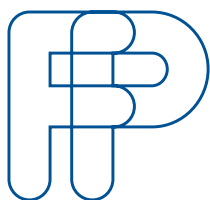


What do I need to know about NHS Continuing Healthcare?

**Information for families of people
with learning disabilities**

Alison Giraud-Saunders



**foundation for
people with
learning disabilities**

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Summary

We each want the best support for ourselves and those we love and many of us don't mind which organisations pay for this support. However, the NHS and councils each have responsibility for different things, laws and policies set the rules about what they can spend money on. 'NHS Continuing Healthcare' (NHS CHC for short) is the name for one of the pots of money that has specific rules. This booklet explains the rules and what they mean, together with questions you may want to ask if this type of funding is suggested for your relative.

In brief, NHS CHC is funding for a complete package of health *and* social care that is paid for by the NHS. This is for people who have been assessed to have a 'primary health need'. There is a system of assessments that will be arranged by the NHS to decide if someone is eligible for NHS CHC. If they are, the NHS will decide how much money to allocate for their support and will agree a plan. It is really important that this is done in a person centred way and involves you as family members.

NHS CHC can be used to support a person wherever they live, and it can be allocated as a personal health budget. From 2014 everyone eligible for NHS CHC should be able to ask for it as a direct payment (until then this option is only available in some places).

The booklet is mainly about the NHS CHC rules for adults. The system is different for children and young people. Up to the age of 18 responsibility for funding can be shared between the NHS, social care and education. It is really important to start planning early for the transition to adult life and the adult funding systems.

Note:

This booklet is about how NHS CHC works in England. There are some differences in other countries of the UK.

At the time of writing (May 2012) the NHS in England is changing. Up until now Primary Care Trusts have been responsible for NHS CHC – for organising assessments, allocating money and agreeing plans. The system is in the middle of change, Clinical Commissioning Groups are taking over these responsibilities. Throughout this booklet I have therefore used the term Clinical Commissioning Group (CCG) instead of Primary Care Trust.

All web links are correct as of March 2013. If the link in the text does not work, copy and paste it into your browser.

The information in this booklet is offered in good faith. It is not legal guidance. The Foundation cannot accept any liability regarding this information.

I've heard this term 'continuing care' - what does it mean?

'NHS Continuing Healthcare' (NHS CHC for short) is the name for a complete package of health and social care that is paid for by the NHS. This is for people who have been assessed to have a 'primary health need' (see below). NHS CHC funding can pay for a person's care wherever they are living – for example, in their own home, with you as family carers or in residential care.

There is a National Framework for NHS Continuing Healthcare. This sets out the rules about assessing people to see if they are eligible for NHS CHC and what should happen next. All NHS organisations and councils must use these rules. This should mean that it works the same wherever you live. However, families say that in practice there is still variation.

The National Framework includes an eligibility assessment tool. This is used to help the NHS decide whether the person has a '**primary health need**'. This depends on four factors:

- the **nature** of their needs, the impact on the person and the types of care and support required
- the **complexity** of their needs and the skills required to care for them
- the **intensity** (quantity and degree) of their needs and the support required
- the **unpredictability** of changes in their needs and the responses required

The person might be eligible for NHS CHC because of one type or level of need, or because of a combination of factors. (See more about this in the next section and the Appendix. The types of health needs that will be considered are listed in the Appendix).

If a person is eligible for NHS CHC, the NHS becomes responsible for funding all their care and support. This decision on eligibility means that the council does not have the legal powers to fund community care services. ('Community care' has specific meaning in law; the council does still have some duties and powers – see section 5).

It is already possible for people who are eligible for NHS CHC to have a personal health budget, giving them more choice, flexibility and control over the health services and care they need. In some areas (personal health budget pilot sites) it is possible to have the money as a direct payment. The Government has said that people eligible for NHS CHC should have the right to request a personal health budget, including a direct payment, from April 2014 (subject to the results of the pilot programme). See section 5 for more information about this.

You can ask for your relative to be assessed for NHS CHC. Often it is the council (social services) that asks for this.

