method of communication of your choice and should include:

- the decision on primary health need, and therefore whether or not you are eligible for CHC
- the reasons for the decision
- a copy of the completed DST
- details of who to contact if you need further information
- how to request a review of the eligibility decision

If you are not eligible your decision letter may also include, where applicable and appropriate, information regarding Funded Nursing Care or a joint package of care. Further information on this is on **page 22**.

How is CHC organised?

If you receive communication that confirms you are eligible to receive CHC it should also contain details of your care plan, or if your care plan is not known at that time you should receive information on what the next steps are.

The LHB is legally responsible to fund your care package from the time the MDT met and made its determination of eligibility. If you have paid for your care or contributed to the cost of your care from this date, you can request the LHB refund these costs to you. However, if the MDT can identify the date that you first had a primary health need it should inform the LHB and you should have your reimbursement from that date.

How long will all this take?

Your Care co-ordinator should contact you within 2 days of the MDT meeting. This is to ensure you fully understand the outcome and to answer any questions you may have.

If you are eligible for CHC, within **2 weeks** of the MDT meeting, your care package should be arranged.

Your LHB should arrange your package of care within **8 weeks** from any intial indication or assessment e.g the checklist, that took place that indicated you may have a primary health need. The 8 weeks *includes* any time you require for rehabilitation or reablement.

It may take longer than 8 weeks if you require a longer period of rehabilitation or reablement, but should not take longer in relation to delays in determining CHC eligibility or arranging a care package.

The Fast Track Process

If you have a condition that is getting rapidly worse and your need for care and support is increasing, possibly because you may be approaching the end of your life, your hospital or care staff should contact an appropriate clinician to ask for a fast track CHC assessment. This would apply in other cases such as following a catastrophic event. The fast track assessment should be completed within 2 working days.

When an appropriate clinician recommends an urgent package of care through the fast track process, this should be accepted and put in place immediately by the LHB. The appropriate clinician would be a registered nurse or a medical practitioner who is responsible for your diagnosis, treatment or care. They should have an appropriate level of knowledge and experience of the type of health needs in question.

How will my CHC be delivered?

The LHB will work with you to decide on the care package that is appropriate to meet all your health and social care needs and help you to maintain your independence, taking your wishes and preferred outcomes into consideration.

In cases where you have been receiving social care, the LA's assessment of your social care needs will be important in identifying your needs and in some cases the options for the LHB in meeting them.

Care planning for needs to be met under CHC should not be carried out in isolation from care planning to meet other needs, and, wherever possible, a single, integrated and personalised care plan should be developed.

The LHB will work closely with you to agree your CHC care plan and package of care in order to meet your assessed needs. It may be different to the package you received under your social care.

Continuity of care and support

Having continuity of care and support has a considerable impact on a person's wellbeing and quality of life.

Your LA and LHB should work together to make every effort to avoid disruption to the care arrangements you already have in place, wherever possible, or to provide smooth and safe transition where change is required in your best interest.

Voice and control, Direct Payments and CHC

If your care is funded by your LA, you may choose to receive this funding in the form of a direct payment (DP). A DP is money that your LA gives to you to spend on meeting your eligible care and support needs. The money can be spent on a wide range of products and services. DPs allow people to make their own choices about their care and support. The Social Services and Wellbeing (Wales) Act 2014 allows people to use DPs to pay for long term residential care as well as other services.

If you then become eligible for CHC, your LHB will pay for all of your health and most of your social care needs. You may have concerns about being able to keep the care support staff you currently have as LHBs cannot provide DPs. In line with a person centred CHC process, if you are already using DPs to pay for social care when you become eligible for CHC, your LHB must work with you as an equal partner, to ensure you still have voice, choice and control over your care arrangements.

The LHB must work with you in a spirit of co-production and make every effort to maintain continuity of the personnel delivering your care, where you wish this to be the case and it can contribute to meeting your needs.

