

Factsheet 20 September 2009

NHS continuing healthcare and NHS-funded nursing care

About this factsheet

This factsheet explains what NHS continuing healthcare is, the process for deciding whether you are eligible to receive it and what to do if you are unhappy with the decision reached. It also explains NHS-funded nursing care – the financial contribution towards the cost of meeting nursing care needs of residents of nursing homes.

This factsheet should be read in conjunction with Age Concern's other factsheets: 10 *Paying for permanent residential care*, 38 *Treatment of property in the means test for a permanent care home place*, 39 *Paying for care in a care home if you have a partner* and 41 *Local authority assessment for community care services*.

The information given in this factsheet is applicable in England. Different rules may apply in Wales, Northern Ireland and Scotland. Readers in these nations should contact their respective national Age Concern organisation for information specific to where they live – see section 8 for details.

For details of how to order other Age Concern Factsheet and information materials go to section 8.

Inside this factsheet

1	Recent developments	4
2	Continuing care	4
3	NHS continuing healthcare	5
	3.1 Background to NHS continuing healthcare	5
	3.2 What is NHS continuing healthcare?	5
	3.3 Who arranges and funds NHS continuing healthcare?	6
	3.4 What is the National Framework?	6
	3.5 Who is eligible for NHS continuing healthcare?	7
	3.6 When should eligibility be considered?	7
	3.7 How is eligibility decided?	8
4	National Framework principles and process	9
	4.1 Involving you and your carers	9
	4.2 Routes to reaching a decision	10
	4.3 Applying the checklist tool	11
	4.4 Multi-disciplinary assessment	13
	4.5 Decision-support tool	13
	4.6 Fast-track tool	16
	4.7 What happens if you are eligible?	17
	4.8 What happens if you wish to challenge a decision?	20
	4.9 Effect on state benefits of NHS continuing healthcare	22
	4.10 Reviewing eligibility decisions	23
	4.11 Your care package if you are not eligible	23
	4.12 Refunds available for unreasonable delay in reaching an initial decision or when disputing a decision	24
5	Challenging NHS continuing healthcare decisions made before October 2007	25
6	NHS-funded nursing care	26
	6.1 How is eligibility for NHS-funded nursing care decided?	27
	6.2 Review of NHS-funded nursing care needs	27
	6.3 NHS-funded nursing care payments	28
	6.4 If you are admitted to hospital	28
	6.5 Short stays in a nursing home	29
7	Useful organisations	29
8	Further information from Age Concern	30

1 Recent developments

- Revised National Framework guidance and revised tools (checklist tool, decision-support tool and fast-track tool) to support decision-making were issued in July and will be used from 1 October 2009. The revisions reflect issues raised during a planned review undertaken one year after the National Framework was first implemented in October 2007.
- Revised NHS-funded nursing care in a care home rates from April 2009 are outlined in section 6.3.

The revised guidance and tools do not change the overall principles or the basis on which decisions about eligibility for NHS continuing healthcare are made. Rather they clarify the process and explain more clearly the types and levels of needs staff will be looking at and recording when they carry out a needs assessment, complete the tools used to support decision-making and ultimately make a recommendation about your eligibility. **This factsheet is based on the revised guidance and tools.**

2 Continuing care

Health and social care professionals may use the following terms when describing support from the NHS or a local authority.

Continuing care is a general term describing care provided over a period of time to meet physical and mental health needs that have arisen as a result of disability, an accident or illness.

Continuing NHS and social care is care available in a range of settings that may involve services from the NHS and social services. It may also be described as a 'joint package of continuing care'.

NHS continuing healthcare – a complete package of ongoing care arranged and funded by the NHS. See sections 3 and 4.

Note: Although these are not the terms used by the Care Quality Commission for different types of care home, for ease of reading we will use the shorter terms: residential home or nursing home, or care home if it can be either.

3 NHS continuing healthcare

3.1 Background to NHS continuing healthcare

When you have long-term care needs it is usually obvious whether the help you need is the responsibility of the NHS or of social services. However, if you have complex needs, the boundaries between health and social care may not always be clear. As services provided by the NHS are free whereas those arranged by social services are means tested, the outcome of any decision as to who has overall responsibility for your care can have significant financial consequences.

Since the early 1990s, the Parliamentary and Health Service Ombudsman has investigated a large number of complaints about local criteria developed using government guidance and about processes followed when making decisions about eligibility for NHS continuing healthcare. The legality of some eligibility decisions was challenged in the courts.