Resources:

- You can read more about eligibility in a leaflet by the charity Counsel and Care at this website: <http://tinyurl.com/c477ehp>
- You can find the updated National Framework and Practice Guidance at this website: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>
- You can find out more about personal health budgets at this website: www.dh.gov.uk/personalhealthbudgets

Capacity and consent

Right from the start, the NHS staff who are working with your relative and you as a family must think about whether the person has capacity (under the Mental Capacity Act) to consent to assessment for NHS CHC. This includes consent for any health and social care professionals who know the person to share information for the assessment.

Everyone must be assumed to have capacity to consent unless an assessment of their capacity shows that they do not. A person with learning disabilities may need a lot of support with information about the assessments and what happens afterwards. You may be able to help the person to make a decision, if you are given good information yourself. Some people may want support from an advocate. The NHS staff should know what advocacy services are available. It is a good idea to ask whether they understand NHS CHC.

If the person does not have capacity to consent to the assessments, the NHS member of staff who is organising the assessment (the assessor) must make a 'best interests' decision. To do this they have to consult with those who know the person best – including the person's family. Some people have a **'Deputy'** appointed by the Court of Protection for personal welfare decisions. The Deputy may be a family member. The Deputy can give consent about any assessments that may need to be done. Becoming a Deputy for personal welfare is not as simple as becoming an appointee for benefits and you would need to think very carefully about whether to apply for this. You can find out a lot more about the Mental Capacity Act, including Deputies, in the information pack for family carers published by Hft (see below).

Capacity to consent must be checked at each stage of the process: assessment, allocation of funding and making a plan for care and support.

Resources:

- Resource pack for families on the Mental Capacity Act: <http://tinyurl.com/89y8pfk>
- Easy read booklet on the Mental Capacity Act: <http://tinyurl.com/bvhmupe>
- Template letter for families about involvement in decisions: <http://tinyurl.com/cbsbpn8>

How do assessments work?

The National Framework for NHS CHC includes two tools to help with assessing a person's eligibility for CHC funding:

- A Checklist to see if the person ought to have a full CHC assessment
- A Decision Support Tool to guide and record the full assessment

The Clinical Commissioning Group (CCG)¹ will appoint someone to co-ordinate the NHS CHC assessment of your relative. Often this will be a nurse who specialises in continuing care assessments. Read more below about how they should do this and who should be involved.

The Checklist

Whether or not the person has capacity to consent to the Checklist, the assessor must try to involve them. They should also involve others who are providing care or know the person well, like you and other members of the family.

The assessor should say what the result of the Checklist is. It is a professional judgement, so you can question it if important information seems to have been missed.

Here is a link to the Checklist: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>.

The full assessment

Sometimes it seems obvious that the person should have a full assessment and then the Checklist step may be missed out. (This is decided by the CCG).

If the Checklist shows that the person might be eligible for NHS CHC, the CCG will usually appoint a co-ordinator. They will be responsible for confirming that the person consents to a full assessment and to the sharing of information between health and social care staff. If the person does not have capacity to consent, the Department of Health's guidance says that assessment is almost always in the person's 'best interests'.

It is therefore likely that the assessment will go ahead as a 'best interests' decision by those contributing to the assessment. The co-ordinator must also think about who else should be involved and consulted as part of the assessment process.

The full assessment, using the Decision Support Tool (see page 8) as a guide and to record the results, should be done by at least two people from different health or social care professions (for example, a nurse and a social worker, or a doctor and a psychologist). They might ask others to do more specialist assessments, or to give information about previous assessments. You and your relative could offer to share any current person centred plans and/or health action plans.

The assessment should be done in a person centred way. It is not just about the person's health needs, but their whole life. A person centred approach will mean working with a person and their family to understand the individual and their strengths and gifts, as well as their needs for support. If your relative is already known to the council's children's services or adult social care, the council should help by contributing information (for example, from community care assessments) and staff time (for example, social worker or care manager involvement in the assessment).

¹Primary Care Trusts have been responsible for NHS CHC – for organising assessments, allocating money and agreeing plans. Clinical Commissioning Groups are taking over these responsibilities. Throughout this booklet I have therefore used the term Clinical Commissioning Group (CCG) instead of Primary Care Trust. CCGs may pay other organisations to do assessments and plans, but it will still be the CCG that is accountable.

