



counsel + care 
for older people, their families and carers

guide

Guide 27:

Continuing Healthcare: should the NHS be paying for your care?

This guide explains the statutory duty of the NHS to assess your health needs for NHS Continuing Healthcare. It covers what NHS Continuing Healthcare is, how eligibility is worked out, how to make an application for this funding and what to do if you are unhappy with the decision made.

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There are differences in the ways each country cares for and supports older people. The information in this guide applies essentially to England, although there may be similarities with countries in the rest of the UK.

We also produce five separate guides for both Scotland and Wales covering the needs assessment process; paying care home fees and making a formal complaint, which are the key areas where the policy and legislation differs significantly from England.

All of the guides we publish may be downloaded from www.counselandcare.org.uk/advice-and-information

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1 What is NHS Continuing Healthcare?

NHS Continuing Healthcare is care provided to a person who has been assessed to have a 'primary health need'.

This care is provided for a period of time to a person aged 18 or over, to meet their physical or mental health needs as a result of a disability, accident or illness, which is arranged and paid for, solely by the NHS as part of its overall duties under the NHS Act 2006. The NHS is responsible for meeting all the person's assessed needs because this care is not of a nature that the local council social services can meet, or is beyond their powers to solely meet.

This care can be provided in a variety of settings, such as a nursing home, a care home, a hospital, a hospice, or in your own home.

2 What entitles you to receive NHS Continuing Healthcare?

2.1 Eligibility criteria in England

In 2007, a National Framework and accompanying directions were implemented to enable a fairer, simpler and more consistent system. The framework created a single national criteria for every Strategic Health Authority (SHA) or Local Primary Care Trust (PCT) in England to use, setting out the legislation, principles and practices defining who is eligible for NHS Continuing Healthcare. Previously, each SHA had its own eligibility criteria. The Framework and accompanying directions were revised in July 2009.

A copy of the National Framework is available from the Department of Health website:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH_103162

A copy of the NHS Continuing Healthcare (Responsibilities) Directions 2009 is available from the Department of Health website:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106175.pdf

Eligibility for NHS Continuing Healthcare depends on whether your primary need is a 'health' need, a concept developed by the

Secretary of State. There is no legal definition of a health need for the purpose of NHS Continuing Healthcare but it has been defined as:

'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).'

Generally, healthcare needs could include:

- unpredictable challenging behaviour;
- mood disturbance and hallucinations;
- the person is immobile and requires careful repositioning;
- the person is incontinent of urine and faeces requiring regular monitoring to minimise risk;
- the person has multiple wounds needing daily monitoring and reassessment;
- artificial intervention is needed to take in food and drink, or the person has difficulty in swallowing;
- the person is at risk of malnutrition or dehydration;
- the person has difficulty breathing and may need mechanical support; or
- the person is experiencing pain and there is difficulty in managing pain which may impact on providing the care.

The above examples (alone or in combination) although are healthcare needs in themselves, are not exhaustive, nor demonstrate

a primary health need. It is the assessment tool (see section 3.4) together with professional judgement which decides on someone's eligibility for NHS Continuing Healthcare.

The artificial barriers between health (care provided by the NHS) and social care (care provided by local council) make it difficult to clearly define what a health need is. The difference is important because NHS services are free but social care is chargeable or means tested. The revised tools used to assess NHS Continuing Healthcare help to make this distinction.

Deciding whether you have a 'primary health need' involves looking at your overall, actual day-to-day care needs, or all your needs including any nursing or other health services that you require to see if the main aspects, or majority of the care that you need is focused on addressing and/or preventing health needs.

The key indicators below demonstrate a 'primary health need':

- **Nature:** the particular characteristics of a person's needs (including physical, mental health or psychological needs); the overall effects of those needs on the individual, including the type of interventions required to manage them.

The nature could refer to the features (chronic, unstable, involuntary, intractable or persistent) of your particular condition(s) in total and how it is managed on a daily basis. Or the nature could refer to the

type of intervention needed to manage the condition(s) which might be invasive treatment, palliative, or responsive medication.

- **Intensity:** both the extent ('quantity') and severity ('degree') of the needs and the support required to meet them, including the need for sustained or ongoing care ('continuity').

Intensity might refer to a chronic condition which requires a certain type or level of care to manage and minimise risk. Or intensity could mean aggressive behaviour that presents a significant risk to self or others requiring regular risk assessments. The interaction of a number of lower level needs could also increase the intensity.

- **Complexity:** how the needs arise and interact to increase the skill/knowledge needed to monitor the symptoms, treat the condition(s) and/or manage the care.

Your needs might be complex as a result of the interaction of a number of symptoms, or secondary effects. Complexity might also refer to the extent of the intervention needed for a single condition. The multiple conditions, treatments and/ or symptoms require urgent or timely intervention, and if this were not provided, this would put you at risk.

- **Unpredictability:** the degree to which needs fluctuate, creating difficulty in managing needs, and the level of risk to the person's

health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have a fluctuating, unstable or rapidly deteriorating condition.

Your needs may be unpredictable because of a fluctuating, unstable or a rapidly deteriorating condition which cannot be reliably anticipated. This includes your physical, mental or psychological health and/or behaviour which requires prompt intervention to manage risks by health professionals or an informal carer.

Unpredictability could also refer to a severe and continuously deteriorating physical condition resulting in rapid dependency or short-term life expectancy. You may need timely intervention to manage your symptoms, avoid deterioration or distress, and minimise risk.

You may have a primary health need on the basis of one indicator alone, while another person may have a primary health need based on a combination of indicators because of the quality and/or quantity of care required to meet their needs. Quality of care means the type of care and quantity of care refers to the level or characteristics.

Eligibility should not be based on:

- where the care is being provided;
- the person's diagnosis;
- the ability of the care providers to manage the care;
- the use (or not) of NHS-employed staff to provide the care;

- the need for/presence of 'specialist staff' in care delivery;
- the existence of other NHS-funded care; or
- any other input (rather than needs-related).