It is against this background that the National Framework for NHS continuing healthcare and NHS-funded nursing care was developed and first introduced in England in October 2007.

Further information about the Ombudsman's investigations and court decisions can be found in the appendix to this factsheet (see page 30).

3.2 What is NHS continuing healthcare?

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

If you live in your own home, the NHS arranges and funds an appropriate care package to meet your assessed health and personal care needs. If you live in a care home, the NHS makes a contract with the home to pay fees covering your accommodation and assessed health and personal care needs.

3.3 Who arranges and funds NHS continuing healthcare?

If you are found eligible for NHS continuing healthcare, the Primary Care Trust (PCT) that holds the contract with your GP practice at the time of your assessment is responsible for arranging and funding a suitable care package. Each PCT has a manager responsible for NHS continuing healthcare.

3.4 What is the National Framework?

The National Framework for NHS continuing healthcare and NHS-funded nursing care is a Department of Health guidance document that:

- sets out clear principles and processes to be followed throughout England for establishing eligibility for NHS continuing healthcare (see section 4)
- clarifies the interaction between the assessment for NHS continuing healthcare and NHS-funded nursing care (see section 6).

It aims to minimise local interpretation and improve the clarity, transparency and consistency of the decision-making process by providing:

- guidance that must be followed by all PCTs in conjunction with their local authorities and by hospital staff involved in the assessment process
- a national assessment process supported by the three tools – checklist tool, decision-support tool and fast-track tool
- common paperwork to record evidence that will inform decision-making.

The Framework and the three tools to support the decision-making process have been used in England since 1 October 2007.

Revisions to both the Framework and the tools were published in July 2009 for use from 1 October 2009. They clarify the process and explain more clearly the types and levels of needs that staff look for and record when they assess your needs, complete the tools used to support decision-making and ultimately make a recommendation about your eligibility.

Note: The guidance and three tools with accompanying notes can be found at www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_079276

3.5 Who is eligible for NHS continuing healthcare?

Eligibility for NHS continuing healthcare does not depend on who provides your care or where care is provided or on having a particular condition or diagnosis.

Eligibility decisions should be independent of budgetary constraints and rest on whether your need for care is primarily due to your health needs. This is referred to as having a 'primary health need'.

Certain characteristics of your needs, in combination or alone, may demonstrate a 'primary health need' because of the quantity and/or quality of care needed to manage them. So when assessing your needs, staff consider them in relation to these characteristics:

- **nature:** the type of needs, and the overall effect of those needs, including the type (quality) of interventions required to manage them
- **intensity:** both the extent (quantity) and severity (degree) of the needs and the need for regular interventions to manage them
- **complexity:** how the different needs arise and interact to increase the skill needed to monitor and manage care
- **unpredictability:** unexpected changes in your condition that are difficult to manage and the degree of risk to you or others if adequate and timely care is not provided.

These characteristics are reflected in the descriptions of the different levels of need that feature in the checklist tool and decision-support tool. These tools help inform staff making a recommendation about your likely or actual eligibility for NHS continuing healthcare. See sections 4.3 and 4.5.

These characteristics are also considered by staff deciding whether to recommend 'fast tracking' a patient so they can receive an urgent package of NHS continuing healthcare in an appropriate location. See section 4.6.

3.6 When should eligibility be considered?

A PCT must take reasonable steps to ensure that an assessment for eligibility for NHS continuing healthcare is carried out in all cases where it appears necessary and regardless of where you are living at the time.

Note: There are three sets of Directions that explain this duty to determine eligibility in cases where it appears necessary. They are:

The NHS Continuing Healthcare (Responsibilities) Directions 2009

The Delayed Discharge (Continuing Care) Directions 2009

The National Health Service (Nursing Care in Residential Accommodation (Amendment) (England) Directions 2009.

Not everyone with ongoing health needs is likely to be eligible but there are times to make sure your eligibility is considered by applying the checklist. You should ask hospital staff, or speak to your GP or social services:

- when you are ready to be discharged from hospital and are not being offered rehabilitation or other NHS-funded services that may lead to an improvement in your condition. Your eligibility must be considered before a decision to find a permanent place in a nursing home is made
- whenever your health and social care needs are being reviewed as part of a community care assessment
- if your physical or mental health deteriorates significantly and your current level of care – at home or in a care home – seems inadequate
- when, as a resident of a nursing home, your nursing care needs are being reviewed. This should be undertaken at least annually (see section 6)
- if you have a rapidly deteriorating condition with an increasing level of dependency and may be approaching the end of your life.