The Decision Support Tool includes 12 'domains' of need (such as mobility, behaviour and communication – see the full list in the Appendix). Each domain is divided into levels of need, ranging from 'no needs' to 'priority'. These levels are sometimes thought to be a scoring system (so a score of 'X' would trigger eligibility for NHS CHC). However, this is not the case: the results simply guide a professional judgement about eligibility. The levels do not determine the care to be provided or the funding to be allocated.

Four of the domains have a 'priority' category. If a person's needs meet one of these descriptions, the clear expectation is that they will be considered eligible for NHS CHC. These four domains are:

- behaviour
- breathing
- drug therapies
- altered states of consciousness

See the Appendix for more information.

You can find the Decision Support Tool here: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>.

Whether or not the person has capacity to consent to the assessment, the assessors must try to involve them. They must also involve others who are providing care or know the person well, like you and other members of the family. The assessors should record their views using the Decision Support Tool. Using this and their professional judgement, they will make a recommendation to the CCG about whether the person is eligible for NHS CHC. This is not affected by **where** care is to be provided, or **who** provides the care. Paragraph 13 of the National Framework says: "Eligibility for NHS continuing healthcare places no limits on the settings in which the package of support can be offered or on the type of service delivered." The CCG should usually accept the recommendation recorded on the Decision Support Tool.

The CCG must write to say what the result of the assessment is, along with the reasons for the decision. This should normally be done within 28 days of the Checklist being completed. The decision is a professional judgement, so you can question it if important information seems to have been missed or you disagree with the result. (See section 6 – 'What if I'm unhappy').

Sometimes people are not aware that a CHC assessment has been done, because it has not been properly explained to them. This is not in line with the guidance and you can complain if you think this has happened.

Can we refuse the Checklist or the full assessment?

Yes, the person can refuse if they have capacity. If they do not have capacity and a 'best interests' decision is required, you as their family can say if you think that completing a Checklist or full assessment would not be in the person's 'best interests'. However, you do not have the authority to refuse it on the person's behalf just because you are related to them (unless you have a Lasting Power of Attorney or are a court appointed Deputy for health and personal welfare decisions).

The person completing the Checklist or co-ordinating the full assessment must make their own decision about whether it should be completed. Not doing so could deprive the person of support or funding to which they may be entitled. The guidance says that an assessment would usually be in the person's 'best interests' and therefore should be carried out. The council might decide that they do not have the legal power to provide funding or support if they believe the person is eligible for NHS CHC and so it is important that a proper assessment is carried out.

Sometimes people consider refusing because they are worried that they might lose choice and control over their support. However, a council is not obliged to continue to provide support just because someone has refused an NHS CHC assessment. If the person is eligible for NHS CHC, the CCG should do everything they can to personalise support and help people keep choice and control. The Department of Health has made it clear that the NHS can already offer personal health budgets (at the time of writing, in Spring 2012, personal health budgets can be taken as direct payments in pilot sites). You can read more about this in section 5.

If you're unsure about whether an assessment is in your relative's best interests, you should talk to the NHS CHC co-ordinator about your concerns. They may be able to reassure you, or the discussion may help you decide if you need extra advice or support through the process.

What happens about support while assessments are done and decisions made?

Your relative may well be getting support, perhaps funded by the council, before they are referred for assessment for CHC. All this support should continue while assessments are done and decisions made. The guidance is clear that support should not be withdrawn by one organisation until alternatives are in place. You can complain if this seems to be happening.

Resources:

- NHS Continuing Healthcare Checklist: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>
- Decision Support Tool for NHS Continuing Healthcare: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>
- Responsibilities Directions: <http://tinyurl.com/cqnxjw7>

What happens if my relative is assessed and is found not eligible for NHS Continuing Healthcare?

Your relative may already have an up-to-date care plan and services funded by the council. If not, you should ask for a community care assessment for your relative. You may also be eligible for a carer's assessment.

You may want the council to review your relative's plan and support; you could ask them to use the information from the NHS CHC assessment to do this.

