Creu Cymru oed gyfeillgar
Creating an age friendly Wales

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NHS continuing healthcare and NHS-funded nursing care in Wales

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Contents

1 Information about this factsheet

NHS continuing healthcare (NHS CHC)

This factsheet provides detailed information on NHS continuing healthcare (NHS CHC) in Wales, including:

- An explanation of what NHS CHC is and when possible eligibility should be considered;
- the process for deciding whether someone is eligible to receive it;
- how the services will be delivered for those who are eligible; and
- what to do if you are unhappy with the decision reached.

There is a brief flowchart on the NHS CHC eligibility process in section 5.8 below. This can be used in conjunction with the more in-depth information on the different stages and aspects involved in the process, which are covered in the rest of the factsheet.

Retrospective NHS CHC claims

There is a section on retrospective claims for NHS CHC where someone has paid for care in the past, but believes that they should have been eligible for CHC.

However, there are now strict cut off deadlines for making such claims – see section 14 below.

Weekly NHS-funded nursing care

Also in this factsheet, you can find further information on NHS-funded nursing care – the NHS's financial contribution towards the cost of meeting the nursing care needs of nursing home residents who are **not** eligible for NHS CHC, but ***have*** been assessed as needing services provided by a registered nurse – see section 15 below.

Note: The information given in this factsheet is applicable in Wales. Different rules apply in England, Northern Ireland and Scotland. Contact Age UK, Age NI and Age Scotland respectively for further information.

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2 Introduction – what is NHS continuing healthcare (NHS CHC)?

Note: NHS continuing healthcare will be referred to by the abbreviation NHS CHC throughout this factsheet.

NHS CHC is a package of care arranged and funded solely by the NHS to meet physical and/or mental health needs that have arisen because of disability, accident or illness. It can be provided in any setting including, but not limited to, a care home, a hospice or your own home.

Eligibility is decided via a full assessment (see sections 4 and 5) where the *'nature'*, *'intensity'*, *'complexity'* or *'unpredictability'* of someone's health needs mean that they have to be actively managed by the NHS.

Eligibility decisions for NHS CHC rest on whether your need for care is primarily due to your health needs – often referred to as having a **'primary health need'** (as opposed to a need for care due primarily to social care needs that fall within the remit of social services departments, rather than the health service – see below).

2.1 Does a care need fall within the remit of the health service (NHS) or the local authority social services department?

When you have long-term care needs the type of help you need may be the responsibility of:

- the NHS; **or**
- of your local authority social services department.

Sometimes it will be obvious which of the two will have responsibility – however, if you have complex needs, the boundaries between health and social care may not always be clear (and indeed, you may receive a mixture of services from each organisation).

Over a number of years, NHS CHC has been a controversial subject, in part because of uncertainties and debate in regard to where the divide between healthcare and social care rests.

As services provided by the NHS are free, whereas those arranged by social services are generally means tested and therefore – depending upon your financial circumstances – you are likely to have to pay towards these services, the outcome of any decision as to who has overall responsibility for your care can have significant financial consequences.

Services beyond the powers of a local authority to provide

Certain services are beyond the powers of local authority (LA) social services departments to provide – this will be the case where legislation has stipulated that it is an area that the health service must cover (for example, this is confirmed in section 47 of the *Social Services and Well-being (Wales) Act 2014*: "a local authority may not meet a person's needs for care and support...by providing or arranging for the provision of a service or facility which is required to be provided under a health enactment, unless doing so would be incidental or ancillary to doing something else to meet needs under those sections").

However:

"the fact that someone has health needs which are beyond [those LA powers], does not, of itself, mean that the individual is eligible for [NHS] CHC"[1].

For example, a person in this scenario may require (and be entitled to) services from both the NHS (those that are above what the LA can provide) and their local authority social services department at the *same* time, but would have been judged to not have a sufficient level of health needs to qualify for NHS CHC.

In other words, the **'primary health need'** test, referred to above, will not have been met.

Note: Sections 4 and 5 of this factsheet examine the procedure that should be followed by professionals involved in your care in determining whether you have a 'primary health need' and thus will be eligible for NHS CHC.

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[1] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022).

2.2 What is the difference between a healthcare need and a social care need?

The Welsh Government has defined the difference between a healthcare and a social care need as follows:

“Whilst there is not a legal definition of a healthcare need (in the context of continuing NHS healthcare), in general terms it can be said that such a need is one related to the treatment, control or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional)”.

“In general terms (not a legal definition) it can be said that a social care need is one that is focused on providing assistance with activities of daily living, maintaining independence, social interaction...and (in some circumstances) [finding and] accessing a care home or other supported accommodation”.

“Social care needs are directly related to the type of welfare services that [local authorities] have a duty or power to provide. These include, but are not limited to...practical assistance in the home; assistance with equipment and home adaptations; visiting and sitting services; provision of meals; facilities for occupational, social, cultural and recreational activities outside the home...and assistance in finding accommodation (e.g. a care home)”[2].

Note: “Deciding on the balance between local authority and health service responsibilities with respect to long-term care has [also] been the subject of key court judgments”[3]. These have influenced developments in NHS CHC policies, including the introduction of a National Framework (which is covered in sections below).

[2] This quote is from a previous version of Welsh Government best practice guidance in regard to NHS CHC (‘Continuing NHS Healthcare for Adults: Practice Guidance to support the National Framework for Implementation in Wales – Frequently Asked Questions, Welsh Government, November 2010’). It is no longer in use, but the general principles can still be said to be accurate with regard to the differences in social care needs and healthcare needs.

[3] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022).

2.3 Background to NHS CHC

Since the 1990s, the Parliamentary and Health Service Ombudsman has investigated a large number of complaints about eligibility for NHS CHC. Additionally, following devolution, the Public Services Ombudsman for Wales has highlighted inconsistencies in the application of NHS CHC eligibility criteria in annual reports and investigations of individual cases. The legality of some eligibility decisions were also challenged in the courts.

Key events in relation to NHS CHC[4]:

- In 1999, an important Court of Appeal judgement – known as the **Coughlan judgement** (*R v. North and East Devon Health Authority ex parte Pamela Coughlan*) – ruled that eligibility criteria used by the health authority concerned were far too restrictive[5].
- In 2003 a Health Service Ombudsman [in England] report was published. It found that health authorities were using overly restrictive eligibility criteria that were not properly in line with government guidance or with the Coughlan judgment. The Ombudsman found that "a number of people had been wrongly charged for elements of their care when they should have been treated as eligible for CHC and all their care provided free by the NHS". It was recommended that efforts should be made to remedy any financial injustice to patients (a recommendation also accepted by the Welsh Government).
- In March 2006, the High Court heard a challenge, on behalf of Mrs Grogan (the **'Grogan case' –** *R v. Bexley NHS Care Trust ex parte Grogan*), who argued that she had been wrongly denied fully funded care. In his judgement, the judge criticised the lack of clarity in government guidance in use at that time, including inconsistencies in the area of assessing and weighing the nature, complexity, intensity or unpredictability of people's health needs when making eligibility decisions (these factors still play a key role in current Welsh Government guidance – see section 3 below).

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[4] Since the Government of Wales Act 1998, health is an issue that is devolved to the Welsh Government. The UK Government's Department of Health has no jurisdiction in Wales. However, the issue of NHS CHC in Wales has developed against the background of developments in England.

[5] The Court found social services had been asked to take on healthcare responsibilities for a nursing home resident that went far beyond the duties imposed upon them by law (hence current legislation now making clear that social services cannot be expected to carry out functions that are beyond their remit, as touched upon in section 2.1 above).

- It was against this background that a National Framework for NHS continuing healthcare and NHS-funded nursing care was developed and first introduced in Wales in August 2010, with the aim of improving decision making for NHS CHC. Since then, there have been a number of further updates to the National Framework in use in Wales – for information on the current one, see section 3 below.

3 Welsh Government guidance on NHS CHC – the National Framework

The following document is the Welsh Government's current guidance for NHS organisations and local authority social services departments on NHS CHC and the processes that should be followed when examining a person's eligibility:

Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)

A copy can be accessed on the Welsh Government website at:

www.gov.wales/national-framework-nhs-continuing-healthcare

The National Framework is the main document that has been used to inform the content of this factsheet.

4 Who might be eligible for NHS CHC?

4.1 Eligibility decisions – 'primary health need' and the National Framework

As stated in section 2 above, eligibility decisions for NHS CHC rest on whether your need for care is primarily due to your health needs. This is referred to as having a 'primary health need' and is the "sole criterion" for determining eligibility[6].

[6] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)

The diagnosis of a particular disease or condition – for example, Alzheimer's disease or cancer – does not determine eligibility, as people with the same diagnosis or health condition can have very different needs.

As touched upon in the previous section, the Welsh Government's National Framework provides the rules and guidance for determining a primary health need. The Framework aims to improve the transparency and consistency of the decision-making process and sets out:

- Principles and processes to be followed throughout Wales for establishing eligibility for NHS CHC – see sections 4 and 5.
- Guidance that must be followed by all staff involved in the assessment process (for example, medical professionals in hospitals, or social workers from your local authority's social services department).
- A national assessment process supported by a *Decision Support Tool (DST)* – see section 5.3 below – and (for use in certain circumstances) a *Checklist Tool*, though the Framework doesn't mandate this – see section 5.1.
- Common paperwork to record evidence that will inform decision-making.
- The Framework also explains the interaction between the assessment for NHS CHC and NHS-funded nursing care.

4.2 What factors might demonstrate a 'primary health need'?

The Framework states that certain characteristics of your needs – in combination or alone – may demonstrate a primary health need because of the **quantity and/or quality** of care needed to manage them ('quality' in this context refers to the type of care that is required to manage needs).

Establishing a primary health need will be based on the 'totality' of all the actual day-to-day care needs[7].

Therefore, when assessing your needs, staff consider them in relation to the following characteristics:

[7] Ibid

Nature	● The type of needs, including their particular characteristics – the needs can be related to physical health, mental health or psychological needs and consideration is required in regard to the overall effect on the individual's health and wellbeing. ● The type (quality) of interventions required to manage them will be important – for example, are there particular skills or training required to anticipate and address the need; or could someone do it without specific in-depth training? ● Also, is the person's condition deteriorating or improving? ● Consideration should also be given as to what the consequences would be if the needs were not met in a timely way.
Intensity	● This regards both the extent (quantity) and severity (degree) of an individual's needs and the support required to manage them – for example, this might include a requirement for regular interventions and sustained/ongoing care (continuity) to ensure the needs are met. ● Consideration may need to be given to the number of carers needed at any one time to ensure needs are met. ● Also, does the care provided relate to needs over several domains?
Complexity	● How different needs present and interact to increase the knowledge and skill needed to manage care, monitor symptoms and treat a condition. ● "This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions" (for example, if needs impact upon each other, it might make the situation more difficult to address overall).

	● "It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need"[8] – could this make it more difficult to provide the care required?
Unpredictability	● This includes unexpected changes and fluctuations in someone's condition that are difficult to manage and challenge the staff who provide care. ● A further factor will be the level (quantity) of monitoring required to ensure that the individual and others are safe and the degree of risk if adequate and timely care is not provided. ● Someone with unpredictable healthcare needs is likely to have either a fluctuating, unstable or rapidly deteriorating condition. Questions to be considered include: ➢ whether the individual or those who support him/her are able to anticipate when the need(s) might arise? ➢ Does the level of support often have to change at short notice? ➢ To what extent is professional knowledge or skill required to respond spontaneously and appropriately?