3.7 How is eligibility decided?

Staff should follow the Framework guidance, using one or more of the three tools provided – checklist, decision-support tool and fast-track tool.

Note: You may find it helpful to see a copy of the tool(s) in advance. They should be available from the staff who will be using them and can be found on the Department of Health website (see section 3.4)

The process for deciding eligibility is described in the following section.

4 National Framework principles and process

4.1 Involving you and your carers

Staff should ensure that you and your family understand at the outset how they will decide if you are eligible for NHS continuing healthcare. At each stage, decisions made and their rationale should be transparent and communicated clearly in writing.

Where possible, when the checklist is applied or a full assessment is taking place or the decision-support tool is completed, you and where appropriate a family member or representative should be enabled to play a central role.

If you are found eligible for NHS continuing healthcare, the final decision about your care plan and location of care rests with the funding PCT. However, when your care plan is drawn up, your wishes and expectations of how and where you might be cared for should be recorded and taken into account and considered, along with any risks that may be associated with where you are cared for and fair access to PCT resources.

Giving consent

You should be told if staff consider you may be eligible for NHS continuing healthcare. Your informed consent should be explicitly sought and staff should let you know whether they are seeking your consent to apply the checklist or complete a full assessment of your needs or completion of the decision-support tool. You can withdraw your consent at any stage in the process if you wish.

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

When you lack capacity to give consent

If it is agreed that you lack capacity to give consent, staff should check whether, under the Mental Capacity Act 2005, you have appointed someone to have Lasting Power of Attorney (LPA) to act on your behalf on health and welfare matters or whether someone has been appointed a Welfare Deputy by the Court of Protection. A partner, family member or other 'third party' cannot give or refuse consent on your behalf unless this is the case.

If no one has been appointed to act in one of these ways, staff will be responsible for making decisions on your behalf and must act in your 'best interests', having consulted with those who have a genuine interest in your welfare. This will usually include your family and friends. The expectation is that everyone who is potentially eligible should have the opportunity to be considered. The outcome of a 'best interests' decision should be recorded.

Advocacy

If the PCT (or local authority) ultimately has to make a 'best interests' decision that involves a change of residence – it may be considering a move to a care home when drawing up your care plan – it has a duty under the Mental Capacity Act to instruct and consult an Independent Mental Capacity Advocate (IMCA).

The IMCA's role is to seek information about what would be in their client's 'best interests', represent their interests and challenge any decision that does not appear to be in their 'best interests'.

Even when you have capacity to make your own decisions, you can ask a family member to act as an advocate and help you make your views known. You can ask the person co-ordinating your assessment for details of local advocacy services that you could approach for advice and support.

Note: You can find out more about LPAs, IMCAs and the Mental Capacity Act 2005 from the Office of the Public Guardian. See section 7.

4.2 Routes to reaching a decision

Times when you should ensure your eligibility is considered are raised in section 3.6.

There is an option using the '**fast-track tool**' to recommend you move quickly onto NHS continuing healthcare. It can be used if you have a rapidly deteriorating condition with an increasing level of dependency and appear to be reaching the end of your life. See section 4.6.

However this is not the usual route. For most people the type and level of their needs should prompt the application of the '**checklist tool**'. This in turn may trigger a **full assessment of eligibility, using the 'decision-support tool' and ultimately a recommendation about your eligibility.**

You may also be recommended for a full assessment without completion of the checklist tool.

4.3 **Applying the checklist tool**

The checklist is designed to help staff identify who needs a full assessment of their eligibility and to ensure there is a rationale for any decision reached. It can be applied in a hospital or non-hospital setting by a doctor, nurse, other health professional or social worker who is familiar with the guidance.

The threshold has been set deliberately low to ensure that all those who require a full assessment will have this opportunity.

Note: A decision to apply the checklist should not be taken to imply that you will or should be eligible for either a full assessment or NHS continuing healthcare itself.

You should be offered the opportunity to be involved when the checklist is completed and asked if you would like a family member, advocate or other representative present. Their name should be included on the completed checklist if you do.

Hospital discharge

The Guidance draws attention to the fact that an assessment of eligibility that takes place on a busy acute hospital ward, may not allow your potential for further recovery to be recognised or allow your needs to be adequately reflected.