Even if your relative is not eligible for full NHS CHC funding, the NHS still has some responsibilities towards them:

- first, everyone is entitled to the general health services we all use
- second, in most areas there are health services especially for people with learning disabilities (usually in a community learning disability team)
- third, the CCG may agree to contribute towards a jointly funded package of support, based on the health needs identified through the NHS CHC assessment. Some authorities say that they do not offer joint funding – the person will be funded either by the council or the NHS. The NHS CHC Practice Guidance says (paragraph 58.1): “Where there are overlapping powers and responsibilities, a flexible, partnership-based approach should be adopted based on the most appropriate organisation to meet the specific need.”

If your relative's needs change, you can ask for them to have another assessment for NHS CHC.

If a person is not eligible for NHS CHC and they live in a care home with nursing, and they have been assessed as needing the services of a registered nurse, they will be eligible for a contribution towards their care fees from the NHS. This is called NHS Funded Nursing Care (FNC). This is paid directly to the care home. You can talk to the care home manager about this.

Resources:

- NHS-funded Nursing Care Practice Guide: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

What happens if my relative is eligible for NHS Continuing Healthcare?

The CCG will appoint a case manager. This is often a nurse who specialises in NHS CHC. They may or may not have experience of working with people with learning disabilities.

What happens next?

The most important step of all is getting a plan agreed for your relative's support. The team that completed the NHS CHC assessment may also be the people who draw up the plan, and they may make a start on it at the same time as the assessment. However, assessment for eligibility (focused on needs and deficits) is very different from working with a person and their family to understand the individual and their strengths and gifts, as well as their needs for support. A personal health plan should start with this and focus both on achieving health outcomes and enabling the person to lead the kind of life they want.

The National Framework says (paragraph 42): "The process of assessment and decision making should be person centred. This means placing the individual, their perception of their support needs, and their preferred models of support at the heart of the assessment and care-planning process".

The good practice guidance is quite clear that the case manager must involve and listen to the person and to those who know the person best. Your relative may well have an existing plan and package of support. This should not be changed just because the NHS becomes responsible for funding. However, it is a good chance to have a review and make sure that the support is right. It is really important to make sure that the plan is clear about all the kinds of support your relative needs to achieve their person centred outcomes. Remember, this is about all the support they need, not just health care.

Your relative may already have a social worker, a support 'broker' or other people who can help with making a plan. There may be an advocacy organisation or family carer organisation in your area that can help with this. There are lots of resources available about person centred planning and circles of support. Here is a link to one that is for families: <http://tinyurl.com/crqlkqz>

If your relative does not have capacity to make some or all of the decisions about their support plan, the case manager will draw up a plan that they decide reflects your relative's best interests. This would of course require them to consult and involve those who know the person best, including you as their family. As noted earlier, some people have a 'Deputy' for personal welfare decisions; the Deputy can give or refuse consent about what should be included in the person's plan. Again, any decision they make must be in the person's best interests.

Personalised support

As in social care, the CCG is expected to organise personalised services and to offer the person as much choice and control as possible. The National Framework says the NHS should: "commission services using models that maximise personalisation and individual control and that reflect the individual's preferences, as far as possible." This is emphasised particularly for people who may have had a direct payment for social care in the past, "so that unnecessary changes of provider or of care package do not take place purely because the responsible commissioner has changed" (paragraphs 169-170).

It is also important for you to know that the law for NHS CHC is a little different from that for adult social care. The Practice Guidance says (section 83): “The starting point for agreeing the package and the setting... should be the individual’s preferences... Cost has to be balanced against other factors... such as an individual’s desire to continue to live in a family environment.” However, the NHS CHC Framework says (paragraph 167) that “the package to be provided is that which the PCT assesses is appropriate for the individual’s needs”. This means that the CCG could decide on a plan that is different from what you and your relative would prefer.

In some cases the NHS has decided that it is too expensive for someone to have support at home and they should go into a care home. This has been challenged successfully by some people (see next page) so, if they try to make a decision that is different from what your relative wants or you believe they need, you can challenge their decision. For example, in making their decision they must pay attention to laws such as the Human Rights Act. That is why it is so important to be clear about the desired outcomes for your relative (see page 16 – ‘What if I’m unhappy?’).

Article 19 of the United Nations Convention on the Rights of Disabled Persons, which has been ratified by the UK, describes the right to independent living. However, this has not been turned into specific UK law, so you cannot use it to go to court in the UK. You need to use laws like the Human Rights Act.