2.2 Eligibility criteria in Scotland

In Scotland, 'CEL (2008) 6' was published by the Scottish Government in February 2008. It updates and clarifies the current guidance on continuing healthcare to take account of recent health and social care policy changes. It establishes that the central factor to consider is whether a person's current needs are primarily 'health' needs. It is available from: www.sehd.scot.nhs.uk/mels/cel2008_06.pdf

Any decision about eligibility in Scotland should be made using local criteria based on the principles of the national guidance. It should occur after an assessment by a multidisciplinary team under the Single Shared Assessment approach. For more information on Single Shared Assessments see our guide:

Assessment and services from your local council in Scotland (guide number 50).

For more information on Continuing Healthcare in Scotland, contact the Scottish Helpline for Older People (tel.: 0845 125 9732; www.olderpeoplescotland.co.uk).

2.3 Eligibility criteria in Wales

The 'National Framework for NHS Continuing Healthcare 2010' aims to provide greater consistency in interpretation of the eligibility criteria across the country. The Welsh National Framework may be viewed at:

<http://wales.gov.uk/docs/dhss/publications/100614chcframeworken.pdf>

or you can contact Age Concern Cymru (tel.: 029 2043 1555; www.accymru.org.uk) for more information about NHS Continuing Healthcare in Wales.

3 How should it be decided whether you are eligible?

3.1 Checklist for eligibility

To decide if you meet the criteria for NHS Continuing Healthcare in England, the assessment tools as set out in the National Framework must be used. The assessment tools cannot be changed, amended or abbreviated in any way, as this may mean that you have been incorrectly assessed.

With your consent, the first step will be a screening process using the NHS Continuing Healthcare Checklist, unless the Decision Support Tool (see section 3.4) or the Fast Track Pathway Tool (see section 5) is more appropriate. The purpose of the Checklist is to encourage fair assessments, so that resources are directed towards those most likely to be eligible for NHS Continuing Healthcare.

A nurse, doctor, other qualified healthcare professional, a social worker or a social care assistant can apply the Checklist, then consider if you meet the eligibility criteria for a full NHS Continuing Healthcare assessment. Whoever applies the Checklist should be familiar with the National Framework guidance and the Decision Support Tool (see section 3.4) and be trained to use them as a legal requirement. You should have the opportunity to be represented by an advocate and be present when the assessment is carried out, so that your views and wishes can be taken into account. Whatever the outcome of the Checklist, a copy of the completed Checklist, the

decision, together with the reasons for it, should be communicated in writing to you and your carer (if appropriate), as soon as reasonably practicable.

For many people, it might be clear from the outset that they are not likely to have NHS Continuing Healthcare needs, so an assessment will not be carried out. Despite this, you may request that they carry out an assessment. If a full assessment is denied, you should be informed of your right to ask the PCT to reconsider their decision and also to complain through the NHS complaints procedure (see section 9).

A copy of the Checklist tool may be viewed at:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103328.pdf

3.2 Checklist and hospital discharge

If you are in hospital when the Checklist is applied and has indicated that you need a full assessment, then, although this can be carried out whilst in hospital, a decision can be made at this stage to provide other NHS services, such as intermediate care or rehabilitation, and then to carry out a full assessment at a later date. The aim of intermediate care is to provide a programme of therapy to maximise your independence whilst minimising the effects of your needs.

The PCT should ensure that a full assessment is carried out once it is possible to make a reasonable judgement about your ongoing needs.

3.3 Assessment of eligibility

If you are referred for a full assessment for NHS Continuing Healthcare, the PCT will arrange for a coordinator to be appointed, who is responsible for identifying the multidisciplinary team and coordinating the process until a decision about eligibility is made.

Your assessment should be carried out by a multidisciplinary team made up of two or more people, preferably from at least two different disciplines currently involved with your care, usually from both health and social care backgrounds. This could be a medical consultant or doctor, ward nurse or specialist nurse, a psychiatric nurse, a speech and language therapist, an occupational therapist, a social worker or another social care professional. The directions require that, as far as is reasonably practicable, the PCT should consult with the relevant local council before making any decision about eligibility for NHS Continuing Healthcare. The local council should also provide advice and assistance to the PCT, including providing any information from a needs assessment, where it has carried one out, and any information on changed needs since the last assessment. If you have been involved, or your care has previously been arranged by the mental health team, the Care Programme Approach assessment (normally carried out for people with enduring mental health difficulties) should be used as evidence of your needs when completing the Checklist and Decision Support Tool.

You should receive a multidisciplinary assessment of your health and social care needs, where accurate and up to date information is included in the assessment. You should also be able to talk about your wishes for your future care. It should be carried out with your knowledge and consent, and you should be supported where possible to be involved in the assessment, with the assistance of a carer or independent advocate where appropriate. The assessment process should take into account the direct knowledge of your needs, including evidence from risks and specialist assessments. For example, skin viability or psychiatric assessment.

Regardless of whether you are found to be eligible for NHS Continuing Healthcare, the PCT and the local council should always consider whether the assessment has identified needs that require action to be taken such as by referring you to an appropriate service.

3.4 Decision Support Tool

In order to make the decision-making process as consistent as possible, a national 'Decision Support Tool' has been developed. A copy of the Decision Support Tool may be viewed at:
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103329.pdf

The tool is not an assessment in itself, it is a special form designed to encourage consistency and ensure that the multidisciplinary team takes all relevant factors into account when deciding a person's

eligibility for NHS Continuing Healthcare. Your needs should be recorded on 12 'care domains', which are sub-divided into low, moderate, high, severe or priority needs, depending on the domain. A primary health need is demonstrated by having a priority level need (*) or if you have:

- a total of two incidences of identified severe needs across all care domains; or
- one domain recorded as severe, together with needs in a number of other domains; or
- a number of domains with high and/or moderate needs.