If you are about to be discharged from hospital, particularly if your admission to hospital was not planned, it is important for staff to consider whether there is potential for your condition to improve if further NHS-funded services, such as rehabilitation or intermediate care services, are provided in another part of the hospital or other appropriate setting. If you are offered additional NHS-funded services, a note should be made to apply the checklist once your period of rehabilitation is complete.

If the checklist is applied as part of the discharge process and it indicates a need for a full assessment, staff may wish to offer further NHS-funded services before carrying this out. Again a note should be made to carry out the full assessment once this additional support has finished.

The checklist is based on the 12 'domains' or areas of need that feature in the decision-support tool. The decision-support tool is explained in section 4.5.

For each domain, there are descriptions that represent '**no and low**' needs, '**moderate**' needs and '**high**' needs.

Staff must choose the description that most closely matches your current needs, taking into account well-managed needs and any increased needs that might be expected over the next three months. These choices must be backed up by evidence that should be available on request.

A full assessment is required if there are:

- high levels of need in two or more domains or
- moderate levels of need in five or more domains or one high and four moderate levels or
- one high level of need in one of the four domains that carries a priority level in the D-ST and any levels of need in other domains.

Staff are able to recommend a full assessment even though you do not meet the above threshold.

Once the checklist is completed you, and/or your family where appropriate, should be informed of the decision and given a clear explanation of the basis of the decision. You should also be given a copy of the completed checklist, which should give enough detail to enable you and your family to understand why that decision was made.

If you disagree with the decision, you should be told that you can ask the PCT to reconsider and told who to contact if you wish to do this. The PCT should give your request due consideration, taking account of all available information including extra information provided by you or your carer.

Note: You should receive a clear, written response and be told of your right to complain using the NHS complaints procedure if you remain dissatisfied with their position.

If you are to have a full assessment of your eligibility, the time taken between the PCT receiving notification that this is needed and an NHS continuing healthcare funding decision being made should not normally exceed 28 days. Timescales should be clearly communicated to you, and where appropriate your family, if it is likely to take longer than this. You should not be left without appropriate support while waiting for an eligibility decision. See section 4.12.

4.4 **Multi-disciplinary assessment**

Once you are referred for a full assessment, the PCT is responsible for co-ordinating the whole process until a decision about your eligibility and the funding of your care has been reached and a care plan agreed. The PCT should appoint someone employed by them, or by mutual agreement by another organisation, to co-ordinate this process.

An appropriate range of health and social care professionals, which may include those not currently caring for you but who have a direct knowledge of you and your needs, should be invited to contribute to your assessment so that all your physical and mental health and social care needs can be looked at and evaluated individually and together – including ways in which they interact with each other – to give an accurate reflection of your current needs and likely changes in the near future.

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

4.5 **Decision-support tool**

Information collected during your assessment is used to complete the decision-support tool that helps inform the eligibility decision.

The tool features 12 ‘domains’ or areas of need – 11 specific domains and a 12th which is an open domain for needs that don’t readily fit into the other 11.

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

‘No need’ ‘low’ ‘moderate’ ‘high’ ‘severe’ ‘priority’

The descriptions given for the levels in each domain minimise the use of medical terms so that they can be understood by you and your family.

The domains are:

- 1 **Behaviour** ▶▶
- 2 Cognition ▶
- 3 Psychological and emotional needs
- 4 Communication
- 4 Mobility ▶
- 6 Nutrition – Food and Drink ▶
- 7 Contenance
- 8 Skin including tissue viability ▶
- 9 **Breathing** ▶▶
- 10 **Drug therapies and medication: symptom control** ▶▶
- 11 **Altered states of consciousness** ▶▶
- 12 Other significant care needs to be taken into consideration ▶

▶▶ indicates this domain goes up to priority level of need

▶ indicates this domain goes up to severe level of need

The decision-support tool is completed by a **multi-disciplinary team** (M-DT) identified by the co-ordinator. The team should have at least two professionals usually from both health and social care professions. Other professionals who have an up-to-date knowledge of your needs and potential may also be included.

When the D-ST is completed you should be invited to be present or represented where possible. You should be given sufficient notice of the date for you to arrange for a family member or advocate to be present if you wish. If this is not possible, your views or those of your representative, should be obtained and actively considered when completing the D-ST. Those completing the tool should note within it whether you or your representative were present and/or represented and, if not, the reason why.