The Department of Health has made it clear that the NHS in England can already offer personal health budgets. Two models can already be used anywhere:

- ‘Notional’ budget: the NHS tells you how much money is in your budget and you discuss with your case manager how it is to be spent
- ‘Third party’: the NHS pays money to an organisation such as an Independent User Trust or a service provider to manage on your behalf. You and this ‘third party’ make a support plan that says how the money will be spent²

If your relative lives in one of the personal health budget pilot sites, they may also be able to receive a budget as a direct payment. The pilot scheme is being evaluated. The Government has said that, subject to the results of the evaluation, from April 2014 everyone who is eligible for NHS CHC will have the right to ask for a personal health budget (including having it as a direct payment).

A personal health budget might be helpful for a person with complex needs or behaviour that challenges, particularly if their family feel that this would give them greater choice and control over their support package.

It is important to be clear exactly what is included in your relative’s plan as a need for which the NHS accepts funding responsibility. There are rules that prevent these costs being ‘topped up’, for example by the person’s family. However, there is nothing to stop extra things being paid for if the NHS has not accepted responsibility for them. For example, if the CCG has not included going clubbing in the plan, this could be paid for by the person or their family.

² At the time of writing (May 2012), it is still the case that a ‘third party’ employing staff to provide personal care to your relative must be registered with the Care Quality Commission (CQC). However, the Government is changing the regulations so that “providers of personal care to an individual where that care is arranged by a parent, carer or a trust set up to organise care are not required to register with CQC”. (Department of Health ‘Response to a consultation on proposed changes to regulations for Care Quality Commission registration’, 2012)

Right to family life

A disabled woman who required 24-hour care was awarded NHS CHC funding. She wanted to live at home with her family, with a substantial package of paid support. The Primary Care Trust (PCT) wanted to place her in a residential home. They said this was because it was cheaper than care at home and they thought the quality of care would be better, particularly if there was a crisis. The High Court ruled that the PCT had not taken proper account of the impact of this on her family life: her quality of life at home and her own wishes to live at home. The PCT was therefore obliged to reconsider, taking her right to respect for her family life into account.

Rachel Gunter v South Western Staffordshire Primary Care Trust (2005)

Resources:

- Department of Health personal health budget pilot website: <http://www.personalhealthbudgets.england.nhs.uk/>
- Personal health budget paper on NHS CHC: <http://tinyurl.com/c24pskr>
- Personal health budgets and Independent User Trusts: <http://tinyurl.com/c9slfna>

What effect does NHS CHC have on other services and benefits?

If your relative is assessed as being eligible for NHS CHC, it will not be lawful for the council to fund 'community care' services (but see the section below on other duties and powers the council still has).

The rules are different depending on where your relative is going to live:

- in a registered care home
- at home (whether with you or in other accommodation)

In a registered care home the NHS becomes responsible for all the costs of accommodation and care. Eligibility for Disability Living Allowance for people living in registered care homes has been the subject of a series of recent court cases. The most recent position at the time of writing is set out in a Department for Work and Pensions document (February 2012): <http://tinyurl.com/czoqp94>. You would need to check the position for your relative with someone who has welfare rights expertise.

If the person is living at home, the NHS becomes responsible for all the costs of their health care and related social care, but the person is still responsible for the other costs of daily living, such as rent, food and heating. It is possible that the NHS might meet some transport costs, if they are related to a specific part of the support package. For example, if the NHS pays for some day activity, the costs of getting there should be included. The NHS or the council may also pay for some support for family carers (such as short breaks).

Social security benefits should not be affected for a person living at home. **However, if a person has been receiving Independent Living Fund money, this would stop.**

What responsibilities and powers do the council still have?

Even if a person is assessed as eligible for NHS CHC, the council still has some duties (things they must do) and powers (things they can do if they choose):

- The NHS and Community Care Act 1990 Section 47(1) imposes a duty on local authorities to carry out an "assessment of need for community care services with people who appear ... to need such services". They must then decide whether any assessed needs require them to provide services.
- The Carers and Disabled Children Act 2000 Section 1 gives carers the right to an assessment where they provide a substantial amount of care regularly for another individual.
- Although the council cannot pay for community care services to meet needs that are eligible for NHS CHC funding, they do have a power to pay for some other kinds of support for independent living, such as 'access to community facilities'. For example, the council might agree to pay for a support worker to take someone swimming.
- The CCG and the council have some overlapping responsibilities for equipment and adaptations to property (see page 15 'What else should we ask about?').