Although it is currently unlawful for DPs to be used to pay for healthcare or social care that the NHS is responsible for providing, it is **not** unlawful for LAs and LHBs to work together to provide you with voice and control in respect of your health and social care needs.

LHBs should consider a range of options to ensure you have voice and control over the care that you receive, including the following examples:

- Maintaining staff
  If you develop a primary health care need, the health board must work to maintain continuity of staff delivering care, where you wish this to be the case and it can contribute to meeting your needs. The health board could employ staff (either directly or via an agency), e.g. personal assistants, previously employed by you under direct payments.
- Independent User Trusts
  LHBs could also consider providing funding to an Independent User Trust, to manage your care. This is where a relative and/or other interested parties set up a trust which becomes the provider of your care. The LHB then pays the trust to provide specified health and social care services for you.

You may be able to keep some DPs for the parts of your care for which the LA is still responsible, e.g. opportunities for social inclusion. Partner organisations must work together to explore all the options available to maximise an individual's independence.

Further guidance on these measures will be published on the Welsh Government website.

The location of care

The LHB should work closely with you to determine your care plan and location of care, for example in your home, in a care home, in a supported living arrangement or in a hospice. When drawing up and agreeing the plan, your preferences and those of your relatives or advocate on how and where your care is provided should be taken into account. Your LHB should seriously consider your preferences, alongside any risks and benefits associated with different types of care and fair access to LHB resources.

The care plan will capture needs and the package of care should meet those needs fully. If you are not happy with the LHB's proposed care package and cannot resolve your concerns informally, you should access the NHS complaints procedure, contact details **on page 2**6-28.

CHC in your own home

Your care package will be delivered by carers, district nurses and/or other appropriate staff in your home.
If you were living at home prior to being eligible for CHC and receiving DPs from your LA to directly fund your personal assistants, your LHB could utilise these staff, who may be family or friends who know your care needs very if they are trained and competent and able to meet your assessed healthcare needs. As set out in the CHC National Framework "every effort should be made to maintain continuity of the personnel delivering the care, where the individual wishes this to be the case and it can contribute to meeting their needs."

CHC in a hospice

If you are reaching the end of your life it may be appropriate for you to receive your CHC in a hospice. However, the Welsh Government's CHC National Framework recognises that you may wish to remain at home at this time.

CHC in a care home

Care home services are regulated by and registered with Care Inspectorate Wales under the Regulation and Inspection of Social Care (Wales) Act 2016. Some care home services include nursing care.

If you are eligible for CHC and need to live in a care home, the NHS makes a contract with the care home and pays fees covering your accommodation, board and to meet your assessed health and personal care needs. The following are some issues to be aware of:

- If it is agreed that you should move into a care home, your preferences are an important part of the evidence to be considered in choosing the most suitable care home to meet your needs.
- LHBs may have a contract with one or more care homes in the area, but your assessed needs will determine whether they are suitable. In exceptional circumstances, LHBs should consider requests for e.g. a larger room or a placement in a higher than usual cost care home and they should consider these on a “case by case basis”.
- LHBs must discuss with you, your family or advocate the reasons for the preference. If you have clinical needs (for example, you have challenging behaviour and require a larger room because it is identified that your behaviour is linked to feeling confined, or if you consider that you would benefit from a care provider with specialist skills rather than a generic care provider), consideration should be given as to whether it would be appropriate for the LHB to meet this. If no clinical need is established the LHB will need to make a decision which balances your needs and preferences with the requirement for appropriate use of public funds.
- If you are already living in a care home and wish to remain there following your CHC assessment, the LHB would need to be satisfied that your assessed needs can be appropriately met. If it is not possible for your current care home to meet your needs, you will need to discuss your options with the LHB.

What will happen if you are already a resident in a ‘high cost’ care home at the time that you become eligible for NHS CHC?