These characteristics are reflected in the descriptions of the different levels of need that feature in the **Decision Support Tool (DST)**. This tool helps inform staff making a recommendation about your eligibility for NHS CHC – see section 5 below.

Note: Eligibility decisions should always be independent of budgetary constraints.

[8] Ibid

‘Fast tracking’

The characteristics described above – ‘nature’, ‘intensity’ etc – are also considered by staff deciding whether to recommend ‘fast tracking’ a patient so they can receive an urgent package of NHS CHC in an appropriate location. Fast tracking is only available in certain situations, however – see section 5.10 below for further information.

4.3 When should eligibility be considered?

The role of Local Health Boards (LHBs)

A Local Health Board (LHB) must take reasonable steps to ensure that an assessment for NHS CHC is carried out in all cases where it appears to them that there may be a need for such care.

LHBs are responsible for delivering all NHS healthcare services within the geographical area they cover – this will include services provided as part of an NHS CHC package. There are seven LHBs which cover Wales. NHS 111 Wales (see section 16 for contact details) can tell you which LHB will cover your area. Alternatively, you can obtain further information from the Welsh Government website at:

www.gov.wales/nhs-wales-health-boards-and-trusts

LHBs are responsible for overseeing the NHS CHC decision making process, though local authority social services departments *also* often have a role to play.

The role of local authority social services departments

Adult social services teams are responsible for assessing people’s need for social care services and deciding whether those needs meet national eligibility criteria (social care services include services such as personal care at home, respite care, community transport, meals on wheels, or assistance with a care home placement – for further information see Age Cymru’s Factsheet 41w *Social care assessments for older people with care needs in Wales*).

As part of their care needs assessment process, the local authority social services department **must** inform the relevant LHB if they are reviewing someone's care needs and feel that there is a possibility that the person has needs that fall within the remit of the NHS, *including* where they suspect there is a potential that the person could be eligible for NHS CHC.

If so – as noted above – the LHB will at that point then need to co-ordinate the process for determining CHC eligibility.

Examples of scenarios where it may be appropriate to consider potential eligibility for NHS CHC

As outlined in earlier sections, not everyone with ongoing health needs is likely to be eligible, but there are times when it would be appropriate to consider whether someone has a need for such care, including:

- **When someone is ready to be discharged from hospital and their long term needs in regard to ongoing care and support are clear to the health and social care practitioners who have been working with them** (also see Age Cymru's Factsheet 37w *Hospital discharge arrangements for older people in Wales* for further information).
- **Once a period of intermediate care, rehabilitation or other NHS-funded service – offered at the end of a period of acute hospital treatment – has finished and it is agreed no further improvement in your condition can be expected** (also see Age Cymru's Factsheet 76w *Reablement, intermediate care and preventative services in Wales* for further information).
- **When someone's social care and support needs are being reviewed via a care needs assessment by the local authority social services department** (also see Age Cymru's Factsheet 41w *Social care assessments for older people with care needs in Wales* for further information).
- **If your physical or mental health deteriorates significantly and your current level of care – at home or in a care home – seems inadequate**.
- **When, as a resident of a nursing home, your nursing care needs are being reviewed** (undertaken at least annually – see section 15 below).

- **If you have a rapidly deteriorating condition with an increasing level of dependency and may be approaching the end of your life** (in this case you may be eligible for your CHC care services to be set up via the *'fast track'* route – see section 5.10 below).

Who should you contact in the above scenarios if NHS CHC has not been discussed with you?

In circumstances such as those outlined above, you can raise the issue of NHS CHC and the possibility of organising an assessment to see if you are eligible with:

- Hospital staff directly involved with your care (in particular, discharge staff).
- Staff co-ordinating your intermediate care or other rehabilitation service.
- Social services.
- Your GP.

5 Reaching an NHS CHC eligibility decision – Multi-disciplinary assessment, Checklist Tool, Decision Support Tool and other key elements

Note: This section contains detailed information on the eligibility process and how decisions are made. However, there is also a brief **flowchart** in section 5.8, which seeks to summarise the different stages involved.

Health and social care staff involved in assessing your needs will need to follow the National Framework guidance and use the Decision Support Tool (DST).

In some, but ***not all***, circumstances it may also be beneficial for them to use a Checklist Tool (see below).

You may find it helpful to see a copy of the DST in advance. It should be available from the staff involved in your care, or see section 5.3 of this factsheet below for a link where you can access a copy online.

5.1 The Checklist Tool[9]

Note: It is not mandatory for the Checklist Tool to be used.

For example, professionals involved in your care may feel you definitely require an assessment for NHS CHC and thus move straight on to the multi-disciplinary assessment and use of the DST – outlined in sections 5.2 and 5.3 below – and miss out the Checklist Tool stage as unneeded.

As the Checklist Tool is not mandatory, when should it be used?

The Checklist Tool can be used by health and social care professionals in cases where it is less clear cut that someone should obviously have a full assessment for NHS CHC. However, there may be the possibility that they could qualify, so using the Checklist can help to ensure that people are not 'screened out' of the process prematurely.

The threshold for using the checklist is set deliberately low to ensure that all who require a full assessment have the opportunity.

The Welsh Government also considers the Checklist to be a useful tool for recording the rationale for decisions on whether or not to proceed to full NHS CHC assessment. This can prove useful in conversations between professionals, individuals and family members, as it can illustrate where a person has only low level needs and will not require a full NHS CHC assessment. This could potentially set people's minds at rest that they are not missing out on funding that they should be eligible for.

Accessing the Checklist Tool

The Welsh Government's Checklist Tool can be found within the main National Framework document at **Annex 3: Example CHC Process Checklist**:

https://gov.wales/sites/default/files/publications/2022-03/continuing-nhs-healthcare-the-national-framework-for--implementation.pdf

[9] You may sometimes hear the Checklist Tool also referred to by other similar names, such as a 'Trigger tool' or 'Screening tool'.

Using the Checklist Tool

The Welsh Government has emphasised that "in order to comply with the ethos of [the National] Framework, the use of the Checklist must not replace professional judgement or dialogue with the individual and/or their representative".

It must also "be completed by at least 2 practitioners, including a representative of the LA [local authority social services]. It can be completed by a variety of health and social care practitioners, who have been trained in its use. This could include, for example: registered nurses employed by the NHS, GPs, other clinicians or LA staff such as social workers, care managers or social care assistants"[10].

The Checklist is based on the same 'domains' or 'areas of need' as the Decision Support Tool (DST). The DST is explained below, in section 5.3.

For each domain, there are descriptions that represent *'no and low'* needs (found in column C of the Checklist Tool); *'moderate'* needs (column B) and *'high'* needs (column A).

The Checklist Tool contains further information on how it should be used and completed by staff. Broadly speaking, they must choose the description that most closely matches your current needs, including taking into account:

- any well-managed needs; and
- any increased needs that might be expected within the next three months.

Note: The National Framework advises that: "The decision-making rationale should not marginalise a need just because it is successfully managed; well-managed needs are still needs. Only where successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on CHC eligibility".

The choices of staff on the Tool must be backed up by evidence.

[10] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)

According to the Welsh Government's guidance "there are two potential outcomes" from the Checklist:

- "a **negative** Checklist, meaning the individual does not require a full assessment…and they are not eligible for CHC"; or
- "a **positive** Checklist meaning an individual now requires a full assessment of eligibility for CHC" (though this doesn't necessarily mean the person will qualify once the full assessment has occurred – it just means they qualify to go through to this next stage).

Note: Is there any action that you can take if the Checklist result indicates a full assessment is not required?

You have the right in this scenario to ask the LHB to reconsider the decision, if you feel you can make a good case that their decision is incorrect. The LHB should give your request due consideration, taking account of any new or extra information you or your representative are able to provide.

How will you know if the Checklist result indicates that a full assessment is required?

A full assessment would be required if the Checklist showed either of the following:

- *Two or more* domains rated as **high** (Column A).
- *Five or more* domains rated as **moderate** (Column B).
- *One* domain rated as **high** (Column A) and *four* rated as **moderate** (Column B).
- One of the four domains that carries a 'priority' level in the DST rated as **high** (column A) and any levels of need in other domains (see section 5.3 for details of the domains within the DST that have a priority level).

Where the Checklist Tool is not used

As indicated at the beginning of this section above, in situations where it is not thought necessary to carry out the Checklist Tool stage, *but* professional staff believe you *may* be eligible for NHS CHC, their decision will be based **purely on the two stages outlined below** in section 5.2 and 5.3 – that is:

- **a full multi-disciplinary assessment**; and
- **completion of the DST**.

Note: If you are in a situation where use of the Checklist Tool has not been thought necessary **and** it's also been decided that you will not be referred for a full assessment, you could make a complaint if you believe you have been 'screened out' of the process too early – see section 9 below.

5.2 Multi-disciplinary assessment

Once you are referred for a full assessment for potential NHS CHC eligibility, the Local Health Board (LHB) is responsible for co-ordinating the whole process until:

- a decision about your eligibility and the funding of your care has been reached; and
- a care plan has been agreed.

The care co-ordinator

The Local Health Board (LHB) should appoint someone employed by them, or by mutual agreement by another organisation, to co-ordinate this process (the 'care co-ordinator').

You should be provided with the care co-ordinator's name and contact number and they should keep you informed of progress throughout the assessment process (including advising you of potential delays and the reason for this).

Where you have expressed a wish for your family to be involved, the care co-ordinator must also liaise with them.

The multi-disciplinary assessment process

A multi-disciplinary assessment is a full, detailed, assessment of an individual's needs. It will actively involve a range of health and social care professionals, across different disciplines, in the collection and evaluation of the assessment information.

Note: It is worth noting that there is no separate assessment process for NHS CHC, in that this type of comprehensive needs assessment will be expected in all cases where someone has potentially complex needs (be they health needs, social care needs, or any other type of need) – what is **unique** to the NHS CHC process is the Decision Support Tool (covered in section 5.3 below). The National Framework stresses that practitioners "are expected to comply with existing Welsh Government...guidance on assessment and care planning" when carrying out a multi-disciplinary assessment – Age Cymru's Factsheet 41w *Social care assessments for older people with care needs in Wales* contains further information on the main care needs assessment processes.

The professionals invited to provide their input into the multi-disciplinary assessment may include those not currently caring for you, but who have a direct knowledge of you and your needs. For example, this may include:

- nurse coordinator/assessors;
- social workers/care manager;
- physiotherapists;
- occupational therapists;
- dieticians/nutritionists;
- GPs/consultants/other medical practitioners;
- community psychiatric nurses;
- ward nurses, specialist nurses, discharge nurses and community nurses;
- care home/support provider staff.

Information or evidence that may be used as part of the multi-disciplinary assessment

This could include, for example:

- health needs assessments and/or nursing assessments;
- social care assessments;
- physiotherapy assessments;
- behavioural assessments;

- occupational therapy assessments;
- your own views on your needs and, where appropriate, your carer's views (see section 5.6 below for information on the importance of a 'person-centred' approach to the assessment and how your views should be considered alongside those of the professionals involved);
- your current care and support plan;
- care home records / non-residential care support records.