The 12 care domains are:

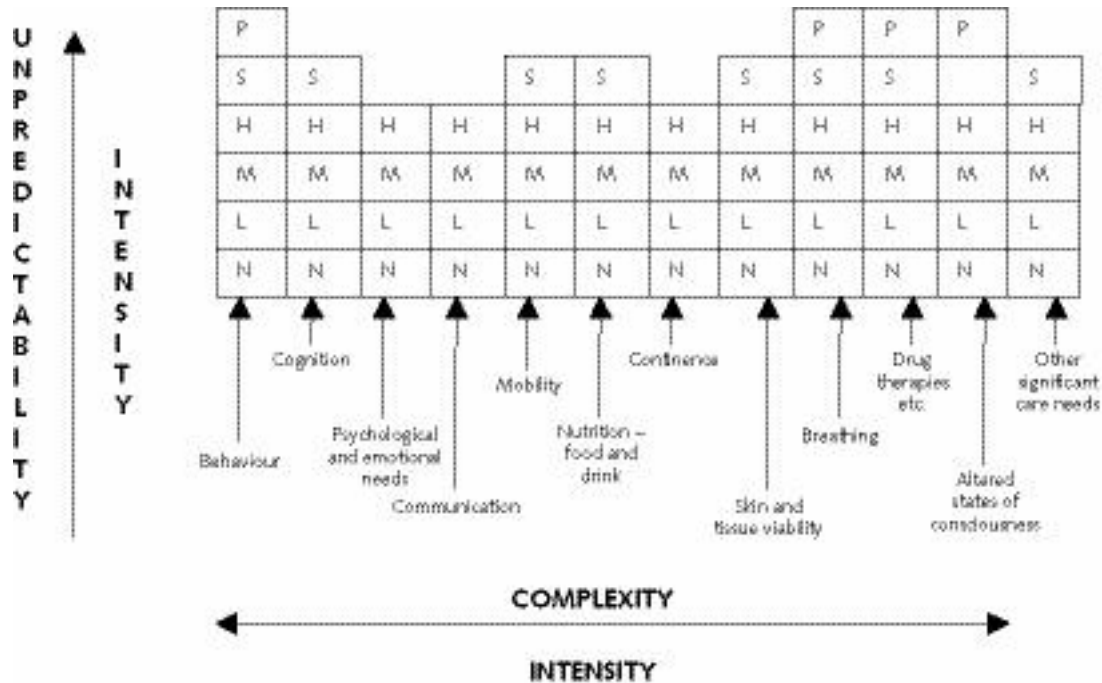
- *Behaviour (for example, dementia, depression and the behaviours and treatment relating to these)
- Cognition (how able are you to understand and process information)
- Psychological and emotional needs (mood disturbance, hallucinations, anxiety or wellbeing)
- Communication (how able are you to express your needs)
- Mobility (your ability to walk or move about without support)
- Nutrition (what care do you need to ensure you receive adequate levels of food and drink)
- Continence – both urine and bowel (including the management of incontinence)

- Skin – tissue viability (open wounds, risk of pressure sores or skin breakdown)
- *Breathing (ability to breath independently or with support)
- *Drug therapies and medication (management of medication/ pain including the ability to manage its safe use)
- *Altered states of consciousness (changes in a person’s mental state or brain activity which could include delirium, panic, coma, trauma)
- Other significant care needs (any other needs).

Once completed, the tool should provide an overall picture of your needs. It should capture its nature, complexity, intensity and/or unpredictability, and consider the quality and/or quantity (including continuity) of care required to meet your needs in full. The multidisciplinary team should also weigh up the overall risk to you from your condition or the risk to others caused by the above factors. If your needs do not fit easily into the categories, the team should still determine and record the extent and type of your need, and take it into account (and record it in the twelfth care domain) when deciding whether you have a primary health need. If there is a disagreement between the multidisciplinary team about the domain level to be chosen, the Framework advises that a higher level of a domain should be chosen with a reason for this.

The following table sets out the full range of the 12 care domains and illustrating the complexity, intensity and unpredictability of needs (N

= No need, L = Low, M = Moderate, H = High, S = Severe and P = Priority).



Department of Health, 2009

The tool in itself does not determine whether you are eligible. The final decision about whether you are eligible will be made using evidence from the completed tool as well as the professionals' clinical judgement.

Once the multidisciplinary team have agreed, they should make a recommendation about your eligibility for NHS Continuing Healthcare to your PCT. Only in exceptional circumstances and for clearly stated reasons, should the PCT not follow the multidisciplinary team's recommendation. An example of an exceptional

circumstance includes lack of evidence to support a recommendation.

The PCT coordinator's opinion or financial reasons should not form part of the PCT's decision not to follow the recommendation. The recommendation should not be determined by where the care is to be provided, or who delivers the care.

You and/or your representative should be fully involved in the assessment and able to contribute to the discussion about your needs. This includes having your views and wishes taken into account and recorded about whether you agree with the domain level chosen and with the way that the Decision Support Tool has been completed. The final outcome should be communicated to you and your representative in writing as soon as possible with:

- clear and concise reasons for the decision;
- details of whom to contact if you want clarification;
- a copy of the completed Decision Support Tool;
- information on how to ask for a review or appeal if the decision is not to award NHS Continuing Healthcare;
- details of the care to be provided if you are eligible.

4 What if I have mental health needs rather than physical health needs?

The Framework cautions against drawing generalisations about eligibility for Continuing Healthcare. This follows a Health Service Ombudsman report which made it clear that Continuing Healthcare is not just for patients with physical healthcare needs but also those with mental healthcare needs, including those relating to dementia, if the level of needs meet the national criteria (see section 2). For example, it may be that the person with dementia is physically mobile, but their condition means that they need intensive supervision to prevent them from being harmed or harming others. The same NHS Continuing Healthcare criteria and assessment should be completed to assess the needs of someone with dementia. This assessment should, where relevant, include the opinion of a psychiatrist or other mental health professional.