- If you are living in a care home when the decision to grant you CHC is made, you need to discuss with your LHB whether you can stay there. This is particularly relevant if your care home is more expensive than the LHB would normally pay to meet needs such as yours. This can happen if you have been self-funding your care or were part funded by the local authority with a relative or other third party ‘topping up’ to meet the fees.
- Topping up is allowed in social care but it is not allowed in care which the LHB is responsible for. In reviewing your current accommodation, the LHB should explore your reasons for wishing to remain in your current home/room and consider if there are any reasons you should stay there (this could include personal needs, such as proximity to close family members). Any possible risks of moving you would need to be assessed before a final decision was made. Such reasons could include for example, your frailty, mental health needs or other relevant needs you have which mean that a move to other accommodation could involve significant risk to your health and well-being.

- The CHC National Framework advises that if someone becomes entitled to CHC and they have an existing high-cost care package, LHBs should consider funding the cost of the existing higher-cost package until a decision is made on whether to meet the higher cost package on an ongoing basis or to arrange an alternative placement.

Moving to a care home in a different area in Wales

You may want to move to a care home that is closer to your family who live in another LHB area. You can suggest this to your LHB but it will be the LHBs decision whether to allow this. If your LHB agrees to your move to another LHB area they will still remain responsible for funding your CHC.

Reviews

CHC reviews should primarily focus on whether your plan or arrangements remain appropriate to meet your needs. It is expected that in the majority of cases there will be no need to reassess for eligibility. However, in some cases, people will move in and out of eligibility for CHC, depending on their needs.

You CHC will be reviewed within 3 months of your care plan being provided, unless this is triggered earlier by you or your family/representative or the provider. Following that it will be reviewed annually. If your condition is expected to get worse, your care package should be reviewed more often.

If you have an obvious deterioration in circumstances, you should have a review within 2 weeks and changes should be made to your care package as needed. The dates for your expected reviews should be provided to you.

If you are receiving secondary mental health services, legally, the LHB is required to review your care at least annually and in line with the Code of Practice to Part 2 and 3 of the Mental Health (Wales) Measure 2010.

If any of your care and support needs change, it may result in a change to your eligibility for CHC. Neither your LHB nor your LA should decide to withdraw any existing funding arrangement without first taking a joint reassessment of your needs, consulting one another, and you, about any changes in the provision of your care.

Therefore, in order to ensure continuity of care, if there is a change in eligibility, it is essential that alternative funding arrangements are agreed and put into effect before any withdrawal of existing CHC funding. Any proposed change should be put in writing to you by the organisation that is proposing to make such a change. If the LA

and LHB cannot agree upon the proposed change, the current funding arrangements should remain in place until their dispute has been resolved.

If you are unhappy with any part of the review you should speak to your co-ordinator. You can ask for a re-assessment of your needs and review of your care plan. If you are still unhappy with the result, you could make a complaint using the NHS Complaints process – Putting Things Right, contact details on **page 28.**

What happens if I'm not eligible for CHC?

Not everyone with on-going health needs is eligible for CHC, but you may have needs identified through the MDT assessment that are not of a nature that your LA can solely meet or are beyond the legal powers of a LA to meet. In these situations your LA takes responsibility for your care and support and works in partnership with your LHB to provide a health and social care package that is tailored to meet your individual needs.

Joint Packages of Health and Social Care

Joint packages of care are where the LHB and LA work together in partnership to agree their respective funding responsibilities in your joint package of care to provide a seamless provision of health and social care. You will be means-tested for services that are the responsibility of your LA.

You should not experience any delay in receiving your care package while this care is being arranged.

Funded Nursing Care

If you do not qualify for CHC you might still be able to receive a NHS-funded nursing care (FNC) contribution because you do have some level of nursing care need. This is only paid if you are assessed as needing nursing care in a care home registered to provide nursing care. The nursing care contribution is a flat weekly amount paid directly to the care home.

Any social care element may be funded by the local authority and/or yourself, depending on your financial assessment. If you are paying for your own care in a care home with nursing, you can still be eligible for NHS-funded nursing care contribution. This does not affect your benefits, and should reduce the cost of the care home placement for you.