The multi-disciplinary assessment ensures that all your physical health, mental health and social care needs can be looked at and evaluated individually and together – including ways in which they interact with each other – to give an accurate reflection of your current needs and likely changes in the near future.

A good quality assessment is crucial both to determining your eligibility for NHS CHC and addressing how your needs can best be met – whether you are eligible for NHS CHC or not.

Information collected through the multi-disciplinary assessment is used by a multi-disciplinary team (MDT) to complete the Decision Support Tool. It will be the role of the co-ordinator to identify the appropriate individuals to comprise the MDT.

The MDT should have at *least* two professionals, usually from both health and social care professions. However, as outlined in the list above, in many situations the team may have more members than this, if there are other individuals who have an up-to-date knowledge of your needs.

Note: Location for the multi-disciplinary assessment to take place

The assessment may not take place whilst you are in an acute hospital bed and could occur in your own home or in another suitable health or community setting. The "Discharge to Recover Then Assess (D2RA) pathways should be the default position"[11] – further information on D2RA can be found in Age Cymru's Factsheet 37w *Hospital discharge arrangements for older people in Wales*.

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[11] Ibid

5.3 The Decision Support Tool (DST)

The DST should draw on the multi-disciplinary assessment findings. It has been "designed to support the decision-making process [and] must only be used following a comprehensive assessment of an individual's care needs" (as per section 5.2 above).

The DST "**is not an assessment in itself**" – rather, it is "a means of recording the rationale [for decisions] and facilitating logical and consistent decision-making"[12].

Note: The DST – *Continuing NHS Healthcare: Decision Support Tool for Practitioners' use only (March 2022)* – can be found in a separate document to the main National Framework. A copy can be accessed on the Welsh Government website at:

www.gov.wales/continuing-nhs-healthcare-decision-support-tool-dst-practitioners

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The DST is a national tool and cannot be altered in any way by individual Local Health Boards.

The tool features **12 'domains'** (which are basically different areas of need). There are 11 specific domains and a twelfth which is an open domain for recording needs that don't readily fit into the other 11.

Each domain is broken down into between four and six levels of need:

- **'No need'**
- **'low'**
- **'moderate'**
- **'high'**
- **'severe'**
- **'priority'**.

[12] Ibid

Note: A few of the domains have 'high' as the maximum level which they can be allocated in the assessment, whereas others can go up to 'severe' or 'priority'.

The levels reflect the nature, intensity, complexity and unpredictability of a need (see section 4.1 above). Medical terms have been kept to a minimum when describing the levels of need in each domain.

The domains are:

	Domain	Maximum level of need which can be allocated to the domain
1	**Breathing**	**Priority**
2	**Nutrition**	***Severe***
3	**Continence**	**High**
4	**Skin Integrity**	***Severe***
5	**Mobility**	***Severe***
6	**Communication**	**High**
7	**Cognition**	***Severe***
8	**Psychological & Emotional Needs**	**High**
9	**Behaviour**	**Priority**
10	**Drug Therapies and Medication**	**Priority**
11	**Altered States of Consciousness**	**Priority**
12	**Other Significant Care Needs**	***Severe***

Completing the DST

In advance of the DST meeting, the care co-ordinator should explain the format and how you and/or your representative can participate.

You or your representative should be fully involved in the process and invited to contribute to the discussion in person or be represented where possible. You should be given sufficient notice of the date, so you can make arrangements to attend. If this is not possible, your views or those of your representative should be obtained and actively considered when completing the DST (also see section 5.6 below). When completing the tool, the following points are important:

- All care domains should be completed.
- The team should use the assessment evidence and their professional judgement to select the level that most closely describes your 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"[13].
- Interactions between needs should be considered as appropriate.
- Needs not covered by one of the 11 domains should be recorded in the twelfth domain and taken into account when making an eligibility decision.
- 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 recommendation is made.

[13] Continuing NHS Healthcare: Decision Support Tool for Practitioners' use only (March 2022).

Staff using the tool should state whether you or your representative were present when the DST was completed (the DST includes a section which specifically asks whether the individual was involved in the completion of the DST, asks for details of their own views on their care/support needs and "whether they agree with the domain levels selected. Where they disagree, this should be recorded", including the reasons for disagreement).

If the individual is represented or supported by a carer or advocate, their understanding of the individual's views should be recorded.

If you have concerns about any aspect of the MDT or DST process that are not resolved by discussing them at the time, your concerns should be noted within the DST, so they can be brought to the notice of the Local Health Board when making their final decision.

Obtaining a copy of the DST

The Decision Support Tool states that:

"A copy of the completed DST…including the recommendation…should be forwarded to the individual (or, where appropriate, their representative) together with the final decision made by the LHB [Local Health Board], including the rationale for the LHB's decision"[14].

5.4 The multi-disciplinary team's recommendation

The multi-disciplinary team (MDT) uses evidence from the completed DST, along with relevant risk assessments and their professional knowledge and experience, to make a recommendation to the Local Health Board as to whether or not your needs have characteristics that demonstrate a 'primary health need' and hence eligibility for NHS CHC.

[14] Ibid

When would a recommendation of eligibility be expected?

A clear recommendation of eligibility would be expected if you have:	**a.)** ***Priority*** level of need in *any* of the four domains where that level can be allocated. **b.)** *Two or more* incidences of identified ***severe*** needs across all domains.
A primary health need *may* also be indicated if there is:	**a.)** One domain recorded as severe *together with* needs in a number of other domains. **b.)** A number of domains with high and/or moderate needs.

In the latter cases, the judgement about whether you have a 'primary health need' must be based on what the evidence indicates about:

- the **nature**; and/or
- **complexity**; and/or
- **intensity**; and/or
- **unpredictability** of your needs.

Note: The MDT should also indicate whether they expect your needs to improve or deteriorate before a three-month review and whether they would recommend an earlier one – see section 12 below for further information on reviews.

Having taken into account any likely deterioration in your condition that could affect your needs, a recommendation for you to be 'fast tracked' on to NHS CHC may be appropriate – see section 5.10 below.

Where eligibility would be unlikely

If all are 'low' needs, this is *unlikely* to indicate eligibility.

The Welsh Government's DST states, however, that "because low needs can add to the overall picture, influence the continuity of care necessary, and alter the impact that other needs have on the individual, all domains should be completed".

Where someone will definitely not be eligible

If needs in *all* domains are 'no need', this would indicate definite ineligibility.

5.5 The Local Health Board's decision

In the majority of cases, the Local Health Board (LHB) "will accept the MDT's recommendations. In exceptional circumstances, and for clearly articulated reasons, the LHB may request additional evidence to support the MDT's recommendations"[15] (also see the point about *'integrity of decision making'* in section 5.6 below).

Once the LHB approves the recommendation, you should be informed in writing.

Note: A decision that you are eligible for NHS CHC is **not** a permanent one. It can be overturned at a later date if a review shows your condition has improved and your needs have changed.

[15] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)

If the recommendation is that you are not eligible, but that you may need care in a nursing home, the completed multi-disciplinary assessment should contain sufficient information to determine the need for **NHS-funded nursing care** – see section 15 below.

5.6 'Underpinning Principles' to the assessment and eligibility process (including a 'person-centred' approach)

The National Framework advises health and social care staff that "no guidance will address all of the potential situations that can present when assessing and meeting an individual's complex needs. There will be occasions when a degree of interpretation is required to apply the guidance in real-life cases". Therefore, practitioners must be able to demonstrate that they have applied certain "underpinning principles". These are:

- **Principle 1: People first**

  The best interests of the individual and treating them with dignity and respect must be the primary focus of those providing assessments.

- **Principle 2: Integrity of decision making**

  "Members of the MDT [Multi-disciplinary team] are responsible for the integrity of their assessments...which should be underpinned with a clear rationale". Recommendations on eligibility made by the MDT "can only be challenged at the quality assurance stage in exceptional circumstances, and for clearly articulated reasons. This process should not be used as a gate-keeping function or for financial control. A decision not to accept the MDT's recommendation should never be made by one person acting unilaterally. The final eligibility decision should be independent of budgetary constraints, and finance officers should not be part of the decision-making process".

- **Principle 3: No decisions about me without me**

  "Individuals are the experts in their own lives". Including them and/or their carers (be they paid or unpaid) "as empowered co-producers in the assessment and care planning process is not an optional extra". Professionals must be mindful that some individuals may require advocacy services – see section 7 below for further information.

- **Principle 4: No delays in meeting an individual's needs due to funding discussions**

  People "must not experience delay in having their needs met because agencies are not working effectively together".

- **Principle 5: Understand diagnosis, focus on need**

  People "do not define themselves by their medical or clinical diagnosis and nor should the professionals who are supporting them. Health and social care providers must work together to gain a holistic understanding of need and the impact on...daily life".

- **Principle 6: Co-ordinated care & continuity**

  "Fragmented care is distressing, unsafe and costly [and]...every effort must be made to avoid disruption to care arrangements wherever possible, or to provide smooth and safe transition where change is required".

- **Principle 7: Communicate**

  "The vast majority of complaints...have poor communication at their core".

  Therefore, "communication with the individual or their representative must be in the language/format or method of their choice". Additionally, "professionals involved in an assessment of the needs of people with severe speech and communication difficulties will need to establish the preferred means of communication before starting the assessment"[16].

5.7 Case studies – examples of where NHS CHC eligibility may or may not be indicated

The Welsh Government produced the following case studies to illustrate where someone would be likely to qualify for NHS CHC and where they would not[17]:

[16] Ibid

[17] The case studies were used in a Welsh Government information leaflet that is no longer is use – however, the examples can be seen as useful background information in terms of demonstrating how different levels of need play a part in NHS CHC eligibility.

Case study 1

"A sixty six year old lady with vascular dementia, mini strokes and subsequent cognitive impairment was admitted [to hospital] following a fall which resulted in a fractured hip. Following rehabilitation Mrs Jones' mobility improved but the ward were unable to continue supporting her due to her aggressive behaviour. Mrs Jones was transferred to an EMI hospital for...assessment and treatment". Identified needs were:

- "Prolonged periods of agitation and restlessness over a 24 hour period [for example] frequently [trying] to remove her clothing in the lounge.
- Severe cognitive impairment with short and long term memory loss.
- Unable to find her way around the ward, know what time of day it was, or recognise others including her close family.
- No awareness of social boundaries and risk, interfering with other patients at times and at risk of retaliation from them.
- Limited mobility following [the] fractured hip; however, had no awareness of her limitations and would attempt to mobilise without staff help, making her at high risk of falls.
- Due to lack of awareness required supervision during the day and a sensor mat at night.
- Constant support and encouragement to meet personal care and continence needs, presenting with physical aggression on interventions. Staff required an awareness of care and restraint procedures, under the supervision of a registered mental health nurse.
- Unsettled over a 24 hour period, requiring half hourly checks at night and night time sedation; there was evidence of frequent periods over 24 hours where Mrs Jones required the support of 1–2 carers.
- Required the administration of medication on an 'as and when' basis.
- Most of the time her communication was muddled and incoherent, so she relied on staff to anticipate her needs.
- Able to eat independently, however she required supervision...and a soft diet...and had had a number of episodes of choking".

Result: CHC eligibility agreed.