The completed tool should give an overall picture of your needs.

When completing the tool, the following points are important:

- all care domains should be completed, ideally on the same day

- the team should use the assessment evidence and their professional judgement to select the level that most closely describes your needs
- your needs should not be placed between levels. If it proves difficult to choose between two levels, the higher level should be selected and the reasons for differences of opinion recorded
- interactions between needs should be considered as appropriate
- needs not covered by one of the 11 domains should be recorded in the 12th domain and taken into account when making an eligibility decision
- needs should not be marginalised because they are successfully managed. Well-managed needs are still needs and should be recorded appropriately.

If it can reasonably be anticipated that your condition will deteriorate and that needs in certain domains will increase in the near future, this should be recorded and taken into account when the final recommendation is made. Such knowledge may also influence the time when a review of your needs should be undertaken.

Reaching a decision

The multi-disciplinary team uses evidence from the completed D-ST, along with relevant risk assessments and their experience and expertise, to make a recommendation to the PCT as to whether or not your needs have characteristics that demonstrate a 'primary health need' and hence eligibility for NHS continuing healthcare. The D-ST has space for their recommendation and for your views or those of your representative.

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

- priority level of need in any of the four domains with that level
- two or more instances of severe needs across all domains.

A primary health need may also be indicated if there is:

- 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.

In this case the judgement whether you have a 'primary health need' must be based on what the evidence indicates about the nature and/or complexity and/or intensity and/or unpredictability of your needs.

If needs in all domains are 'no need', this would indicate ineligibility and if all are 'low' needs, this is unlikely to indicate eligibility.

Only in exceptional circumstances should the PCT disagree with the M-DT's recommendations.

Note: Having taken into account any likely deterioration in your condition that could affect your needs, a recommendation for you to be 'fast tracked' on to NHS continuing healthcare may be appropriate. See section 4.6.

The team is also asked to indicate whether they expect your needs to improve or deteriorate before the three-month review and whether they would recommend an earlier review.

A decision that you are eligible for NHS continuing healthcare can be overturned at a later date if a review of your condition shows your condition has improved and your needs changed.

If the recommendation is that you are not eligible but that you may need care in a care home the team should indicate, with reasons, whether this should be nursing home.

4.6 **Fast-track tool**

When you have a rapidly deteriorating condition with an increasing level of dependency and may be approaching the end of your life, urgent consideration of your eligibility would allow an appropriate care package to be arranged as quickly as possible.

Such changes in your condition could be observed while you are in hospital or by staff caring for you at home or in a care home. If this happens, they should contact an 'appropriate clinician' and ask them whether it would be appropriate to consider completion of the 'fast-track tool'.

An 'appropriate clinician' would be a doctor or nurse responsible for your diagnosis, treatment or care or with a specialist role in end-of-life needs, who would have an appropriate level of knowledge or experience to review your current type of needs.

Decisions to 'fast track' should be made case by case and supported by a prognosis, where possible. Strict time limits that base eligibility for fast tracking on some specified, expected length of life remaining should not be imposed. Care should be taken to explain why a fast-track decision has been made.

A recommendation for an urgent package of care made via the 'fast-track' process should be accepted and actioned by the PCT so that an appropriate package of care is provided in your preferred location where possible. The PCT can then proceed, where appropriate, to reach a decision on your longer term eligibility.

When arranging a care package the PCT should follow the principles set out in the *End of life care strategy*, taking account of your preferences and wishes expressed in your advance care plan.

Note: You can find out more about the *End of life care strategy* on the Department of health website:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPolicyAndGuidance/DH_086277

Care should be taken to minimise the chance of needing to reverse an eligibility decision within a short time. No one who has been identified as eligible for NHS continuing healthcare through the fast-track process should have their funding removed without going through the usual review process set out in the National Framework. See section 4.10.

Funding arrangements should remain in place until any disputes have been resolved through the agreed dispute procedure.

4.7 **What happens if you are eligible?**

The PCT should tell you their decision verbally and in writing, giving clear reasons and the basis on which the decision was made. A copy of the completed decision-support tool should also be available to you. This is not necessarily a permanent decision as your condition and needs may change. Ongoing reviews are built into the process. See section 4.10.

The PCT must provide a care package it thinks appropriate to meet your needs. When drawing up and agreeing your care plan, your preferences and those of your relatives or advocate on how and where your care is provided should be taken into account, together with any risks associated with different types of care and fairness of access to PCT resources. The final decision rests with the PCT.