The Alzheimer's Society (tel.: 0845 300 0336; NHSCC@alzheimers.org.uk) has set up a support group for people who believe that they have wrongly been denied access to NHS Continuing Healthcare funding to help them challenge decisions. Members of the support group are volunteers who have themselves successfully obtained NHS Continuing Care funding. They offer practical support and information based on their own experience.

5 End-of-life care

If you have a primary health need arising from a rapidly deteriorating condition, which may be entering a terminal phase, you will need a package of care to be put in place quickly. If you have this type of health need, you can be 'fast-tracked' for immediate provision of NHS Continuing Healthcare, using the 'Fast Track Pathway Tool'. The Fast Track Pathway Tool bypasses the Checklist and Decisions Support Tool, ensuring that anyone in such a situation is supported to receive care in their preferred location as quickly as possible.

The Fast Track Pathway Tool may be used by a ward sister, registered nurse, consultant or GP responsible for your diagnosis, treatment or care to outline the reasons for the fast-tracking decision. This can be supported by a prognosis, but strict time-limits for life expectancy is not relevant for end-of-life care and should not be imposed. A copy of the Fast Track Pathway Tool can be viewed at:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103327.pdf

If a recommendation is made for an urgent package of care using the Fast Track Pathway Tool, the PCT should accept it and provide the care as quickly as possible. A person should not experience a delay in receiving care while a dispute is taking place.

End-of-life care can be provided in a variety of settings, including in hospital, in a hospice, in a care home or in your own home. You should be able to choose to remain in your own home if your needs can continue to be met in full, with external support when required.

Good end-of-life care practice is currently supported through a National End-of-Life Care Strategy (DH 2008). The Continuing Healthcare Framework complements the strategy because both focus on the needs of the person requiring care. Your needs, and how and where you would prefer to be supported, should be kept at the heart of the process, and the process should be explained to you in a careful and sensitive way.

6 Having an assessment for NHS Continuing Healthcare

Often, people are not informed about NHS Continuing Healthcare or the correct assessment process. The 'NHS Continuing Healthcare (Responsibilities) Directions 2009' state that NHS bodies must take reasonable steps to ensure that an assessment for NHS Continuing Healthcare is carried out in all cases where it appears that the person concerned may have a need for such care. Your PCT also has responsibility for communicating and making available information, in an accessible format, to all those who need it.

6.1 Timescale for decision-making

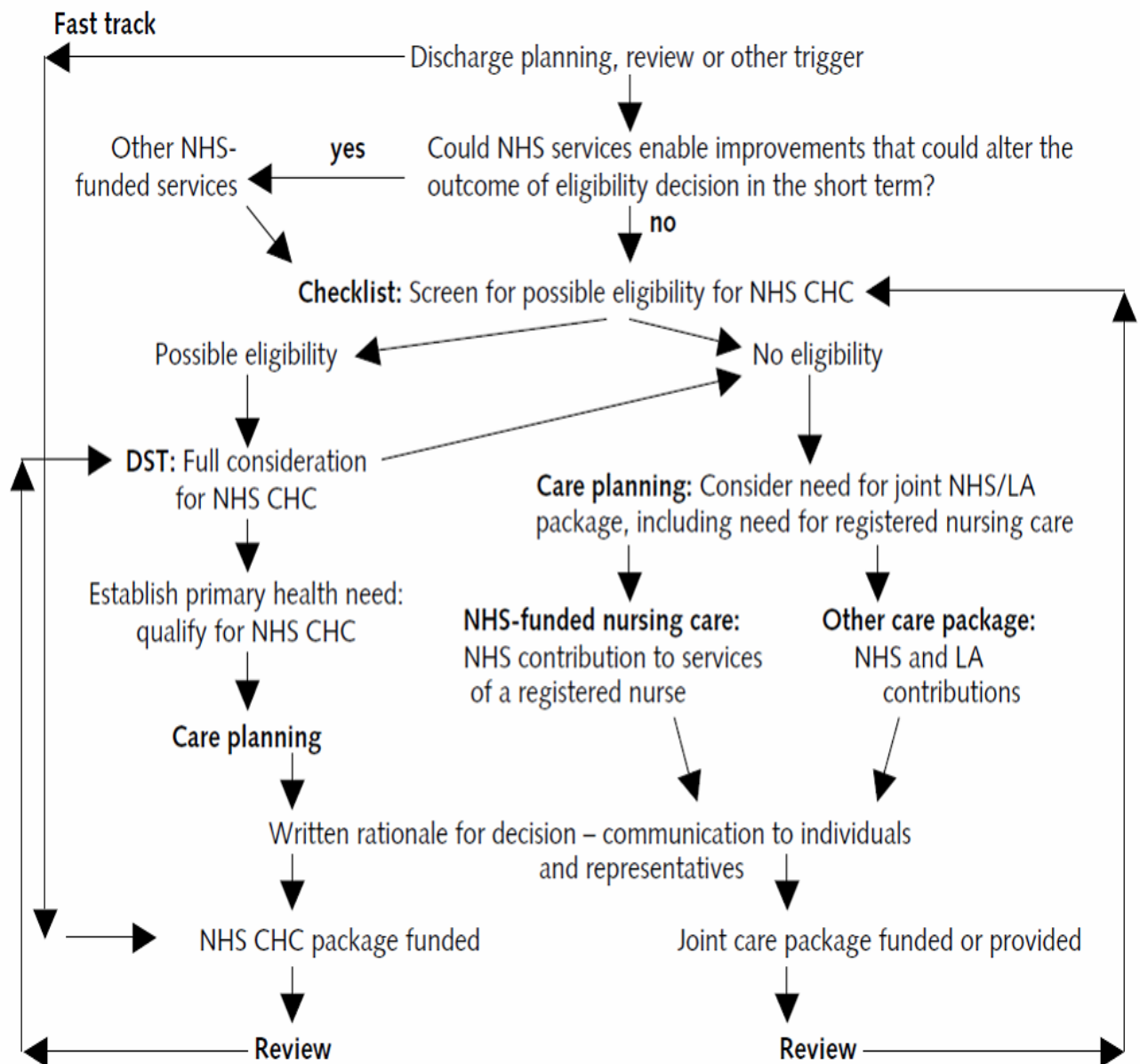
A decision on whether or not you are eligible for NHS Continuing Healthcare should, in most cases, be made within:

- 14 days of a request of a Checklist; or
- 28 days of the Checklist being received (for completion of the Decision Support Tool) – or 28 days of notification of the need for assessment being received

If a Fast Track Tool has been completed, an assessment should be carried out immediately and care should be provided within 48 hours.