What happens if my relative has a direct payment at present?

At the time of writing (April 2012) the NHS is trying out personal health budgets in some areas (<http://tinyurl.com/cb4ayc4>). If you live in one of these areas, your relative may be able to have their NHS CHC funding as a direct payment from the NHS. The Government wants everyone eligible for NHS CHC to have this opportunity by 2014.

If you do not live in one of these areas, the CCG can still personalise the budget for your relative. As in social care, this budget can be held and managed by the CCG or it can be given to a third party, such as an Independent User Trust or a service provider. Unlike a social care personal budget, however, it cannot be given as a direct payment unless you live in one of the pilot areas. There is more about personal health budgets in the section 'Personalised support', above.

The NHS CHC practice guidance is clear that every effort should be made to continue existing support arrangements that are working well. This means that the CCG should work with you and your relative to find a way of ensuring that **a transfer from a social care direct payment to NHS CHC funding does not disrupt your relative's support**. In many areas NHS staff are not yet very familiar with ideas about personal budgets and self-directed support. They may not be very confident about how to put these ideas into practice for people who have CHC funding. You may need to be well informed and supported yourself to negotiate a satisfactory arrangement.

What happens if we refuse the funding?

If your relative has mental capacity to decide about this, they can refuse NHS funding or services. However, that would not oblige anyone else, such as the council, to meet their needs. Therefore they may be left with unmet needs. They can request a new assessment if they change their mind later.

If the person does not have the mental capacity to refuse services, you cannot refuse funding on their behalf unless you have a Lasting Power of Attorney or are a court appointed Deputy for health and personal welfare decisions. Even then you could be challenged as to whether you were acting in the person's best interests.

What else should we ask about?

It is really important to be clear about what the NHS CHC plan and funding covers. The plan should be quite specific about which organisation is responsible for what. For example, it should not say in a vague way that the NHS will be responsible for some equipment or continence supplies. Some families have found that different bits of the NHS argue about these things, so you need to know just who is going to provide what. It is a good idea for your family doctor to know this too.

The NHS and councils have some overlapping responsibilities in law for equipment and for housing adaptations. Many areas have joint equipment services; if your relative needs extra equipment as part of their plan, the CCG should organise this. If your relative has other housing-related needs, the plan should set out how these will be met. This might be by the NHS, or the council, or some combination.

You can find much more detail in the good practice guide at this web address: <http://tinyurl.com/5c2nkn>

What happens about monitoring and reviews?

Once it has been decided that a person is eligible for NHS CHC, the CCG becomes responsible for monitoring their care and support and arranging regular reviews. This will usually be done by a case manager. Sometimes this may be arranged through the council or through a joint learning disability team. A review must be done within three months of the NHS becoming responsible for the person's care. After that the case manager should plan reviews according to the person's needs (at least once a year).

You could ask the case manager how your relative's care and support will be monitored and how you can be involved.

If the person's needs change, it is possible they might be re-assessed. The CCG might decide that they are no longer eligible for NHS CHC. They might then need joint funding from the NHS and the council or just social care funding. Some people could be responsible for funding their own care and support.

Resources:

- The personal health budgets network offers information and peer support: www.peoplehub.org.uk
- You can watch a video about one young man's personal health budget: <http://www.personalhealthbudgets.dh.gov.uk/Topics/latest/Resource/?cid=7942>

What if I'm unhappy with either the process or the results?

If you disagree with the assessment, you can challenge it. If you need to do this, it may be helpful to collect together previous assessments that have been done, together with any person centred plans and Health Action Plans that your relative has. The person in charge of the assessment should try to resolve your concerns. If you still disagree, they should make a note of this in their report.

If you disagree with the decision about your relative's eligibility for NHS CHC and you think the process was not followed properly, you can appeal. There is a system of Independent Review Panels. The CCG should try to resolve your concerns first. If you are still unhappy with the process, they should give you a copy of the procedure that sets out how to appeal.