Case study 2

"Mrs Lee...was admitted to hospital with neurological problems and [an] increasing number of seizures. Following a medication review she remained seizure-free for six weeks. Her seizures were described as mild. In addition to this she had...Alzheimer's [disease], which was diagnosed approximately 3 years previously and the symptoms of this had accelerated since she developed her neurological problems. There was no input from mental health services and she did not present with any management problems". Identified needs were:

- "She had communication difficulties but was able to express and indicate her needs. She did not initiate any conversation but could respond by saying yes or no to direct questions. [Is reliant] on staff to anticipate needs.
- She required a hoist for all transfers from bed to [a] chair. She was able to sit independently in the chair for periods. Pressure relieving equipment was used to prevent any skin/pressure damage.
- She had a good appetite but required staff to cut up her food and on occasions required some assistance [to eat]. She was able to drink from a beaker, without prompting. There was no evidence of any weight loss.
- She was doubly incontinent and had a catheter in place; she was totally reliant on care staff for all continence care, including bowel management. There were no management problems with her catheter and interventions around this need were not considered complex.
- She had some areas of dry skin, scabs and scratch marks from chronic itching. She was seen by a dermatologist and was prescribed cream which was applied four times a day. All other pressure areas were intact.
- Required assistance for basic nursing care around washing, dressing grooming and continence.
- Administration of medication four time[s] daily, by a registered nurse".

Result: Mrs Lee was assessed as **not** eligible for NHS CHC; **however** she did have nursing care needs and was granted NHS-funded nursing care (see section 15).

Case Study 3

"Mrs Jones was aged 60; she was diagnosed with multiple sclerosis a number of years previously and had recently moved into a residential home". Identified needs were:

- "She required a lot of support with personal care, however she could wash her face...[and] was able to communicate her needs.
- She was [doubly incontinent and] she required support from carers to change her incontinence pad[s].
- She was immobile but had an electric wheelchair which she could use independently. She was at risk of falls when in her own home. However, now that she was in an environment where she has access to staff over a 24 hour period this was no longer a risk".

Result: Mrs Jones was assessed by the MDT as **not** being eligible for NHS CHC or NHS-funded nursing care.

5.8 Flowchart: the NHS CHC eligibility process

Circumstances indicate that you may require longer-term care and support (for example, hospital admission or a review of an existing care and support package – in your own home, or in a care home – indicates an increase in needs).

Potentially "NHS rehabilitation / reablement" may be tried first to see if this will improve someone's situation, before returning to the consideration of NHS CHC[18].

Local Health Board to ensure people receive information on NHS CHC, "obtain consent, determine capacity, provide advice re advocacy, and establish the individual's language of choice"[19].Checklist potentially used, but not mandatory – see section 5.1 above.

[18] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)
[19] Ibid

Named care co-ordinator allocated to you. They will oversee the process and answer any questions you have, keeping you informed of timescales and dates of meetings (the co-ordinator will seek your consent to begin the assessment process).

The care co-ordinator will start contacting the various staff who will need to input into the assessment and begin to compile all necessary information. They will also decide on the members of the multi-disciplinary team (MDT).

You may be contacted by various staff during the multi-disciplinary assessment stage. This is because they might need to work with you to undertake additional assessments to ensure they have all the information needed to make the NHS CHC eligibility decision.

Once the multi-disciplinary assessment has been completed, you will be invited by the care co-ordinator to attend a meeting with the MDT where the Decision Support Tool (DST) will be completed. The Welsh Government's guidance (the National Framework) instructs staff that you should be able to contribute fully to the discussions about your needs and provide your views on the DST judgements.

It is at this DST stage that a recommendation will be made as to whether or not you qualify for NHS CHC funded services.

A written explanation of the recommendation about your NHS CHC eligibility will be sent to you. The care co-ordinator will arrange to meet you to discuss what will happen next, including what action you can take if you are unhappy with the decision.

Arrangements will be made to set up your NHS CHC services if you are eligible.

Your needs will be reviewed again, once you have been receiving the services for a few months – see section 12 for further information on the review process.

If you are not eligible for NHS CHC, any other services which you are entitled to must be put in place – see section 13. If you want to pursue a review of the decision that you were not eligible for CHC, see section 9.

5.9 How quickly should services be put in place?

The National Framework includes information on the expected timescale for the completion of the whole eligibility process – i.e. the completion of all assessments that inform NHS CHC decision-making and the subsequent agreement of a care package. It advises that:

"Care packages must be in place no later than **8 weeks** from the point that it was considered an individual may have a primary health need and be entitled to receive CHC. Extension of the timeframe is only acceptable where further rehabilitation is required. It is not acceptable to extend this period due to the CHC eligibility process".

In 'fast track' cases this timescale will be much shorter – see below.

5.10 'Fast tracking' for immediate provision of NHS CHC

You may be eligible for urgent consideration and 'fast tracking' of your CHC eligibility if:

- you have a rapidly deteriorating condition and may be approaching the end of your life; *or*
- there has been "a catastrophic event where professional judgement indicates that the individual has evidently developed a primary health need".

Local Health Boards (LHBs) "**must have a robust fast track process in place to complete the assessment process within two days**"[20].

[20] Ibid

Such changes in your condition could be observed while you are in hospital or by staff caring for you at home or in a care home. If this happens, they should contact an 'appropriate clinician'[21] and ask them whether it would be appropriate for NHS CHC provision to be fast tracked for you.

Decisions to 'fast track' should be made on a case by case basis and the completed fast track assessment should be supported by a prognosis. Strict time limits basing eligibility on a specific 'expected length of life remaining' should **not** be imposed.

Where an appropriate clinician recommends an urgent package of care through the fast track process, this should be accepted and put into place immediately by the LHB.

Review of your needs where a fast track decision has been made

Care should be taken to explain why a fast track decision has been made and to minimise the chance of needing to reverse it within a short time. The National Framework advises "sensitive decision-making is essential in order to avoid the undue distress that may result from an individual moving in and out of CHC eligibility within a very short period of time".

No one who has been identified as eligible for NHS CHC through the fast track process should have their funding removed without going through the usual review process set out in the National Framework – the "review should include completion of the DST by the MDT, including a recommendation on future eligibility"[22] (see sections 5.2 to 5.4 above).

5.11 Pandemic and emergency situations

The current National Framework includes a section on pandemic and emergency situations, not found in previous versions. It advises the following:

[21] The National Framework defines appropriate clinicians as those who are "responsible for an individual's diagnosis, treatment or care [and] who are registered nurses or medical practitioners. The clinician should have an appropriate level of knowledge and experience of the type of health needs to decide on whether the individual has a rapidly deteriorating condition that may be entering a terminal phase".

[22] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)

"There is an appreciation that completing a full CHC assessment in hospital during a declared emergency, such as pandemic influenza [or COVID-19], would be problematic. As CHC is an assessment of long-term needs, decisions on CHC eligibility should not take priority in these situations. The priority instead should be the safety of the patient, and ensuring they receive the care they need".

"In the event of a pandemic or other emergency situation practitioners should refer to the Welsh Government's webpage for up to date information on CHC"[23].

6 Giving consent and mental capacity issues in regard to NHS CHC

Giving consent

At the outset, staff should seek your informed consent to the CHC assessment process and the necessary sharing of personal information about you between individuals and organisations involved in your care.

If you decide not to give consent, the local authority cannot take responsibility for meeting needs that would normally be the responsibility of the NHS. Therefore, the consequences of not giving consent should be clearly explained to you.

When you lack capacity to give consent

If there is concern about your ability to give consent to an assessment and for the sharing of information, your capacity to make this particular decision should be determined according to the *Mental Capacity Act 2005*. This means taking account of the five principles of the Act and includes taking all practicable steps to help you make the decision yourself.

Note: Parts 3.1 to 3.31 of the National Framework provide further information about compliance with the *Mental Capacity Act 2005* and what is expected of health and social care professionals in these situations.

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[23] Ibid

If it is agreed that you lack capacity to give consent, staff should check whether you have appointed an *attorney* via an **LPA (Lasting Power of Attorney)** to act on your behalf on health and welfare matters[24].

If not, they should check whether someone has been appointed a 'personal welfare' *deputy* by the **Court of Protection**[25].

A partner, family member or other 'third party' **cannot** act on your behalf and give consent unless appointed to do so by either of the two ways described above.

If no one has been appointed to act in one of these ways, the person leading the assessment will be responsible for making a **'best interests'** decision on your behalf under the *Mental Capacity Act 2005*. To inform their decision, they must consult with those who have a genuine interest in your welfare. This will usually include consulting family and friends. The outcome of a 'best interests' decision should be recorded.

As touched upon above, the *Mental Capacity Act 2005* is the legislation which governs the rules to be followed where someone lacks capacity to make their own decisions and applies to anyone acting in their 'best interests'. Doctors, nurses, social workers, other health professionals and support staff have a duty to ensure they are trained in its implementation and are expected to understand it as it relates to their own responsibilities.

For further information on mental capacity and the other issues in this section, see Age UK's Factsheet 22 *Arranging for someone to make decisions on your behalf*.

7 Advocacy support in relation to NHS CHC decisions

Local Health Boards and local authorities should ensure that individuals are made aware of local advocacy services that may be able to offer advice and support.

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[24] A person appointed as attorney or deputy in relation to your property and financial affairs only, would not have the authority to make decisions about health and welfare.

[25] See above footnote.

7.1 Advocacy services if someone has capacity

You can ask a family member or friend to act as an advocate and help you make your views known during the assessment process. Alternatively, you can ask the person co-ordinating your assessment about local advocacy services. **Age Cymru Advice** can also help identify whether there are any suitable advocacy schemes in your area – see section 16 for contact details.

7.2 Advocacy when someone lacks capacity

As stated above in section 6, a close family member or friend should be consulted if a 'best interests' decision needs to be made by healthcare or social care professionals.

The National Framework advises that "regardless of whether or not [someone] lack[s] capacity, they may still wish to be supported by an advocate". Therefore, as outlined in section 7.1, a family member or friend may be able to act as an advocate, or they could seek support from a local advice organisation who may be able to offer an advocacy service.

Cases where an Independent Mental Capacity Advocate (IMCA) may be required

If an LHB (or local authority) has to make a 'best interest' decision that involves a change of residence or serious medical treatment – for example, it may be considering whether a permanent move to a care home is appropriate – and you do **not** have a family member or friend who is willing and able to be consulted during the process of reaching such an important 'best interests' decision, it has a duty under the *Mental Capacity Act 2005* to instruct and consult an **Independent Mental Capacity Advocate (IMCA)**.

The IMCA's role is to seek information about what would be in their client's 'best interests', represent those interests and challenge any decision by the LHB that appears to be against these. The *individual* is the IMCA's client, **not** the LHB.

Note: Further information about IMCAs and the *Mental Capacity Act 2005* can be found in Age UK's Factsheet 22 *Arranging for someone to make decisions on your behalf*.

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8 Arrangements if you are eligible – including locations where you may receive NHS CHC

The Local Health Board (LHB) that holds the contract with your GP practice at the time of your assessment for NHS CHC is responsible for arranging and funding your care package. There will be a manager at each LHB with responsibility for NHS CHC.

8.1 Confirmation of the decision

The LHB should tell you their decision verbally and in writing, giving clear reasons and the basis on which the decision was made. A copy of the completed Decision Support Tool should also be made available to you if you wish to see it.

Note: The LHB 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 – see section 12.

The LHB must provide a care package it thinks appropriate to meet your assessed health and social care needs and the 'outcomes' your care package aims to achieve.