Note: If you are dissatisfied with the care package proposed by the PCT and cannot resolve your concerns informally, you should be told how to access and use the NHS complaints procedure.

Your care can be provided in a range of settings.

In a care home

If it is agreed you should move into a care home, you do not have the right to choose either the location, ie the town, or actual care home but you can express preferences. It is usually a nursing home but does not have to be particularly if you have been awarded NHS continuing healthcare through the 'fast track' route, have been living in a residential home and have expressed a preference to remain there.

The PCT may have a contract with one or more nursing homes but your assessed needs will determine whether they are suitable.

It may seem more appropriate for you to move to a home closer to relatives who live in a different PCT area. You may propose this but cannot assume it will be acceptable to the funding PCT.

If it is agreed you can live in a care home in a different PCT area, your care home fees continue to be the responsibility of the PCT that initially agreed your placement. Once you move into the care home, you need to register with a local GP practice. Once registered, any NHS services or treatment unrelated to the reason for your placement in the care home become the responsibility of your GP practice's PCT.

If you are living in a care home when the decision to grant NHS continuing healthcare is made, you need to discuss whether you can stay there with your PCT. This is particularly relevant if your home is more expensive than the PCT would normally pay to meet needs such as yours. The risks and benefits of moving you, including the effect on your physical and mental health, would need to be assessed before a decision is made.

If your current care home cannot meet your needs you would need to discuss this with the PCT.

In a hospice

This may be appropriate if you are reaching the end of your life. However, government policy is, where possible, to allow you to be at home at this time if you prefer.

In your own home

The PCT package you receive should meet all your eligible needs, including personal and social care needs. This is often a more complex care package to arrange and local resources may influence whether care can be provided at home.

If you were living at home prior to being eligible for NHS continuing healthcare, you may have been receiving Direct Payments from your local authority. Although NHS continuing healthcare cannot be provided through direct payments, PCTs can arrange services to maintain a similar package of care to that already in place, to replicate as far as possible the personalisation and control you enjoyed with direct payments.

If you have a partner who is providing or will in future provide a substantial amount of care as part of your care package, the PCT should let them know of their right to ask the local authority for a carer's assessment.

The NHS Operating Framework for 2009/10 describes national NHS priorities for the year. It says:

The Carers Strategy sets out how we can ensure we support carers. One key requirement is that PCTs should work with their local authority partners and publish joint plans on how their combined funding will support breaks for carers, including short breaks, in a personalised way.

Moves with the UK

If you wish, regardless of setting, to receive care in Wales, Scotland or Northern Ireland, there would need to be discussion between your funding PCT and the relevant health body in your chosen country.

Other NHS services

You should receive GP, dental and other NHS services as needed.

4.8 What happens if you wish to challenge a decision?

You or your family can approach the relevant Strategic Health Authority (SHA) for an independent review of the PCT's decision if you have been unable to resolve the matter through the PCT's local dispute resolution process and you are dissatisfied with:

- the procedure followed in reaching their eligibility decision
- application of the criteria of eligibility, ie the primary health need test.

There are two stages in the review process:

- a local review process at PCT level
- a request to the SHA, which may refer the matter to an independent review panel (IRP).

You may have to contribute towards the cost of your care while the review is undertaken. However if the PCT's initial decision is revised, guidance issued in March 2010 explains the refund process. See section 4.12

If using the local review process would cause undue delay, the SHA has the discretion to put your case straight to the IRP.

Each PCT should agree a local review process, including timescales, which should be made publicly available and sent to anyone who requests a review of a decision. It may involve referring your case to another PCT for consideration or advice.

Once local procedures are exhausted your case should be referred to the IRP. The SHA can decide not to convene a panel but before doing this should seek the advice of one of the individuals who can chair a panel. If the SHA decides not to convene a panel you, your family or representative should have a full written explanation explaining why and be told of your rights to use the NHS complaints procedure to take it further.

The IRP has a scrutiny and reviewing role and is required to make a recommendation to the SHA in the light of its findings. It is therefore not generally appropriate for you to be legally represented at an IRP hearing, although you may wish to be represented by a family member, advocate or advice worker. If you wish the support of an advocate, your PCT should have details of local advocacy services.

Note: Details of IRP procedures are in Annex E of the National Framework Guidance.