If you disagree with the care plan, you can use the NHS complaints procedure. The CCG should try to resolve your concerns first. If you are still unhappy with the result, they should give you a copy of the procedure that sets out how to complain. If you need to do this, it is a good idea to collect together previous plans and any evidence about what has worked well for your relative in the past or what has not worked well.

You can ask for help with making a complaint:

- Patient Advice and Liaison Service (PALS): www.pals.nhs.uk . They can help if you are unhappy with NHS services. They can help you if you want to complain
- Independent Complaints Advocacy Service: this service is completely separate from the NHS. They can help you make a complaint. You can get in touch with them through PALS
- Patients Association: this is a charity that is quite separate from the NHS. They have a helpline you can call. The number is 0845 608 4455

What if the council and the NHS don't agree?

The CCG and the council must have a local procedure for resolving disputes between them about an individual's eligibility and funding. While they follow this procedure, they must not withdraw any funding or care from your relative.

Some specific situations

Transition to adult life

Continuing care funding for children and young people is different from that for adults. So it is very important that this is discussed and planned as part of a young person's transition planning.

Staff working in children's services do not always realise how different the rules are for adults and what the effects might be. So you need to be ready to ask lots of questions, using the information in this guide. It is important to start a couple of years before your son or daughter becomes 18, as early planning is really helpful and the whole process can take quite a long time.

The National Framework says (paragraph 136): "A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children's to adult services or because of a change in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a planned manner, in full consultation with the young person. No services or funding should be unilaterally withdrawn unless a joint health and social care assessment has been carried out and alternative funding arrangements have been put in place."

There are lots of resources available to help young people and their families prepare for adult life: <http://www.preparingforadulthood.org.uk/>.

Someone moving from one area to another

Just like anyone else, a person receiving support funded by NHS CHC may wish to move to another area. For example, if you had to move for your work, your relative might want to move to stay close to you. It is very important to discuss this early on with the CCG that is currently paying for your relative's care. They will need to talk to the CCG responsible for the area to which your relative plans to move. The guidance says they should ensure continuity of care and they must make it clear exactly what services will be provided, and by whom, after the move.

Someone who has had other kinds of NHS funding

Some people may have had different kinds of funding from the NHS in the past. For example, they might have:

- moved out of a long stay hospital with NHS funding: this should not change the process for deciding their eligibility for NHS CHC
- had NHS funding that was then handed over to the council: this should not change the process for deciding their eligibility for NHS CHC
- had funding for aftercare following discharge from a mental health hospital (often called 'S.117' funding): this must be treated as separate from NHS CHC

End of life care

There is a special 'fast track' process for assessing someone for CHC if they need an urgent package of care/support because of a rapidly deteriorating health condition that means they may be nearing the end of their life. Only relevant NHS practitioners, such as doctors and nurses, can use the 'fast track' tool. The process is intended to get the right support to the person as quickly as possible. Otherwise the rules are just the same.

Full list of useful resources

Department of Health guidance on NHS CHC

National Framework for NHS CHC and NHS-funded Nursing Care, incorporating practice guidance: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

NHS CHC Practice Guidance: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

NHS CHC Checklist: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

Decision Support Tool for NHS CHC: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

Responsibilities Directions: <http://tinyurl.com/cqnxjw7>

Personal health budgets

Department of Health personal health budget pilot website: <http://www.personalhealthbudgets.dh.gov.uk/>

Personal health budget paper on NHS CHC: <http://tinyurl.com/c24pskr>

Personal health budgets and Independent User Trusts: <http://tinyurl.com/c9slfna>

The personal health budgets network offers information and peer support: www.peoplehub.org.uk

You can watch a video about one young man's personal health budget: <http://www.personalhealthbudgets.dh.gov.uk/Topics/latest/Resource/?cid=7942>

Mental Capacity Act

Resource pack for families on the Mental Capacity Act: <http://tinyurl.com/89y8pfk>

Easy read booklet on the Mental Capacity Act: <http://tinyurl.com/bvhmupe>

Template letter for families about involvement in decisions: <http://tinyurl.com/cbsbpn8>