Your care can potentially be provided in a range of settings (see below), though often it will be in a nursing home.

8.2 The location of care

The final decision about your care plan and location of care rests with the funding Local Health Board (LHB); however, 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. The LHB should seriously consider your preferences, alongside any risks associated with different types of care and fair access to LHB resources.

The funding provided should be sufficient to meet needs identified in the care plan, based on the LHB's knowledge of the costs of those services in their locality.

Note: If you are dissatisfied with the care package proposed by the Local Health Board and cannot resolve your concerns informally, you should be told how to access the NHS complaints procedure. See Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales* for further information.

8.3 NHS CHC in a nursing care home (or sometimes a residential care home)

Note: Some care homes provide accommodation together with personal care only, whereas others can additionally provide nursing care.

The terms 'residential care home' and 'nursing care home' are sometimes used to differentiate between the two types of home.

If you are to live in a care home and qualify for NHS CHC, the NHS makes a contract with the home and pays fees covering your accommodation, board and to meet your assessed health and personal care needs.

In most circumstances, this will be a nursing home.

The following are some issues to be aware of:

- As indicated in the previous section, if it is agreed that you should move into a care home, you do not have the right to choose either the location – i.e. the town – or actual care home, but your preferences are an important part of the evidence to be considered in reaching a decision.
- LHBs may have a contract with one or more nursing homes in the area, but your assessed needs will determine whether they are suitable. The National Framework recognises that there may be "exceptional circumstances, to be considered on a case-by-case basis, where a LHB should consider the case for a higher than usual cost [placement]".

LHBs are advised that they "must liaise with the individual and/or their representative(s) to identify the reasons for the preference [for the more expensive accommodation]. Where the need is for identified clinical reasons (for example, an individual with challenging behaviour who requires a larger room because it is identified that the behaviour is linked to feeling confined, or an individual considers that they 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 the needs and preferences of the individual with the requirement for probity with public funds"[26].

- As highlighted above, care will usually be provided in a nursing home, rather than a residential home, though this doesn't *necessarily* have to be the case. For example, if you have been awarded NHS CHC through the 'fast track assessment' and are already living in a residential home, you may have expressed a preference to remain there. However, the LHB would need to be satisfied that your assessed healthcare needs can be appropriately met in this particular residential setting. 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 resident in a 'high cost' nursing care home at the time that you become eligible for NHS CHC?

If you are already living in a nursing home when the decision to grant NHS CHC is made, you need to discuss with your LHB whether you can stay there. This is particularly relevant if your 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.

Whereas 'topping up' is legally permissible in legislation governing social care, it is not allowed under NHS legislation.

[26] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022).

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 clinical or overriding needs-based reasons for you to remain there (this could include personal needs, such as proximity to close family members "who play an active role in the life of the individual or because the individual has resided in the placement for many years so that they have strong social links with the area and it would be significantly detrimental to the individual to move them"[27]).

Any possible risks of moving you would need to be assessed before a final decision was made. For example:

LHBs "**should consider whether there are reasons why they should meet the full cost of the care package, notwithstanding that it is at a higher rate. Such reasons could include for example the frailty, mental health needs or other relevant needs of the individual which mean that a move to other accommodation could involve significant risk to their health and well-being**"[28].

The Framework also advises that "there may also be circumstances where an individual in an existing out of area placement becomes entitled to CHC and where, although the care package is of a higher cost than the responsible LHB would usually meet for the individual's needs, the cost is reasonable taking into account the market rates in the locality of the placement. LHBs should establish this by liaison with the LHB where the placement is located".

Note: If someone becomes entitled to NHS CHC and have "an existing high-cost care package, LHBs should consider funding the full cost of the existing higher-cost package until a decision is made on whether to meet [this] package on an ongoing basis or to arrange an alternative placement"[29].

If the Local Health Board (LHB) determines that there are insufficient grounds to fund an existing higher cost care home placement

The National Framework advises that:

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[27] Ibid
[28] Ibid
[29] Ibid

“Where a local health board determines, following the recommendations from the MDT [multi-disciplinary team], that circumstances do not justify their funding an existing higher cost placement or services for which they have inherited responsibility, **the LHB does have the authority to move accommodation or change provider**” (emphasis added).

However, “any decisions should be taken in full consultation with the individual concerned and confirmed in writing with reasons given. Advocacy support should be provided where this is appropriate”.

If you wished to dispute the decision you could do so using the NHS complaints procedure – see Age Cymru’s Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales* for further information.

Going to live in a care home in a different area in Wales

If you need to leave your own home, or an existing care home placement, in order to receive NHS CHC, it may seem more appropriate for you to move to a home closer to relatives who live in a different LHB area. As touched upon above, you may propose this but cannot assume it will be acceptable to the funding LHB.

If it is agreed you can live in a care home in a different LHB area, your care home fees remain the **responsibility** of the LHB that **initially** decided your eligibility.

Once you move into the care home, you need to register with a local GP practice. Once registered, any other NHS services or treatment unrelated to the reason for your placement in the care home become the responsibility of your GP practice’s LHB – i.e. the LHB in the new area.

Moving to a different area within the UK

If you wish to receive care in England, Scotland or Northern Ireland, there would need to be a discussion between your funding Local Health Board (LHB) and the relevant health body in your chosen country (for example, the Clinical Commissioning Group (CCG) if it was in England).

As with moves within Wales, the LHB which initially decided on your eligibility retains responsibility for your care. Joint guidance between the Welsh Government and the NHS in England states that:

"Where a CCG or LHB arranges a package of NHS Continuing Healthcare (CHC), (other than a package that is only NHS funded nursing care), the placing body will remain responsible for that person's CHC until that episode of care has ended"[30].

8.4 NHS CHC in your own home

The LHB will be responsible for arranging an appropriate care package to meet your assessed health and personal care needs in your home environment. As part of this, the LHB will be financially responsible for meeting **"all assessed health and associated social care needs"**.

This could include equipment provision and help with daily domestic tasks, such as food preparation, shopping or washing up.

Note: There is, however, a range of everyday household costs that are expected to be covered by your personal income or welfare benefits, "including food, rent/mortgage interest, fuel and water, clothing and other normal household items"[31].

Additional services from the local authority social services department if you receive NHS CHC in your own home

The National Framework recognises that people may have additional support needs which it "may be appropriate for the local authority to address subject to [Social Services and Well-being (Wales) Act 2014] provisions and eligibility guidance".

This might include "assistance and advice regarding property adaptation…deputyship or appointeeship services, safeguarding concerns, carer support or services required to enable the carer to maintain his/her caring responsibilities"[32].

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[30] England / Wales NHS Cross-border Healthcare Services: Statement of values and principles, Welsh Government, November 2018

[31] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022)

[32] Ibid

If you were previously receiving direct payments, you may be able to retain some of this for elements of care which the local authority social services department is still responsible (though, in general, you will not be able to get direct payments when receiving CHC – also see section 8.7 below, however).

You may not always be able to receive NHS CHC services in your own home, rather than a care home

This is often a more complex care package to arrange and local resources may influence whether care can be provided at home.

LHBs are able to take "comparative costs and value for money into account" when determining the model of support to provide you with, though "they must not set arbitrary limits on care at home packages based purely on the notional costs of caring for an individual in a home"[33].

They should also consider a range of different solutions, such as assistive technology, to allow someone to remain in their own home, without costs being prohibitive.

Cost has to be balanced against other factors on a case-by-case basis, such as an individual's desire to continue to live in a family environment.

If a family member will also be providing care

If a family member is to provide care as an integral part of the care plan, the LHB should consider meeting training needs that the carer may require to undertake this role.

In particular, they may need to arrange a risk assessment to ensure the carer is able to participate in the care allocated to them and what needs to be put in place to protect the individual and the carer. The Local Health Board should let the carer know of their right to ask the local authority for a **carer's assessment**. This may result in the provision of services to help support the carer in their caring role.

Although local authorities have a statutory obligation for carers, the LHB may also need to provide additional support to care for the individual during periods where the carer has a break from their caring responsibilities. They will need to assure carers of the availability of this support when required.

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[33] Ibid

8.5 NHS CHC in a hospice

Hospice care may be appropriate if you are reaching the end of your life. However, the Welsh Government's National Framework recognises that there will be circumstances in which you may wish to remain at home at this time.

8.6 Additional privately funded services

Sometimes people may want to use additional privately funded services as well as receiving NHS CHC services. This will need to be considered by the LHB and the National Framework advises that:

'Additional services' "are defined as those which are over and above those detailed in the care plan".

"Such personal contribution arrangements must never be utilised as a mechanism for subsidising the service provision for which the LHB is responsible. Any decision to purchase additional private services must be borne purely through personal choice and not through a lack of appropriate NHS or LA [local authority] provision".

If you have any concerns in this regard about your care package, the "LHB should offer to review" the services[34] – see section 12 below.

The Framework does recognise that there will be instances where an additional private service will be legitimate.

Examples

- Someone who is "assessed as requiring, and is provided with, one NHS physiotherapy session a week [may wish] to purchase an additional session privately".

[34] Ibid

- "An individual may wish to purchase an additional visit each day from the care provider. The LHB must firstly consider whether it should meet the full costs of the care package. If after review, the LHB is satisfied that the services it has commissioned are appropriate to meet the individual's identified needs, the person may choose to initiate a private arrangement with the care provider. In such a case the LHB will need to liaise with the individual and the care provider to ensure that all parties are clear as to the additional support to be provided in the privately funded visits"[35].

8.7 Relationship between NHS CHC and direct payments

If you were living at home prior to being eligible for NHS CHC and were receiving direct payments from your local authority

NHS CHC cannot be provided through the direct payments system (though it is possible this may change in the future – see below). However, LHBs may be able to arrange services to maintain a similar package of care.

The National Framework advises that "where an individual whose care was arranged utilising Direct Payments becomes eligible for CHC funding, the LHB must work with them in a spirit of co-production. Although Direct Payments will no longer be applicable where an individual has a primary health need, this should not mean that the individual loses their voice, choice and control over their daily lives".

It may also be possible to maintain personnel previously used for delivery of the care provided via direct payments:

"When a person develops a primary health care need, the health board must work to maintain continuity of personnel delivering care, where the individual wishes this to be the case and it can contribute to meeting their needs. The health board could employ [personal assistants or other] staff (either directly or via an agency)…previously employed by the individual under direct payments"[36].

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[35] The National Framework goes on to state that: "Although NHS funded services must never be reduced or downgraded to take account of privately-funded care, the LHB and the organisations delivering NHS funded care should, wherever clinically appropriate, liaise with those delivering privately-funded care in order to ensure safe and effective coordination between the services provided. The care plan should detail effective risk management, appropriate sharing of information, continuity of care and co-ordination between NHS funded and privately funded care".

[36] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022).

Welsh Government consultation on extending direct payments to NHS CHC

As discussed above, at the present time, a person receiving NHS CHC cannot receive direct payments to enable them to make arrangements to meet those needs.

However, in a consultation that ran between August 2022 and November 2022, the Welsh Government made a proposal to amend the *NHS (Wales) Act 2006*, to include:

"A power for local health boards to make direct payments to adults (or their representative) who have been determined to qualify for NHS-funded continuing health care. Giving this power to health boards would allow them to make direct payments to people for their CHC, where the person wished to have these. People would then be able to purchase healthcare and care and support that best met their needs"[37].