The care home should give you a written statement with a clear breakdown of how much of the costs are covered by the NHS, the local authority and yourself. You can ask them for a statement if you have not received one.

Challenging a decision

If you don't agree with the LHB decision, you have the right to make an appeal. You must inform the LHB of your intention to appeal within **28 days** of the date you were told of the eligibility decision. Requests made after this time period will only be considered in exceptional circumstances. You must submit you written appeal to the LHB within **6 months** of the date you were told of the eligibility decision. Appeals submitted after this time period will only be considered in exceptional circumstances.

The review does not cover the content of care plans, but you can request a review about:

- the procedure followed in reaching your CHC eligibility decision; or
- the application of the criteria for eligibility – i.e. the 'primary health need' test and whether this has been applied in a correct and consistent manner.

You may also take your case to the Public Services Ombudsman for Wales if you remain unhappy following a review, contact details are on **page 28**.

<u>There are two stages in the appeals process – a local review stage and an Independent Review Panel stage.</u>

<u>Local review stage</u>

If you or your family approach your LHB for a review of the decision, it will firstly be dealt with by your LHB's local review process. Your LHB should provide you with details of their local review process, including timescales, and deal with your request promptly. If you are still unhappy with the decision following the local review process your appeal should progress to the Independent Review Panel stage.

<u>Independent Review stage and timescales</u>

Your LHB must have an Independent Review Panel (IRP) which has an IRP chair, and representatives from an LHB and LA. The IRP process should normally be completed within **four weeks** of the request for a review (unless in exceptional circumstances). This period begins once any action to resolve the case at the local review stage has been completed.

Who is funding my care while I await the outcome of my eligibility review?

The decision that you are not eligible for CHC funding remains in place until the appeals process has been completed. During this time you should receive appropriate care while you wait for the outcome of your appeal, but you may have to contribute towards the cost of your care package during this time.

Your circumstances when you ask for an appeal will affect who is responsible for arranging and/or paying for your care. Your LA and/or NHS may be involved or you may already be arranging and/or funding your own care.

Retrospective review cases

If you feel that you, or someone you care for, were eligible for CHC during a period of time when you were paying for care, you can ask for a retrospective review to get the care fees reimbursed. The LHB is responsible for current and retrospective review cases, they should have an appointed person you can contact about this, contact them to find out who this is. You may have reason to believe that you should have met the eligibility criteria because:

- the LHB carried out an assessment in the past, but there is evidence that the criteria were not applied appropriately; or
- it should have been reasonably apparent to the NHS at the time that you might be in need of CHC services, but the LHB failed to arrange and carry out an assessment.

There is currently a rolling cut-off date for submitting your retrospective review. You have to make your claim within 12 months of the end of the period you are claiming for. Claims outside of the stated cut off dates may be considered in exceptional circumstances.

The LHB will need you to supply proof of care fees that have been paid during the period in question. If you're applying on behalf of someone else, the LHB will need to see documentation to show that you have the relevant legal authority to pursue the claim. These must be provided within 5 months or registering the claim.

You will be sent a questionnaire by the LHB. In this document you will outline your case for why you believe you should have qualified for CHC. When the LHB receives your completed questionnaire, it will make requests to the relevant care providers for records of your care. The LHB will produce a "chronology of need" from all available records.

<u>Stage 1 Review</u>
The LHB will assess the information in the chronology of need against the CHC Checklist Tool. If no potential eligibility is found, the case is closed. If potential triggers for eligibility are found, the case progresses to Stage 2. These decisions are ratified by an independent IRP Chair.

<u>Stage 2 Review</u>
The LHB will add any further available evidence to the chronology of need and assess this information against the 4 key indicators of Nature, Intensity, Complexity and Unpredictability and by applying the Primary Health Need approach for the whole of the claim period.

This will be peer reviewed by a different clinician – or in cases where no eligibility is found, by 2 different clinicians – to ensure the recommendation is correctly supported by evidence and that the criteria have been applied consistently. If there is disagreement between the clinicians, the case will be passed to a Review Panel (IRP).