Other useful guidance and resources

Thinking Ahead - a planning guide for families: <http://www.learningdisabilities.org.uk/our-work/family-friends-community/thinking-ahead>

Planning for the future: <http://tinyurl.com/crqlkqz>

Preparing for adult life: <http://www.preparingforadulthood.org.uk/>

UK Continuing Care Network and UK Health and Learning Disability Network: <http://www.jan-net.co.uk/>

You can read more about eligibility in a leaflet by the charity Counsel and Care at this website: <http://tinyurl.com/c477ehp>

You can find much more detail about housing adaptations in the good practice guide at this web address: <http://tinyurl.com/5c2nkn>

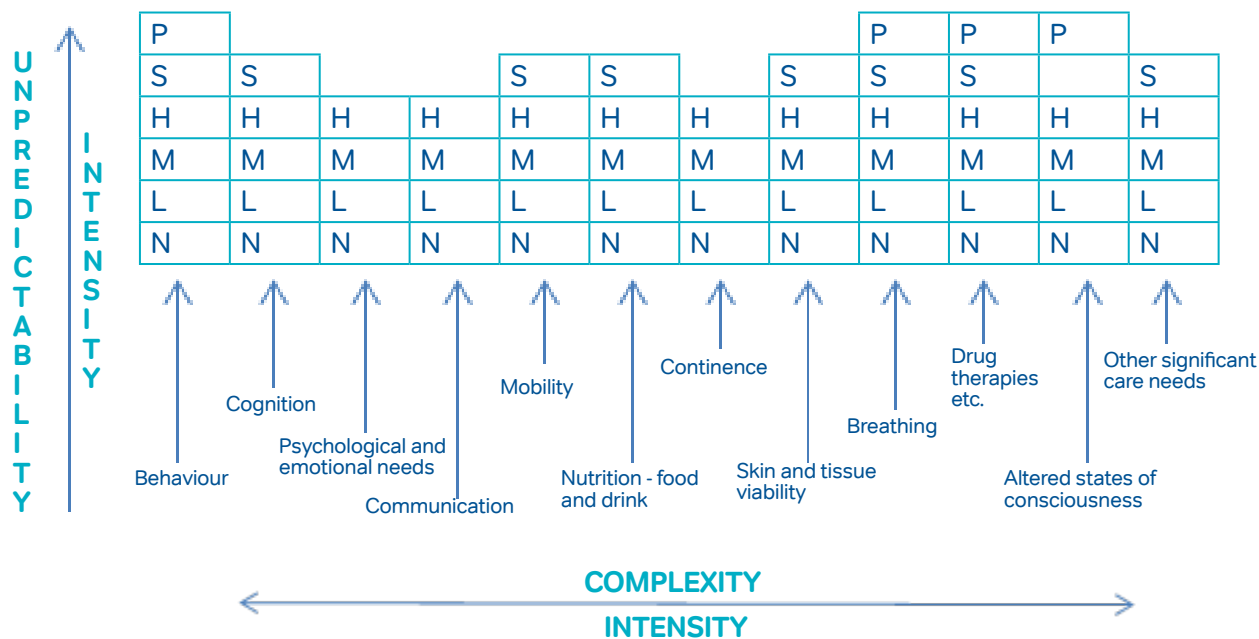
Appendix

More detail about the Decision Support Tool

The Decision Support Tool guides NHS CHC assessors to look at a person's needs in 12 'domains'. These are:

- behaviour
- cognition
- psychological and emotional needs
- communication
- mobility
- nutrition – food and drink
- continence
- skin (including tissue viability)
- breathing
- drug therapies and medication: symptom control
- altered states of consciousness
- other significant care needs

Each domain has descriptions representing: no need, low, moderate or high levels of need. Some also have severe or priority levels of need. This is shown in the chart below. The full descriptions can be found (page 16 onwards) in the Decision Support Tool document: <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>.



- N = no need
- L = low need
- M = moderate need
- S = severe need
- P = priority need

The Decision Support Tool does not include a scoring system that adds up 'points' to determine eligibility. It is intended to support professional judgement. However, a clear recommendation of eligibility for NHS CHC would be expected where an individual is assessed as having a 'priority' level need (in one or more of the four domains where this is possible) or a total of two or more instances of a 'severe' level of need across all care domains.



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