However both the IRP and local procedures should follow the key principles for dispute resolution that are outlined in the Framework. They include:

- gathering and scrutiny of all available and appropriate evidence, whether oral or written, from relevant health and social care professionals, as well as information submitted by the individual, completed tools and the deliberations of the multi-disciplinary team
- compilation of a robust and accurate identification of care needs
- audit of any attempts to gather any records said not to be available
- involvement of the individual or their representative as far as possible, including the opportunity for them to contribute to and comment on information at all stages
- a full record of deliberations to be made available to all parties
- clear and evidenced written conclusions on the process followed by the NHS body and on the individual's eligibility for NHS continuing healthcare, together with appropriate recommendations and action to be taken in the light of the Framework rationale.

The role of the IRP is advisory but its recommendations should be accepted by the PCT in all but exceptional circumstances.

In all cases the SHA should communicate the outcome of the review, with its reasons, to the individual and the PCT.

If the original decision is upheld and you still wish to challenge it, you can ask for it to be referred to the Health Service Ombudsman.

Note: If you are dissatisfied with issues other than the process followed or application of the criteria – such as the type and location of your package of care or content of your care package – you should be told how to access and use the NHS complaints procedure. This is explained in Age Concern Factsheet 66, *Resolving problems and making a complaint about NHS care*.

4.9 Effect on state benefits of NHS continuing healthcare

Attendance Allowance

If you are self funding your care in a care home and receiving Attendance Allowance (AA) or Disability Living Allowance (DLA) and will receive NHS continuing healthcare in a care home, you should notify the Disability Benefits and Attendance Allowance helpline (see section 7). Your benefit will cease on the 29th day after the PCT begins to fund your care or sooner if you have recently been in hospital.

If you are living at home and claiming AA or DLA but will receive NHS continuing healthcare in a care home, you should notify the helpline. Your benefit will cease on the 29th day after the PCT begins to fund your care or sooner if you have recently been in hospital.

If you are living at home and claiming AA or DLA and will continue to live at home with an NHS continuing healthcare package, you can continue to receive AA and DLA.

Other benefits

Your **State Pension** is not affected by your eligibility for NHS continuing healthcare.

You lose the severe disability element of your **Pension Credit** award when you are no longer entitled to AA or DLA (care), and this may affect the amount of Pension Credit you receive.

4.10 **Reviewing eligibility decisions**

If you have been considered for NHS continuing healthcare and the NHS is providing or funding any part of your care package, a case review should be undertaken no later than three months after the initial eligibility decision.

Reviews should take place annually after that, as a minimum.

The multi-disciplinary team making the original recommendation after a full determination of your eligibility for NHS continuing healthcare may have made a specific recommendation about the timing of your next review. See section 4.5.

If you are receiving NHS continuing healthcare as a result of 'fast tracking' and it is appropriate to consider your longer term needs, your review should include completion of the D-ST by a multi-disciplinary team along with their subsequent recommendation on future eligibility.

The review will determine whether your needs have changed and consequently whether your care plan needs revising.

4.11 **Your care package if you are not eligible**

If it is agreed that you are not eligible for a full consideration of your eligibility following application of the checklist, a joint health and social care assessment will identify your needs. When your care package is agreed, your PCT and local authority will need to decide where their responsibilities lie. You will be means-tested for services that are the responsibility of social services.

If you are found not eligible following a full consideration for NHS continuing healthcare, needs identified during your assessment and your views on how your needs can best be met will form the basis of your agreed care plan and care package which may include the provision of equipment. It is likely you will have needs for services from both the NHS and social services. You will be means-tested for services that are the responsibility of social services.

NHS services that may be provided in their own right regularly or on an ad-hoc basis alongside social care services include:

- care provided in a nursing home by a registered nurse (see section 6)
- rehabilitation and recovery services such as speech therapy

- assessment and/or support from community-based NHS staff such as district nurses, continence nurses, specialist diabetic nurses
- palliative care services.

Note: For more information about care assessments and charging procedures when care services are provided by a local authority see the other Age Concern factsheets listed on page 1.

4.12 **Refunds available for unreasonable delay in reaching an initial decision or when disputing a decision**

You may be entitled to a refund to cover any costs you have incurred when a PCT eligibility decision is:

- unjustifiably delayed or
- revised following reconsideration by the PCT or as a result of an Independent Review Panel (IRP) recommendation.