The rationale for this proposed change was outlined as follows in the consultation:

"Over a number of years, concerns have been raised that transferring from local authority direct payments for care and support to a CHC package, arranged by the NHS to meet all health and care needs, compromises people's control over their care arrangements. Some people with complex health conditions are choosing to refuse assessments for CHC or declining to take up CHC packages. Reasons for this include not wanting to lose the flexibility they have through direct payments, as this may interrupt their existing arrangements for care; concerns about this impacting on other benefits and support received; and the change contributing to a reduced sense of independence"[38].

9 What happens if you wish to challenge a decision?

You can challenge a decision where you are dissatisfied with the LHB in regard to:

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[37] Welsh Government Consultation Document Proposals for primary legislation in relation to children's social care, Continuing Health Care, mandatory reporting and regulation and inspection (Date of issue: 17 August 2022. Action required: Responses by 7 November 2022).

[38] Ibid

- **the procedure followed in reaching their NHS 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.

Note: If you are dissatisfied with issues other than the above – for example, issues such as the type, location or content of your care package – you should be told how to raise these using the NHS complaints procedure. This is explained in Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales*.

You would also use the above route if you felt that you had been 'screened out' of the NHS CHC eligibility process too early – for example, if the Checklist Tool was applied and the results indicated that your needs were not sufficient to go through to a full CHC assessment, but you felt this was an unfair decision.

9.1 The Review process for challenging decisions

There are two stages in the review process, as outlined below in sections 9.2. and 9.3:

- a **'Local Resolution'** stage; *and*
- an **Independent Review Panel** stage.
- You can also contact the **Public Services Ombudsman for Wales** if you remain unsatisfied, effectively adding a third stage to the process.

9.2 Local Resolution

If you or your family approach the relevant LHB for a review of their decision, it will initially be dealt with via a local resolution process.

This will involve a 'peer review' of the decision, undertaken by an external team "from another directorate or LHB". This should be set up "as soon as [it] is practicable to do so"[39].

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[39] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022).

The local review process, including timescales, should be made publicly available by the LHB and sent to anyone who requests a review of a decision.

If the issue cannot be resolved at the local resolution stage, it should be elevated to the Independent Review Panel if:

- Local resolution and peer review "indicates that there is an element of doubt";
- "the individual or their representative has significant additional information to present"; *or*
- "exceptional circumstances apply"[40].

Note: "In all cases where a decision not to convene a panel is made, a full written explanation of the basis of its decision should be provided to the individual and/or their representative, together with a reminder of their rights under the NHS Complaints Procedure"[41] (see Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales* for further information).

9.3 The Independent Review Panel (IRP) stage

As with the local resolution process, the Independent Review Panel's remit does not cover aspects such as reviewing content of care plans, only the decision-making process relating to whether someone will be eligible for NHS CHC.

The National Framework advises that LHBs must have access to a standing Independent Review panel, comprising as a minimum:

- an independent chair
- a representative from an LHB and
- a representative from a local authority.

The panel "will also have access to expert opinion"[42].

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[40] Ibid
[41] Ibid
[42] Ibid

The Independent Review Panel process should normally be completed within **four weeks** of the request to initiate the panel being received. This period begins "once any action to resolve the case informally [i.e. the local resolution stage] has been completed, and should be extended only where unavoidable because of exceptional circumstances"[43].

Note: "While the review procedure is being conducted any existing care package, whether hospital care or community health services, should not be withdrawn until the outcome of the review is known"[44].

The IRP's recommendation

The IRP is required to make a recommendation to the LHB in light of its findings. Its role is advisory, **but the LHB should accept its recommendations in all but exceptional circumstances**.

In all cases the outcome of the IRP review should be communicated to you in writing, together with the reasons for the conclusions which have been reached.

Can the LHB refuse to convene an Independent Review Panel

The National Framework advises that:

"The LHB has the right to decide in any individual case not to convene a panel. It is expected that such decisions will be confined to those cases where the patient falls well outside the eligibility criteria or where the case is very clearly not appropriate for the panel to consider. Before taking a decision the LHB should seek the advice of the chair of the review panel. In all cases where a decision not to convene a panel is made, the LHB should give the patient and their family or carer a full written explanation of the basis of its decision, together with a reminder of their rights under the NHS Complaints Procedure" (again, see Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales* for further details).

[43] Ibid
[44] Ibid

9.4 Escalating your case to the Public Services Ombudsman for Wales

If the original decision is upheld by the Independent Review Panel and you still wish to challenge it, you can contact the Public Services Ombudsman for Wales and ask if they will examine your case – see section 16 for their contact details.

9.5 Funding your care once you challenge the LHB's decision

Once the LHB tells you that you are not eligible, this decision remains in place unless or until the local resolution process or Independent Review Panel recommends that you should be eligible. You should receive appropriate care while awaiting the outcome of the review, but may have to contribute towards the cost of your care package during this time.

Your circumstances when you ask for a review will affect who is responsible for arranging and/or paying for your care. The local authority and/or NHS may be involved, or you may already be arranging and/or funding your own care.

10 NHS CHC eligibility – refunds for unreasonable delays

Note: This section has information in regard to possible reimbursement of care costs where there has been a delay regarding a current NHS CHC eligibility decision – if you are seeking reimbursement in regard to a *retrospective* claim, see section 14 instead.

Reimbursement for a delay in reaching an initial NHS CHC eligibility decision

The National Framework advises that the Local Health Board (LHB) has a legal responsibility to fund care from the point that it "confirms the MDT's [multi-disciplinary team's] advice on eligibility" (see section 5.4 and 5.5 above).

"**However, the principles of good public administration dictate that, if an individual has paid for their care in the interim, they should be reimbursed**".

The reimbursement "would normally commence from the date on which the MDT met and made its determination of eligibility. However, the MDT should advise the LHB if they can, in their reasoned professional judgement, identify a date at which the primary health need became evident and the individual should be reimbursed accordingly"[45].

Note: The Framework doesn't address reimbursements for a delay in the MDT carrying out (or finishing) an assessment (rather, it focuses on the LHB being responsible for the delay once the MDT have reported to them). If you feel that you have paid an excess amount for care, due to a delay with assessments and the MDT reaching decisions, you could request that the LHB provides a reimbursement for costs you wouldn't otherwise have incurred (on a similar 'principle of good public administration' basis, as outlined above). Section 5.9 has information on how long the whole CHC process should take.

If you are unhappy with the way the LHB handles this request, you could use the NHS complaints procedure – see Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales* for further information.

Reimbursement of costs when challenging a decision?

The Framework does not appear to include guidance in regard to reimbursement where costs have been incurred by an individual during the local review or Independent Review Panel (IRP) stages of challenging a decision.

However, if you are in this situation, you could request that the LHB provides a reimbursement for costs you wouldn't otherwise have incurred, on the same basis as the 'Note' above.

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[45] Ibid

11 Effect on state benefits of NHS CHC

Disability benefits

Notify the Department for Work and Pensions via their **Disability Service Centre** if you get a disability benefit and are due to receive NHS CHC funding – see section 16 for contact details. The main disability benefits are *Attendance Allowance (AA)*, *Disability Living Allowance (DLA)* or *Personal Independence Payment (PIP)*.

If you will receive NHS CHC in a **nursing home**, 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 will receive NHS CHC in a **residential 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 will continue to live **at home** with an NHS CHC care package, you can continue to receive these disability benefits. You can check that you are receiving them at the appropriate level.

State Pension and Pension Credit

State Pension is not affected by eligibility for NHS 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).

12 Regular reviews of NHS CHC eligibility decisions

If you have been considered for NHS CHC and the NHS is providing or funding any part of your care package, the following reviews should be carried out:

- As a minimum there will need to be an initial review of the care plan **within three months of the care package first being provided** (unless this is triggered earlier by the individual, their representative, or the care provider).

- Following this, a further case review should take place **annually**, as a minimum (though "where an individual's condition is anticipated to deteriorate, more regular review[s] may be necessary"[46]).

Note: The National Framework advises that you and/or your representative and the care provider "must be provided with the contact details of a named care co-ordinator, so that any changes in [your] condition or circumstances can be promptly addressed".

You, and where appropriate a family member or carer, must be fully involved in the review process. You should be informed about why the review is required, where it will take place, and which professional staff will be involved. You should also be given the "opportunity to re-assess [your] own needs and be offered appropriate support to do so"[47].

12.1 Carrying out the review

"The most recently completed DST [Decision Support Tool] should be available at the review and used as a point of reference to identify any potential change in needs. Where there is clear evidence of a change…to such an extent that it may impact on the individual's eligibility for CHC, the LHB should arrange a full reassessment".

"Where reassessment of eligibility for CHC is required, a new DST must be completed by a properly constituted MDT"[48], as per the process outlined in sections 5.3 and 5.4 above.

Note: The National Framework stipulates that "LHBs should ensure an individual's needs continue to be met during [the] reassessment of eligibility process".

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[46] Ibid
[47] Ibid
[48] Ibid

12.2 If the review indicates your needs have changed

You may continue to be eligible for NHS CHC or, alternatively, if you are judged to no longer qualify, you may be eligible for other types of care instead – see section 13 below for further information.

However, it is important to note that any decision to remove eligibility should be undertaken **jointly** by the LHB and relevant local authority.

Any "risks and benefits to the individual of a change of location or support (including funding) should be considered carefully before any move or change is confirmed".

This would include weighing up whether improvements in a progressive condition might only be temporary and thus CHC shouldn't be withdrawn. For example, the National Framework states that the MDT should advise "if, in their professional opinion, any stabilisation of a progressive condition…is likely to be short-term. In such cases commissioners should balance the contribution of well-managed need to the current assessment and the benefits to the individual of continuity of care provision".

The review information should be used to inform your updated care plan, a copy of which should be provided to you.

If you are unhappy with the results of the review, you may request a re-assessment of the decision. If your complaint concerns the decision-making process relating to the application of the primary health need test, then see section 9 above, otherwise you will need to follow the NHS complaints procedure (see Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales*).

Note: There should be a dispute resolution process in place for use when the LHB and local authority disagree about eligibility – where this happens "**current funding arrangements should remain in place until the dispute has been resolved**".

Also, "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 funding"[49].

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[49] Ibid

13 Your care package if you are not eligible for NHS CHC

If you are found to not be eligible for NHS CHC, but an alternative package of care is required (for example, weekly NHS funded nursing care in a nursing home, or a joint package of care in the community), the lead role will normally lie with the **local authority**. The NHS will work **alongside** the local authority to develop and implement an appropriate care plan.

Needs identified during your multi-disciplinary assessment should inform the subsequent care plan. You will be **means-tested** for services that are the responsibility of the local authority social services department.

NHS services that may be provided in their own right, regularly or on an occasional basis, alongside care from social services include:

- Care provided in a nursing home by a registered nurse – **i.e. the weekly NHS-funded nursing care payment** (covered below in section 15).
- Rehabilitation and recovery services, such as speech therapy.
- Assessment and/or support from community-based NHS staff (known as 'Community health services'), such as district nurses, continence nurses or specialist diabetic nurses.
- Palliative care services.

For more information about care assessments and charging procedures when care services are provided by a local authority, see Age Cymru's other factsheets on these topics, including:

- Factsheet 41w *Social care assessments for older people with care needs in Wales;*
- Factsheet 46w *Paying for care and support at home in Wales;* and
- Factsheet 10w *Paying for a permanent care home placement in Wales*.