If you are in hospital, the process is likely to be speedier, especially if you are in an acute hospital bed. However, if you ask for a review of

the decision, because you have been turned down for NHS Continuing Healthcare, this should take place within 14 days. The diagram below shows the different stages of the decision-making and assessment process for NHS Continuing Healthcare. You may find it useful to help you identify if there are any stages of the process which have been missed out.



Department of Health, 2009

7 Can I choose where my care is provided?

If you are assessed by the multidisciplinary team as meeting the criteria for NHS Continuing Healthcare, the PCT responsible for your GP will pay for your care. A care plan will then be produced outlining the extent of your needs, how your needs will be met and by whom, and the potential outcomes that can be achieved.

The Government is promoting a change in culture within the NHS to offer patients more right to choice about how and where their medical care is provided. Despite this, there are still limitations in the provision of NHS Continuing Healthcare, and it still depends on where you live and what resources are available. The National Framework for NHS Continuing Healthcare makes clear that the PCT will provide the package of care that is most appropriate to meet your assessed needs, but also acknowledges that your preferences, wishes and expectations should be taken into account before coming to a decision.

The core values and principles of the framework for NHS Continuing Healthcare states:

‘When deciding on how their needs are met, the individual’s wishes and expectations of how and where the care is delivered should be documented and taken into account, along with the risks of different types of provision and fairness of access to resources.’

Before the care is provided, you should have an opportunity to discuss with the PCT coordinator the type and location of the placement, together with the benefits and risk associated with each one, taking into account your needs and circumstances. For example, you may prefer to be placed in a hospice because you are in the final stages of a terminal illness, or you may prefer to spend your last days at home. The choice of placement will not only depend on the type and level of care needed, but also whether your home is suitable or can be adapted. Considerable weight should also be given to your quality of life and family environment. PCTs can take the cost of providing the care in a particular place into account but this should be based on a comparison with the actual cost of other options, such as at a care home, and should also consider specific reasons why you wish to remain in a certain environment.

If you have chosen to have your NHS Continuing Healthcare needs met in a particular residential care home but the care home has concerns that your needs may not be ones that can be met within their registration requirements, such as a need for nursing care, you may wish to discuss other ways of delivering the nursing support with the PCT coordinator dealing with your case.

If you are unhappy about plans for the location of your care, you may wish to put your concerns in writing to the PCT Continuing Healthcare coordinator, requesting a meeting and detailing your reasons for objecting. For example, it would appear unreasonable if

the location suggested for the care was too far for family and friends to be able to visit. However, if this location was the only one able to meet your ongoing health needs, because, for example, it has special equipment needed for your condition, it may not be unreasonable as your needs can be met there. If the PCT coordinator agrees there is no health reason why your care needs could not be met at home but your needs could not be met by existing community services, the PCT may be able to commission specific resources to meet your needs at home.

8 How long does NHS Continuing Healthcare last?

Although NHS Continuing Healthcare is for people with long term care needs, once awarded it does not last indefinitely. It can be stopped when your needs change. For example, if your needs stabilise or your condition improves. This should be made clear from the outset as regular reviews are carried out to ensure that the care provided continues to meet your needs.

A review of your needs should be carried out after three months of you first receiving Continuing Healthcare funding and then on a yearly basis thereafter.

If you are assessed as no longer qualifying for Continuing Healthcare, you can ask for the decision to be looked at again, especially if you feel that the assessor failed to take all your health needs into account. You can do this by asking for a review or an independent review of the decision (see section 9).

9 What if it is decided that I am not eligible for NHS Continuing Healthcare?

If you wish to challenge the Checklist outcome or the decision not to carry out a full assessment using the Decision Support Tool, you should obtain a copy of the completed Checklist. You should then ask the person who carried out the assessment to retake their decision, or contact the relevant PCT for reconsideration, providing any additional information which will help improve your chance of eligibility. If you are not satisfied with the outcome, you have a right to make a complaint using the NHS complaints procedure. For more information about making a complaint to the NHS, see our guide: **Complaints about community care and NHS services** (Guide number 18).

Similarly, if you have been refused NHS Continuing Healthcare following the use of the Decision Support Tool or Fast Track Tool (full assessment), you should ask to see the assessment, completed tool and criteria included in the National Framework on which this decision has been based. If you are denied a copy of the completed assessment, your local Independent Complaints Advocacy Service (ICAS), Patient Advice and Liaison Service (PALS) (www.pals.nhs.uk), or an independent advocate may be able to support you to obtain it. To contact these local organisations, look in your local telephone directory or your local library or GP surgery.

If you are still unhappy with the decision you will need to ask for a review of your case. This will generally be arranged at a local level, possibly reviewed by a neighbouring PCT. You can request a review of the decision by writing to the Chief Executive of your PCT, stating clearly that you feel that you have primary health needs that fit the criteria for NHS Continuing Healthcare. Each PCT should provide you with details of their local review process, including any timescales to respond.

The contact details for the Chief Executive of your PCT can be obtained by calling NHS Direct (tel.: 0845 46 47). You may also wish to send a copy of the letter to the Strategic Health Authority (SHA) whose contact details are also available from NHS Direct. Please remember to keep copies of any correspondence you send or receive because you may need to refer back to these at a later date. You can contact the Independent Complaints Advocacy Service (ICAS) for support with the review process. To find your local ICAS service, contact POhWER (tel.: 0300 456 2370; www.pohwer.net).