The recommendation on your eligibility will be made on the evidence available. It can be 1 of 4 possibilities:

- **matching**- the period of eligibility found matches the claim period in totality from the trigger date
- **partial**- eligibility is found for part of the claim period from the trigger date
- **no eligibility** found for any part of the claim period from the trigger date
- **Panel** - the reviewer has been unable to make a decision as the information available is complex or the clinicians are unable to agree on the period of eligibility.

Dependant on the recommendation made, your case will go along 1 of 3 pathways:

- **matched** cases will go directly for ratification
- **partial** and **no eligibility** cases will be forwarded to claimants with the opportunity to discuss the findings
- **Panel** cases - an Independent Review Panel will be convened.

You will be invited to discuss your case where partial or no eligibility has been found:

- Partial eligibility- the discussion will aim to reach a mutually acceptable period of eligibility based on the evidence available and/or new evidence that has not previously been available. If agreement is reached at this stage, the case will be forwarded for scrutiny and ratification. If no agreement is reached, the case will be forwarded for IRP consideration.
- No eligibility- the discussion will provide opportunity for further explanation of the CHC criteria and to check that the claimant/representative has understood the lack of evidence on eligibility.

In all cases if you are found eligible for either the full or part period of the claim, timely reimbursement should be made.

You may also take your case to the Public Services Ombudsman for Wales if you remain unhappy following a review. Contact details are on **page 28**.

Please note health boards will have more detailed information on how to make a retrospective claim and how the process works and they will share this with you when you contact them.

How eligibility for CHC affects your benefits

Disability benefits

The main disability benefits are *Attendance Allowance (AA)*, *Disability Living Allowance (DLA)* or *Personal Independence Payment (PIP)*. These are paid directly to you whereas with CHC, fees are paid directly to care providers.

If you are receiving your CHC care package at home, you can continue to receive these disability benefits. You can check that you are receiving them at the appropriate level.

If you are receiving your CHC in a **care home with nursing**, AA and both care *and* mobility elements of DLA and PIP are suspended after 28 days from the time the LHB funding begins, or sooner if you were recently in hospital.

If you are receiving your CHC in a **residential care home**, the care component of disability benefits is suspended after 28 days from the time LHB funding begins, *but* DLA or PIP mobility components continue.

If you are receiving social care and support in either kind of care home setting that is arranged and funded by your local authority (you will be required to contribute towards these costs from any eligible income you continue to receive), the care component of disability benefits is suspended after 28 days, but DLA or PIP mobility components continue.

State Pension and Pension Credit

State Pension is not affected by eligibility for CHC. If you receive Pension Credit, you will lose the severe disability element of your Pension Credit award when you are no longer entitled to AA, DLA (care component) or PIP (daily living component) and this is likely to affect the amount of Pension Credit you are eligible for.

How to contact your LHB

Swansea Bay University Health Board

Retrospective Claims Administrator
Long Term Care Team Block A,
Neath Port Talbot Hospital
Baglan Way
Port Talbot
SA12 7BX
Tel: 01639 684561

General enquiries

- Email: sbu.inquiries@wales.nhs.uk
- Telephone ABM Headquarters on (01639) 683344
- Website: Swansea Bay University Health Board

Aneurin Bevan University Health Board

Complex Care
Cwmbran House
Mamhilad Park Estate
Pontypool
IRP Administrator – 01495 332173
Business & Performance Manager – 01495 332358

General enquiries

- Telephone: (01873) 732732 ;
- Email: abhb.enquiries@wales.nhs.uk
- Website: Aneurin Bevan University Health Board

Betsi Cadwaladr University Health Board

Block 5,
Carlton Court
St Asaph Business Park
St Asaph
LL17 0JG

General enquiries

- Telephone: (01248) 384 384
- Email: - info.bcu@wales.nhs.uk
- Website: Betsi Cadwaladr University Health Board