14 Retrospective challenges to NHS CHC decisions

Note: Retrospective reviews are "different from an appeal against a current CHC assessment and decision on eligibility"[50] (for a current case, see section 9 of this factsheet for further information).

A request for a retrospective review can be made when someone believes that they may have been wrongly charged for care, due to their potential eligibility for NHS CHC not being considered adequately at the time. For example, 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.

14.1 Will your case qualify for a retrospective review?

The National Framework sets out the process, as follows:

- Your case can only be looked at if "the end of the claim period to be considered will be **no longer than 12 months** before the date of [your retrospective review] application.
- "If the claim period is after a MDT/Independent Review Panel (IRP) decision of no eligibility, the period to be reviewed may go back to the date of the decision as long as it is no longer than 12 months".
- "If the claim period is prior to a MDT/IRP decision, no longer than a 12 month period will be reviewed".

[50] Ibid

Exceptional circumstances

"Applications outside of the stated claim period may be considered in exceptional circumstances where there is justification. Such circumstances can include for example, the claimant suffering critical illness…or living abroad"[51].

Note: The National Framework also stipulates that you must, "**within 5 months** of registering" your retrospective claim, "provide evidence of proof of fees paid to [a] care home or domiciliary agency [and] where the claimant is not the patient, their right to make the claim on the individual's behalf" – see section 14.2 below.

14.2 Who can submit a claim?

In addition to the actual person concerned, who feels they missed out on CHC funding, the following people can make a retrospective claim:

- A person "authorised by the individual to receive reimbursement on his/her behalf".
- Someone who holds "a registered…Power of Attorney or who is a Court-appointed deputy for an individual who lacks mental capacity".
- Where the care user is now deceased, "an executor named in the Grant of Probate in respect of the deceased's estate or an administrator named in the Grant of Letters of Administration of the estate"[52].

14.3 Who should you contact?

You should make your request for a retrospective review to the relevant LHB which covers the area where the care took place. The National Framework advises that "each LHB should publish a point of contact to which retrospective claims may be submitted".

NHS 111 Wales (see section 16 for contact details) can advise you of the correct LHB if you are unsure. Alternatively, you can obtain further information from their website (see the link above, in section 4.3).

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[51] Ibid
[52] Ibid

14.4 Assistance with your claim

You may seek advice from the LHB itself, who should provide appropriate information to assist you to navigate through the process.

Advocacy

Alternatively, you could seek assistance from a local advice organisation – in particular, one that can provide an advocacy service.

You can contact **Age Cymru Advice** for information on whether there are any independent advocacy services in your area – see section 16 below for contact details.

Your local Community Health Council (CHC) may also have some experience in this area and be able to offer you advice. CHCs are a statutory and independent voice in health services in Wales. They should work to enhance and improve the quality of local health services. Each CHC runs a Complaints Advocacy Service – again, see section 16 for contact details.

Note: Is legal representation required?

You do **not** have to use a solicitor. You can go through the process yourself and this will be free of charge.

The process for making a claim can be complicated, so some people choose to appoint a solicitor to assist them. If you do use a solicitor, it will be important to find one who is experienced in this particular type of work.

You should discuss their fees with them first before you ask them to take on your case.

Also, it's important to note that the National Framework says "if eligibility is found [in a retrospective case], reimbursement will **not** cover the costs of any legal fees incurred" (emphasis added).

You might also have heard about 'claims management companies' who offer a service to reclaim care fees that potentially should have been met via NHS CHC. You should be aware that although these companies may be offering a 'no-win-no-fee' deal, it is likely that they will charge a 'success' fee which will be a certain percentage of any sum recovered (and possibly a substantial percentage).

14.5 How is the claim processed?

The National Framework outlines the following steps:

- "A claim form (including a request for the claimant's views)…and an Information Booklet are sent to the claimant" by the LHB.
- 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 – see section 14.2 above).
- On receipt of the proof of payment and legal authority to make the claim, "requests are made to the appropriate care providers for records"[53].
- A 'chronology of need' is then produced from the records available "and the claimant's views".
- There is then a two-stage process which the LHB must use to conduct the retrospective review.

The two stages of the retrospective review

- **Stage 1 Review**

The Checklist (as outlined in section 5.1 above) will be applied to the 'chronology of need' to identify any triggers for full consideration of eligibility for CHC.

"If there are no triggers for consideration of eligibility, the case is closed at this point". An IRP (Independent Review Panel) Chair must ratify if the recommendation is 'no eligibility' or 'partial eligibility'. If the Chair "disagrees with the recommendation of partial or no eligibility, then the case should proceed to Stage 2 on the basis of the highest level of eligibility suggested e.g. full rather than partial; partial rather than no eligibility".

"Claimants should be sent a written explanation of the outcome of the application of the Checklist to their claim"[54].

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[53] The National Framework states that: "in accordance with the all-Wales protocol for obtaining records, all agencies are allowed a maximum of 3 months to provide the records or to inform LHBs that they have been destroyed, lost or are unavailable for any other reason".

[54] Continuing NHS Healthcare: The National Framework for Implementation in Wales (originally published July 2021; Version 2: March 2022).

Note: The Framework does also state that "if the claimant…is already eligible for FNC [NHS Funded Nursing Care] or CHC, the case should proceed directly to Stage 2, without the need for a Stage 1 Review.

- **Stage 2 Review**

The National Framework explains that where triggers for CHC "are found for all or part of the period" the Stage 1 'chronology of need' is transferred to a Stage 2 review. "All other records are added" and this document is then used by the clinical reviewer "to analyse the evidence and make a recommendation on eligibility. This is done by analysing the information in the chronology using the 4 key indicators of Nature, Intensity, Complexity and Unpredictability, applying the primary health need approach for the claim period" (the indicators are detailed in section 4.2 above).

Once the analysis has been completed, the retrospective review document "will be peer reviewed by a different clinician to ensure the recommendation is robust, based on the evidence available and that the criteria have been consistently applied. If the clinicians do not agree, the case will be referred to the Independent Review Panel (IRP)" (see section 9.3 above for information on the IRP).

The National Framework states that in cases where no eligibility is found, "the document will be peer reviewed by at least one further different clinician to ensure that…evidence supports the recommendation made".

Results of the retrospective review

The eligibility recommendation will be either of the four options below:

Matching	In these cases, "the period of eligibility found matches the claim period in totality". As such, this type of case will proceed towards full reimbursement of fees for the relevant period.
Partial	This is where "eligibility is found for part of the claim period". You will be invited to a meeting where discussion will take place "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 move on to reimbursement for the relevant period. If agreement cannot be reached, the case will be sent to the IRP for further consideration.
No eligibility	This is where review indicates that there is no eligibility for any part of the claim period. However, you will still be invited to a further meeting to provide an "opportunity for further explanation of CHC criteria and to check that the…lack of evidence on eligibility" has been understood.
Panel case	This will occur where the reviewer "has been unable to make a decision as the information available is [too] complex"[55]. An IRP will be convened in these circumstances to further examine the case and reach a decision. You will be invited to attend and participate fully in the panel meeting.

14.6 What will happen if your claim is successful?

The National Framework states that:

"If eligibility is demonstrated for either the full or part period of the [retrospective] claim, the principles of good public administration demand that timely restitution be made".

You will receive reimbursement of the care fees paid, during the period identified in the retrospective review as when you should have been eligible for NHS CHC funding.

Note: You won't receive any compensation – it is just reimbursement of care fees which were paid.

14.7 If you are dissatisfied with how your claim is treated

If you are dissatisfied with the way your retrospective NHS CHC claim has been handled, you can make a complaint using the NHS complaints procedure. This is explained in Age Cymru's Factsheet 66w *Resolving problems and making a complaint about NHS care in Wales*.

[55] Ibid

If you remain unhappy with the outcome following this, you could choose to escalate your case to Public Services Ombudsman for Wales – see section 16 for contact details.

15 Weekly NHS-funded nursing care contribution for people resident in a nursing home

15.1 NHS-funded nursing care – overview

The NHS is responsible for meeting the registered nursing costs of all residents in care homes that provide nursing care (nursing homes)[56].

This is known as the NHS funded nursing care contribution and you should receive it if you are not eligible for fully funded NHS CHC, but have still been assessed as requiring certain services from a registered nurse in providing, planning or supervising elements of your care.

Important: If you may be eligible for fully funded NHS CHC, this possibility needs to be considered first. Eligibility for the weekly NHS-funded nursing care should only be considered instead, *once it has been agreed that you are **not** eligible for NHS CHC*.

What services do registered nurses provide?

Services provided on a regular basis by a registered nurse are likely to involve:

- provision of nursing care;
- planning and reviewing a care plan;
- monitoring and reviewing medication needs; and/or
- identifying and addressing potential health problems.

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[56] Residential homes do not employ registered nurses because their residents receive nursing and other health related care from NHS staff based in the community. Consequently, these homes do not receive an NHS-funded nursing care contribution from their LHB.

15.2 How will the rest of the nursing home fees be covered?

The NHS-funded nursing care contribution is only for the registered nursing part of someone's care. It does not include time spent by any other staff who are involved in your personal care and, as such, the NHS funded nursing care contribution will only meet a relatively small part of the overall care home fees.

All other aspects of the care package will be paid for by the person themselves, if self funding, or alongside funding assistance from their local authority social services department, should the authority's financial means test indicate that the person doesn't have sufficient resources to fully self fund (see Age Cymru's Factsheet 10w *Paying for a permanent care home placement in Wales* for further information).

You may need to ask for clarification regarding the NHS funded nursing care contribution if it isn't clearly separated from the main fee in the information provided to you about the fee and how it has been worked out.

15.3 Welsh Government guidance on the weekly NHS-funded nursing care contribution

Guidance on the weekly NHS-funded nursing care contribution for people resident in a nursing home dates back to 2004, though in the current National Framework the Welsh Government states that it will be "subject to review during the lifetime of this Framework".

At the time of writing – November 2022 – the current guidance is:

National Assembly for Wales Circular (NAFWC 25/2004): NHS Funded Nursing Care in care homes, 2004

Note: There is a link to it within the National Framework, or it can be accessed at:

www.wales.nhs.uk/documents/whc-2004-024-e.pdf

15.4 How much is the NHS-funded nursing care contribution?

The NHS funded nursing care contribution tends to be updated for each financial year, though there is sometimes a delay in it being announced.

The figure for the financial year April 2022 to March 2023 is **£201.74 per week**.

The figure is the same for the whole of Wales.

The NHS does not make these payments to you. Instead, it makes them either:

- directly to the nursing home; or
- to the local authority, if the contract for providing your care and accommodation is between the local authority and the nursing home.

Note: If you are reading this factsheet from April 2023 onwards, you may wish to speak to your Local Health Board (LHB) for information on whether the figure has been updated (see section 4.3 above for information on finding their contact details). You could also contact Age Cymru Advice – see section 16.

15.5 How is eligibility for NHS-funded nursing care decided?

As noted at the beginning of this section, it is not appropriate to consider your need for NHS-funded nursing care in a nursing home until it has first been agreed that you are not eligible for NHS CHC and that a place in a nursing home is the best option for meeting your needs.

If you are found not eligible for NHS CHC following a full assessment, your need for registered nursing care should be recorded on the Decision Support Tool (DST) by the multi-disciplinary team (MDT). This information should then be used to draw up your care plan.