9.1 Requesting an Independent Review

If you remain dissatisfied with the decision and/or the process used, you may wish to request that your case is heard by your SHA's Independent Review Panel. If using the local process would cause undue delay, the SHA can agree that your case proceed direct to the Independent Review Panel, without going through the local process.

The Practice Guidance for NHS Continuing Healthcare directs PCT's to try to resolve disputes 'informally' up to the date of the IRP.

You can ask to attend the panel meeting or submit your views in writing. If you decide to attend, you can ask to bring a representative or advocate with you for support or to speak on your behalf, if you would prefer this. The panel members will need to satisfy themselves that the views of any person acting on your behalf accurately represent your own views and do not conflict with your wishes or best interests. Involved health and social care professionals and other relevant individuals, such as a care home manager, should be able to attend or submit their views as well. It may be a good idea to seek advice on how to ensure your argument for NHS Continuing Healthcare is best made to the panel.

In preparation for the meeting you may wish to:

- Gather all documentation, including the eligibility criteria for NHS Continuing Healthcare, the Checklist and the Decision Support Tool. Additional assessments from social services, health services and the care home can also be obtained to highlight your needs.
- Identify if all your medical and social care needs have been accurately recorded on the Decision Support Tool, and highlight any needs that may have been missed out.

- Look for any inconsistencies in the way that your needs have, or have not been recorded in your assessment or Decision Support Tool.
- Critically look at the 12 domains to see if a higher priority could be given for each domain.
- Provide concrete examples from the notes and tools to demonstrate why and how the criteria has been met.

The Independent Review Panel will look at cases where:

- The criteria has been wrongly applied for NHS Continuing Healthcare; or
- There is a dispute about the process used by the PCT to reach the eligibility decision.

The Independent Review Panel will not look at issues which should be dealt with using the NHS complaints procedure, including:

- The content of the eligibility criteria
- The type and location of services offered
- The content of any alternative care package offered
- The quality of treatment provided.

Under the revised directions, every SHA must give clear information to the public on how Independent Review Panels work and the areas they do and do not cover. You should have access to an

independent advocate to support you throughout the review process, where this is needed.

A case may not be accepted for an Independent Review if it is felt that your needs fall well outside the NHS Continuing Healthcare criteria. In such circumstances, the SHA should give you a full written explanation of the reasons for such a decision and remind you of your right to challenge this under the NHS complaints procedure.

The panel may recommend that your case should be reconsidered by the PCT, addressing any problems with how the process was carried out or how the criteria were applied. Alternatively, the panel may recommend that on the evidence submitted, you should or should not be considered eligible for NHS Continuing Healthcare.

A full record of the panel hearing should be kept and you and any other involved people should receive a copy of the recommendations. The decisions of an Independent Review Panel should be accepted by the SHA in all but exceptional circumstances. The SHA should let you and the PCT know the outcome of the review. If a SHA decides, in exceptional circumstances, not to accept an Independent Review Panel's recommendation, it should explain this in writing to you, the PCT and the chair of the panel, giving reasons why they are not accepting the decision.

The PCT in turn should accept the recommendation of the panel, in all but exceptional circumstances. If a PCT decides, in exceptional circumstances, not to accept an Independent Review Panel's recommendation, it should explain this in writing to you and the SHA, giving reasons why. In such circumstances, you have the right to pursue the matter through the NHS complaints procedure, and you should be informed in writing by the SHA or PCT of this right.

9.2 The Parliamentary and Health Service Ombudsman

If you are still not satisfied with the decision regarding your entitlement to NHS Continuing Healthcare or if it was not agreed by the PCT for your case to be heard by an Independent Review Panel, you may wish to make a complaint to the Parliamentary and Health Service Ombudsman (PHSO) (tel.: 0345 015 4033; www.ombudsman.org.uk). The Ombudsman is responsible for investigating complaints and unfair decisions made by NHS bodies. It will normally be expected that your case has already been investigated locally by the PCT and independently by the SHA before you contact the Ombudsman, but there may be special circumstances when you take your case directly to the Ombudsman.

If you feel the Ombudsman has not fully considered your complaint or they have done something incorrectly, you have a right to make a formal complaint about the Ombudsman itself. For more information, see: www.ombudsman.org.uk/make-a-complaint/unhappy-with-our-service.

Accordingly, the Ombudsman's decisions can be subject to judicial review procedures but you must make an application, usually within three months. You can seek legal representation if you are not satisfied with the Ombudsman outcome or you may wish to obtain legal support to challenge the overall decision not to award NHS Continuing Healthcare.

10 Refunds

When a decision on eligibility for NHS Continuing Healthcare is delayed or disputed, you may be entitled to a refund from the local council or an ex-gratia payment from the PCT to cover any costs you may have incurred as a result.

A copy of the NHS Continuing Healthcare Refunds Guidance is available from the Department of Health website:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_114985.pdf

10.1 Refunds for unreasonable delay

If a PCT decides that you are eligible for NHS Continuing Healthcare and takes unjustifiably longer than 28 days to reach this decision, the PCT should refund the local council the costs of any care services provided from day 29 until the date the decision was made. If you have made financial contributions to the local council, these payments should be refunded to you by the council. If you paid for your care in full you should receive an ex-gratia payment from the PCT (see section 10.3).

The refund should be made unless the PCT can demonstrate that the delay is reasonable as it was due to circumstances beyond the PCT's control. This could include a delay in getting access to copies of assessments or care records from a third party, or a delay in setting

up a multidisciplinary team. However, PCTs should make all reasonable efforts to ensure that the required information and decision is made available within 28 days.

10.2 Refunds after a review

If after the PCT decided that you were not eligible for NHS Continuing Healthcare you then disputed this and, as a result, the PCT revised its decision, the PCT should refund any costs incurred by the local council. If you made financial contributions to the local council, the local council should reimburse you in full. If you had paid for your care in full you should receive an ex-gratia payment from the PCT (see section 10.3).