Cardiff and Vale University Health Board

Retrospective Continuing Care
Retrospective CHC Team
Email: Retro.Chcadmin@wales.nhs.uk
Tel: 02920 335509

General enquiries

- Telephone: (029) 2074 7747
- Email: Intranews@wales.nhs.uk
- Website: Cardiff & Vale University Health Board

Cwm Taf Morgannwg University Health Board

Geraldine Thomas
Registered Nurse Reviewer
Cwm Taf LHB Headquarters
Ynysmeurig House
Unit 3 Navigation Park
Abercynon
Rhondda Cynon Taf
CF45 4SN

General enquiries

- Telephone: (01443) 744800
- Email: cwmtaf.concerns@wales.nhs.uk
- Website: Cwm Taf Morgannwg University Health Board

Hywel Dda University Health Board

Aldyth King – Long Term Care Administrator (Carmarthenshire Locality)
Hywel Dda University Health Board
Block 6 Prince Philip Hospital
Bryngwynmawr,
Dafen Llanelli
SA14 8QF

General enquiries

- Telephone: (01267) 235151
- Contact: On-line Feedback Form
- Website: Hywel Dda University Health Board

Swansea Bay University Health Board Retrospective Claims Administrator Long Term Care Team Block A, Neath Port Talbot Hospital Baglan Way Port Talbot SA12 7BX Tel: 01639 684561 **General enquiries** • Email: sbu.inquiries@wales.nhs.uk • Telephone ABM Headquarters on (01639) 683344 • Website: Swansea Bay University Health Board	**Aneurin Bevan University Health Board** Complex Care Cwmbran House Mamhilad Park Estate Pontypool IRP Administrator – 01495 332173 Business & Performance Manager – 01495 332358 **General enquiries** • Telephone: (01873) 732732 ; • Email: abhb.enquiries@wales.nhs.uk • Website: Aneurin Bevan University Health Board
Powys Teaching Health Board Complex Care Team. Room 90 Neuadd Brycheiniog Cambrian Way Brecon Powys LD3 7HR **General enquiries** • Telephone: (01874) 711661 • Email: geninfo@powyslhb.wales.nhs.uk • Website: Powys Teaching Health Board	

Other useful contacts to access advice, guidance and support, on what healthcare you are entitled to from the NHS, and how you can complain if the service is poor, are listed below.

NHS Wales complaints and concerns: Putting Things Right If you have concerns about your care or treatment, talk to the staff involved with your care as soon as possible. They will try to resolve your concerns immediately. If this does not help, or you do not want to speak to the staff, you can **contact the health board or trust's complaints team**. https://gov.wales/nhs-wales-complaints-and-concerns-putting-things-right#section-49684
If you are not satisfied with the health board or trust's response, you can contact the **Public Services Ombudsman for Wales**. 1 Ffordd yr Hen Gae Pencoed CF35 5LJ Call: 0300 790 0203
Equality and Human Rights Commission Call: 02920 447710 (non helpline calls only) Email: wales@equalityhumanrights.com
Community Health Councils Community Health Councils provide free confidential advice and support to patients who have a complaint about NHS services. Call: 02920 235 558 Email: enquiries@waleschc.org.uk
Citizens Advice You can contact an adviser through the national phone service Call: 03444 77 20 20
Advocacy Support Cymru Specialises in the provision of professional, confidential and independent advocacy for those eligible in secondary care and community mental health settings. Call: 029 2054 0444 Email: info@ascymru.org.uk **Carers Direct – for carers** Call 0300 123 1053 Ask your question using webchat Get help by email
Carers UK – for carers Call 0800 808 7777
Family action – support for parents and carers Call 0808 802 6666 Text 07537 404 282 Email: familyline@family-action.org.uk

Use this page to write important information

Name: _____

Date booklet was provided: _____

Name of Care Co-ordinator and contact details:

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Date of MDT: _____

Other Contacts:

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Notes:

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