15.6 Regular reviews of NHS-funded nursing care needs

A case review should be undertaken no later than **three months** after the initial eligibility decision.

This is to reassess your care needs, ensure they are being met and confirm that a nursing home place is still appropriate.

Following this three-month review, further reviews should take place at least **annually**. It may be clinically appropriate to have more frequent reviews and one should be arranged if your healthcare needs change significantly.

Note: The National Framework advises that LHBs "must ensure that the individual, their family/representative and care home provider have the information and contacts available to enable them to identify changes in need which indicate a timely review is required".

As part of each review, your potential eligibility for NHS CHC should always be considered.

If you self-fund your place in a nursing home, you need to ensure you have the three month and annual reviews. The care home manager should be aware of the LHB arrangements for nursing care reviews.

15.7 Hospital stays when you are receiving the weekly NHS-funded nursing care contribution

If you are admitted to hospital, the Local Health Board (LHB) does not pay nursing care costs to the care home during your hospital stay.

However, you can ask the LHB to pay a retainer to help safeguard your care home place during your time in hospital. Welsh Government guidance advises that:

A payment equivalent to the NHS funded nursing care rate should "be made by the NHS to the care home to retain a resident's bed for a period (normally up to six weeks, but this may be varied to co-ordinate with local authority contractual arrangements where appropriate) during periods of hospital admission".

"The Local Health Board and/or the local authority, where appropriate, will make arrangements with the home manager for the latter to inform them when such admissions occur, and when the resident returns to the home".

There must also be "mutual agreement between the local authority and the Local Health Board, in consultation with the resident and/or an appropriate representative, before the decision is made that a placement need no longer be retained, and funding withdrawn. The effect of this on delaying the resident's discharge from hospital must be taken into account".

"Any changes in needs following hospitalisation will [also be an important factor] in determining any potential change in care home requirements"[57].

15.8 Effect on state benefits of receiving the weekly NHS-funded nursing care contribution

Disability benefits

If you are fully self funding the nursing home placement, except for the weekly NHS-funded nursing care payments, your eligibility for disability benefits such as Attendance Allowance (AA), Disability Living Allowance (DLA) or Personal Independence Payment (PIP) shouldn't be affected.

If you are receiving AA, DLA (care component) or PIP (daily living component) and the local authority (LA) is assisting towards the rest of the nursing home fees not covered by the NHS contribution, then payment of each of the benefits will normally stop after four weeks of being resident in the home.

State Pension and Pension Credit (PC)

State Pension is not affected by receiving the weekly NHS-funded nursing care contribution, though it is taken into account as income if you ask the LA for help with the rest of the nursing home fees not covered by the NHS contribution.

You may still be able to receive PC if you live in a nursing home. Entitlement is not affected by receiving the weekly NHS-funded nursing care contribution, but a number of other factors may alter your entitlement – for example:

- if you have a partner who will remain living at home, *or*
- you lose the severe disability element of your PC award due to AA, DLA (care component) or PIP (daily living component) being stopped as a result of receiving LA assistance towards the nursing home fees – see above.

[57] Welsh Health circular and National Assembly for Wales circular (NAFWC 25/2004 / WHC (2004)024): NHS Funded Nursing Care in care homes Guidance, April 2004

Note: Age UK's Factsheet 48 *Pension Credit* and Age Cymru's Factsheet 10w *Paying for a permanent care home placement in Wales* have further information on the above topics.

15.9 Which Local Health Board (LHB) has responsibility for your NHS-funded nursing care contribution?

The LHB which covers the area where your nursing home is located will have responsibility for the NHS-funded nursing care contribution.

If you move to a nursing home in a *different* LHB area in Wales, you will become the responsibility of that LHB when you register with a GP there.

15.10 The NHS-funded nursing care contribution if you move elsewhere in the UK

England

Welsh Government guidance provides information on what will happen if you require the weekly NHS-funded nursing contribution, but will be moving from Wales to England:

"The basic principle is that the arrangements for and level of funding applicable in the destination [Clinical Commissioning Group (CCG)] will apply" – for example, the weekly figure in England is different. "The level(s) of funding will be that in operation in the destination [CCG]"[58].

Note: CCGs in England are equivalent to LHBs in Wales.

- **Self-funders** – the English CCG "responsible for the care home should carry out the [eligibility] determination (if possible, normally prior to entry to the care home) and fund the nursing care at the appropriate rate". "If this is not possible, the LHB of origin will undertake an assessment to determine that NHS Funded Nursing Care is required, and inform the destination [CCG]".

[58] Ibid

- **Local authority funded residents** – "the assessment should be carried out in Wales (in conjunction with the Welsh LA), by the Welsh LHB. The responsible English [CCG] where the care home is located will be notified, confirming that the person requires care from a registered nurse. The English [CCG] will need to arrange for a further assessment and determination to be undertaken within 28 days of admission, to identify the appropriate band of nursing care. The English [CCG] will fund the nursing care at the appropriate rate, and inform the Welsh LA, which will agree the accommodation and personal care costs of the placement with the care home concerned"[59].

Scotland or Northern Ireland

According to the Social Care Institute for Excellence, when a "cross-border placement is between Wales and Scotland [or] Wales and Northern Ireland...the first [local] authority's health service will retain responsibility for the costs of NHS-funded nursing care"[60].

16 Useful organisations

Age Cymru Advice

Free and confidential information and advice on matters affecting the over 50s in Wales.

Tel: 0300 303 44 98

E-mail: advice@agecymru.org.uk

Website: www.agecymru.org.uk/advice

Age Cymru organisations (local)

Your local Age Cymru may be able to provide advice and support on a range of issues. **Age Cymru Advice** can provide details of your local Age Cymru (see above), or visit the Age Cymru website at:

www.agecymru.org.uk/local

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[59] Ibid

[60] Cross-border placements: Issues that may arise with cross-border placements, Social Care Institute for Excellence website: www.scie.org.uk/publications/guides/56-cross-border-placements/issues.asp (last accessed 29 November 2022).

Citizens Advice Bureaus (CABs)

National network of free advice centres offering confidential and independent advice, face to face or by telephone.

Tel: 0800 702 20 20

Details of your nearest CAB can be found at:

www.citizensadvice.org.uk/wales

Community Health Councils (CHCs)

CHCs are a statutory and independent voice in health services in Wales. They work to enhance and improve the quality of local health services. For information on the CHC covering your area, see the NHS 111 Wales website at:

https://111.wales.nhs.uk/localservices/communityhealthcouncils

Disability Service Centre

The Disability Service Centre is part of the Department for Work & Pensions and can advise on claims for Attendance Allowance, Disability Living Allowance or Personal Independence Payment.

Website: www.gov.uk/disability-benefits-helpline

Healthcare Inspectorate Wales (HIW)

The HIW is the independent inspector and regulator of NHS healthcare and independent healthcare organisations in Wales.

Tel: 0300 062 8163
E-mail: hiw@gov.wales
Website: www.hiw.org.uk

NHS 111 Wales

NHS 111 Wales can provide contact details for local services and telephone or web advice on health issues and common illnesses.

Tel: 111

Website: www.111.wales.nhs.uk

Older People's Commissioner for Wales

Independent champion for older people across Wales.

Tel: 03442 640670
E-mail: ask@olderpeople.wales
Website: www.olderpeople.wales

Public Services Ombudsman for Wales

The Ombudsman looks to see whether people have been treated unfairly by a public body, such as the NHS or a local authority.

Tel: 0300 790 0203
E-mail: ask@ombudsman.wales
Website: www.ombudsman.wales

Welsh Government

The devolved government for Wales.

Tel: 0300 060 4400
E-mail: customerhelp@gov.wales
Website: www.gov.wales

17 Further information about Age Cymru

17.1 Who we are

Age Cymru is the national charity for older people in Wales. We work to develop and deliver positive change with and for older people.

Our vision is an age friendly Wales.

Our mission is to make life better for older people.

Together with our local partners:

- We provide information and advice.
- We deliver wellbeing programmes.
- We provide independent advocacy.
- We support carers.

- We campaign and research.

Age Cymru

Mariners House
Trident Court
East Moors Road
Cardiff
CF24 5TD

029 2043 1555

www.agecymru.org.uk

Registered Charity 1128436

17.2 How we can help

Age Cymru Advice: our information and advice service for matters affecting people over 50 in Wales

Age Cymru Advice is committed to being the foremost information and advice service to older people in Wales. We aim to provide effective, accessible, high-quality information and advice while offering a free, impartial and confidential service.

Age Cymru Advice can assist older people themselves, their family, friends, carers, or professionals. All of our guides and factsheets are available to download from our website, or you can contact our advice line to have copies posted to you for free.

Local support

Age Cymru Advice also acts as a gateway to our local services. Face to face support via local offices and home visits may be available to people requiring additional or more specialised support.

Getting in touch

If you want to talk to one of our expert advisers, in Welsh or English, call us on **0300 303 44 98**. Our advice line is open between 9am and 4pm, Monday – Friday.

(Calls are charged at the same rate as a call to a standard 01 or 02 number. They will also be automatically included in any landline or mobile inclusive minutes package).

You can also:

- email us at **advice@agecymru.org.uk**; *or*
- visit our website at **www.agecymru.org.uk/advice**

Age UK *Information & Advice* Quality Assured

Gwasanaeth Cwbl Achrededig sy'n cynnwys adolygu gan gymheiriad
Fully Accredited Service with peer review

IAQF Cymru Wales

darparu gwybodaeth a chyngor o safon i bobl Cymru a hynny mewn modd sy'n gyson
providing a consistent approach to quality information and advice for the people of Wales

Helplines Partnership Member

advice quality standard

www.facebook.com/agecymru

www.twitter.com/agecymru

www.youtube.com/agecymru

Sign up to our newsletter

Our quarterly newsletter contains details of our campaigns, services and how you can support our work. Sign up today by visiting:

www.agecymru.org.uk/agematters

17.3 How you can help

All the information and advice we provide is free and completely impartial. In many cases our timely intervention can be life changing. We are an ageing population and more people than ever are coming to us for support. You can help us be there for those that need us most.

Make a donation

No matter how small or large, donations make a massive difference and help us continue our important work.

Call: **029 2043 1555**
Visit: **www.agecymru.org.uk/donate**

Every donation we receive helps us be there for someone when they need us.

- £10 helps towards a fully trained expert advice worker to respond to queries from people who need the support of our information and advice service.
- £20 helps towards the cost of us producing free information guides and factsheets that provide useful advice on issues affecting people over 50.

Fundraise

Whether it is having a bake sale, running a marathon or knitting small hats for the Big Knit, there are so many ways to raise vital funds to support our work.

Call: **029 2043 1555**
Visit: **www.agecymru.org.uk/getinvolved**

Volunteer with us

All volunteer roles at Age Cymru support us to improve lives and help us work towards an age friendly Wales. However you'd like to get involved, we'd love to hear from you.

Call: **029 2043 1555**
Visit: **www.agecymru.org.uk/volunteer**

Leave us a gift in your will

With a gift to Age Cymru in your will, you can do so much to make sure older people have the support they deserve in the years to come. Leave a world less lonely.

Call: **029 2043 1555**
Visit: **www.agecymru.org.uk/legacy**

age Cymru
Creu Cymru oed gyfeillgar
Creating an age friendly Wales