10.3 Ex-gratia payments

If you have arranged and paid for care services privately while you were disputing a decision on eligibility for NHS Continuing Healthcare, which was then revised by the PCT or while there was a delay in the decision making process, you may be eligible for an ex-gratia payment. The PCT should consider making an ex-gratia payment to you in order to restore your finances to the position they would have been, had matters been carried out correctly. This is to remedy any injustice or hardship suffered as a result of the incorrect decision. If you feel that the amount of money is not enough to cover the costs you incurred, you can challenge it through the NHS complaints process.

11 Making a retrospective application for NHS Continuing Healthcare funding

It may be that having read this information, you feel that a decision made in the past about NHS Continuing Healthcare funding was incorrect. If this is the case, there are a number of steps you may wish to consider before applying for a refund or review of the decision:

- Decide what period you wish a retrospective review to be carried out for and obtain from the PCT a copy of the eligibility criteria used during that time. PCTs reviewing decisions made before implementation of the original Framework should use the most relevant, lawful criteria for the period under consideration. This might mean using the pre-National Framework criteria, so long as they are compliant with the Coughlan and Grogan judgments. For further information about these judgements, see the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (revised 2009) available from:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103162.
- Read the criteria closely to see if had, or may have needs that fit the criteria and as a result may have been wrongly charged for your care.
- Write or telephone the PCT where you were being cared for at that time to ask for a retrospective review. If you decide to call, it is important to follow this up with a written request for a retrospective review.

- You should have your letter acknowledged by the PCT and receive a consent form to sign and return to the PCT.
- Once the necessary forms have been returned, the Continuing Healthcare Team can begin to process your request.
- The NHS Continuing Healthcare Team is responsible for collating information about your health and social care needs from various sources, (dependent on your care needs at that time). This might include records from hospital admissions, records from any residential homes you stayed at, any records held by social services, district nurses or G.Ps.
- You should be informed in writing about the outcome. You should receive information on how to appeal and make a complaint if you are not happy with the decision.

11.1 Time-limits for retrospective reviews

Retrospective reviews for NHS continuing Healthcare funding can no longer be raised with the PCT or SHA for any period before April 2004, unless there are 'exceptional circumstances' why a review was not requested prior to this date. Retrospective reviews relating to NHS Continuing Healthcare (or where an assessment was absent) should have been raised with the PCT or SHA prior to the 'cut-off-date' of 30 November 2007.

You can still apply for retrospective reviews, for any period after April 2004.

In January 2007, Mike Pearce challenged Torbay Care Trust regarding payment of his mother's care home fees. His mother, Mrs Ruby Pearce, had been in a nursing home, for which she had sold her home to pay for

the fees. She died two years before the Ombudsman ruling. Since her death, Mike Pearce challenged the local PCT to pay for the fees of the nursing home, arguing that they should have been paid under NHS Continuing Healthcare funding. His mother was unable to do anything for herself, other than chew or swallow. The Health Services Ombudsman ruling stated that the PCT must reimburse Mike Pearce £50,000 in retrospective care fees which they now acknowledge they should have met. The Pearce case has important consequences for other people making a retrospective challenge; you may find it useful to make reference to this case if you are considering an appeal.

12 What is a NHS nursing care payment?

If you live in a nursing care home and do not meet the eligibility criteria for NHS Continuing Healthcare, an assessment for NHS-funded nursing care should follow. This is because you may be eligible for a NHS-funded nursing care payment of £108.70 a week instead. The payment will help towards the nursing care part of your care home fees. It does not cover the accommodation, board or personal care costs of your care home fees.

The NHS nursing care payment is only paid if you are assessed as needing care in a nursing home. The assessment will be carried out by a registered NHS nurse who will take into account all of your nursing needs, taking into account what would happen if the support was not provided.

The payment is normally paid direct from the NHS to the nursing home. If you are self-funding your care home placement, this payment will reduce your contribution to your care home fees. If you are receiving funding from your local council towards your care home fees, this payment will reduce the local council's contribution towards your care home fees. For more information about NHS nursing care payments, see our guide: **Care home fees: paying them in England** (guide number 16).

13 Joint packages of health and social care

If you live in your own home and have healthcare needs but not at the level for NHS Continuing Healthcare, the responsibility for your care will rest with the local council social services to organise a joint package of health and social care. With the combined package, the NHS and the local council jointly fund and provide services.

The local council social services is then responsible for carrying out a financial assessment to determine what your contribution will be towards the social care part of the package.

Depending on your needs, social services can arrange accommodation, such as: sheltered housing, residential care, nursing accommodation, or support services, such as help with washing, dressing, going to the toilet, preparation of meals, supervision of medication, assistance with transfers or a laundry service in your home, enabling you to live independently in the community.

For more information about getting help and support from your local council, see our guide:

Assessment and services from your local council in England (guide number 12).

14 Personal Health Budgets

Person Health Budgets (PHB) are part of a wider drive to personalise public services. The concept aims to help people have greater choice, flexibility and control over their care and the money spent to meet their assessed needs. At the moment, you do not have an automatic right to a PHB. This is at the PCT's discretion.

A PHB could include:

- a notional budget held by the PCT commission;
- a budget managed on your behalf by a third party; or
- a cash payment to the individual, known as a direct payment.

Currently a direct payment can only be provided to those already involved in pilot schemes approved by the Secretary of State. However PCTs are encouraged to consider providing other forms of PHB where appropriate, such as a notional budget held by the PCT. If the pilots are considered successful when they end in October 2012, you will be able to request for a PHB from April 2014. More information about PHBs is available from:

www.personalhealthbudgets.dh.gov.uk.

If you were already in receipt of a direct payment from social services, prior to becoming eligible for NHS Continuing Healthcare, you have a right to ask for a PHB, or that the direct payment continues, if withdrawal of the direct payment will have a detrimental effect on your care.

15 Can I pay more to choose a care home of my choice?

NHS services are free at the point of delivery, so patients should never be charged for, or asked to pay a top up to receive NHS care as this would contravene the founding principles and legislation of the NHS.

In regards to NHS Continuing Healthcare, if you voluntarily request to pay for additional health services, in addition to free NHS services, this should be discussed in the first instance with the PCT involved. The PCT will need to know why you wish to do this, ensuring that the existing package under NHS Continuing Healthcare is both sufficient and appropriate to meet your assessed needs. This will include reviewing your care to identify if there are any other NHS services that can be provided to meet your needs. Where the PCT agrees that you can pay for additional services privately, there must be a clear separation between the care and funding provided by the NHS to that purchased privately.

For example, it may be that you have been assessed as needing two physiotherapy sessions per week under NHS Continuing Healthcare, but you want to purchase additional physiotherapy sessions. The PCT should review your care to see if they should be providing more sessions in accordance with your assessed needs. If they decide they should not be, you can make private arrangements to employ, pay and have care delivered for these extra sessions separately. Financial arrangements for the privately funded care are entirely a matter between you and the relevant provider. It should not be included in any service agreement

between the PCT and the provider. If you intend to do this, discuss with the PCT how the additional private care will be managed, transferred and how consistency of care will be maintained in meeting your needs. For example, ensuring that both physiotherapist (private and NHS) use the same techniques.

In many cases, it may not be possible to make this distinction or separate arrangements for your care, especially if you want to pay a top up to stay in a care home of your choice because the PCT will contract to pay in full for your accommodation and personal care. Some people may want to pay for a more expensive room, for example because it is larger or has ensuite facilities. Before you agree to this, you should ensure that you are in a stable financial position to continue to pay the top-up, as long as it is needed, otherwise you may have to move to a cheaper room/care home.

Again, first you must discuss with the PCT why you wish to pay more. The PCT should then seek to review your care to identify if they have a duty to pay more, (for example the PCT should include personal needs such as proximity to family or health reasons) but if not, it is at the discretion of the PCT to allow this. If you are unhappy about this, you have a right to make a complaint to the NHS.

15.1 If I am already in a care home that costs more than the Primary Care Trust is willing to pay, can I be asked to move?

If you are already in a higher priced care home prior to becoming eligible for NHS Continuing Healthcare because you were paying for your own

care, or a third party paid a top up for your care when you were funded by the local council, the PCT can ask you to move to a cheaper care home. However, before moving the PCT should consider if they should pay more for your care so that you can remain in your existing care home and consider the risks involved in any change of care or location. For example, if your care home is the only care home where you can maintain regular contact with family members, or if your frailty, mental health needs or other needs mean that a move to another care home could involve a significant risk to your health and well being; the PCT should pay more.

If the PCT does not consider that there are reasons to justify them paying more, this should be communicated to you in writing. You have a right to dispute this by making a formal complaint using the NHS complaints procedures. You also have a right to help from an independent advocate.

16 Effect on benefit entitlement

16.1 Living at home

If you receive NHS Continuing Healthcare in your home, your benefits should not be affected. However, if you receive payments from the Independent Living Fund, these will usually stop after 7 days. This is because you have to receive social services funding to be entitled to payments from the Independent Living Fund (not NHS Continuing Healthcare funding).

If you receive Supporting People funding you may not be affected as it is not funded by social services. The Supporting People Commissioning body dealing with your case can advise you about their local eligibility criteria.

16.2 Living in a care home or in a hospital

If you are living in a care home or hospital, your state pension is not affected. If you receive Bereavement Allowance or Industrial Injuries Disablement Benefit, these will continue and will not be affected. Neither is the amount of Pension Credit you receive as long as it does not contain a severe disability premium. However, you will lose your entitlement to Disability Living Allowance (DLA) or Attendance Allowance (AA) after 28 days. If someone is receiving Carers' Allowance for supporting you, this will also stop when your DLA or AA stops. For further advice about the effect of NHS Continuing Healthcare on your benefit entitlement, contact your local Citizens Advice Bureau (tel.: 08444111444; www.citizensadvice.org.uk) or Age UK or Age Concern (tel.: 0800 1696565; www.ageuk.org).

17 Carers' needs

If you are caring for a person at home who receives NHS Continuing Healthcare, you are still entitled to an assessment of your needs as a carer. The Department of Health has provided PCT's with funding to help assist carers in their role which can include providing help and assistance with training that you may need to continue caring. The local council social services are also responsible for carrying out an assessment of your needs as a carer to enable you to have a life outside of your caring role. This is known as a carer's assessment.

Depending on the support services available in your local area, some of the needs identified in your carer's assessment but provided for the cared-for person, such as a respite break in a nursing home or a sit-in service, may be paid for by the NHS. There may also be other needs that social services can help with; for example support with independent living expenses and specialised equipment and adaptations.

Following a decision by the Health Service Ombudsman in 2004 (known as the Pointon case), NHS bodies should consider psychological needs as well as physical needs in their assessment for eligibility for NHS Continuing Healthcare. This support provided could include providing respite breaks to carers in the patient's own home, rather than arranging for the patient to go into a hospital to provide the carer a break. This fact may be particularly important for those patients who have dementia and might not understand why they have been moved from their home. You can read

about the Pointon case by going to:

www.ombudsman.org.uk/pdfs/pointon.pdf

For more information on support for carers you may want to contact Carers UK (tel.: 0808 808 7777; www.carersuk.org), a national carers support organisation. You may also want to see our guide:

Carers: What Support is Available? (guide number 10).

Our advice workers can advise on a wide range of issues affecting older people, their families and carers. We publish a range of guides about care and support for older people, which may be downloaded from our website www.counselandcare.org.uk, or requested by calling our guide order line on 020 7241 8522.

This guide is not a full explanation of the law and is aimed at people aged over 60.

Counsel and Care
Twyman House
16 Bonny Street
London NW1 9PG

Tel.: 0845 300 7585

Email: advice@counselandcare.org.uk

Website: www.counselandcare.org.uk

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