Note: New guidance was issued in March 2010 to clarify the position. You can find the guidance at:

NHS Continuing Healthcare Refunds Guidance March 2010

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114986

Refunds for unjustifiable delay

The National Framework states that in most cases the PCT decision on eligibility should take no longer than 28 days from the date it receives either the completed Checklist or a request for a full assessment.

If a PCT decides you are eligible but ‘unjustifiably’ takes longer than 28 days to reach the decision, it should refund to the local authority the costs of services provided from day 29 to the date the decision was reached. **If you and the local authority have been contributing towards the cost of your care**, the local authority should reimburse you in full.

If you were funding all your care, you should receive an ex-gratia payment from the PCT. This is to restore your finances to the state they would be in

had the delay not occurred and to remedy any injustice or hardship you suffered as a result of the delayed decision.

Examples of 'unjustifiable' delays might include delays in receiving records or assessments requested from a third party or delays outside the PCT's control, in convening a multi-disciplinary panel. However the PCT should aim to develop protocols to help it meet the 28 day deadline.

Refunds following a revised decision

If you dispute a PCT's initial eligibility decision and this decision is revised following further consideration or as a result of a recommendation by an IRP, the PCT should reimburse any costs incurred by the local authority. **If you and the local authority were contributing to the cost of your care**, the local authority should reimburse you.

If you were funding all your care costs, you should receive an ex-gratia payment from the PCT. This should aim to restore your finances to the state they would have been in had the correct decision been made at the outset and to remedy any injustice or hardship as a result of the incorrect decision.

The period of reimbursement or ex-gratia payment should start from the date the initial PCT decision was made (or earlier if an unjustifiable delay has been acknowledged) until the date the revised decision comes into effect.

If you wish to dispute a PCT decision on whether to provide or on the amount of redress it intends to provide, you should use the NHS complaints procedure.

5 Challenging NHS continuing healthcare decisions made before October 2007

If you believe that you or a relative may have been wrongly denied NHS continuing healthcare before the introduction of the National Framework on 1 October 2007, you can ask the PCT to review their case. This might be because of a failure to consider a relative's or your own eligibility or because you believe an incorrect decision was made at the time.

The review will be based on the eligibility criteria operating during the period of time you wish to challenge. Cases can only be reviewed covering a period after 1996 as this is when national guidance was first introduced. You may find it helpful to read the appendix at the back of this factsheet (see page 30) as it gives brief details of the principles behind the national guidance used by local NHS organisations to set their eligibility criteria before the introduction of the National Framework.

A report by the Health Service Ombudsman in 2003, also discussed in the appendix, prompted a major review of cases going back to 1996. In July 2007 the NHS chief executive wrote to PCTs explaining a desire to bring the review process to a close. He asked PCTs, using appropriate awareness-raising initiatives, to encourage local people who wanted to request a review of a case that involved care provided mainly before April 2004 to raise it with them before November 2007. However, you can still ask the PCT to review such a case, indicating why you have not raised it before. The PCT has a duty to ensure that no one with a legitimate claim to a review misses out.

Note: There will be a manager at each PCT with responsibility for NHS continuing healthcare. NHS Direct can tell you which PCT you need to contact (see section 7).

6 NHS-funded nursing care

NHS-funded nursing care is funding paid directly to nursing homes for care provided by registered nurses employed by the homes. Services provided on a regular basis by a registered nurse are likely to involve:

- provision of nursing care
- supervision or monitoring of care provided by a non-registered nurse
- planning and reviewing a care plan
- monitoring and reviewing medication needs
- identifying and addressing potential health problems.

6.1 **How is eligibility for NHS-funded nursing care decided?**

It is not appropriate to consider your need for NHS-funded nursing care in a nursing home until it has been agreed that you are not eligible for NHS continuing healthcare and that a place in a nursing home is the best option for meeting your needs..

The decision about your eligibility for NHS continuing healthcare could have been made following application of the checklist or a full consideration of your eligibility for NHS continuing healthcare or as part of a joint NHS and social care assessment at home or in a residential home.

As when determining your eligibility for NHS continuing healthcare, staff should consider, before agreeing that a place in a nursing home is your best option, whether you have the potential to recover further in the near future if you receive additional NHS-funded services. This is particularly relevant if you have been living at home and are about to be discharged from hospital following an unplanned admission.

When you have a full consideration of your eligibility for NHS continuing healthcare, as described in section 4.5, and the multi-disciplinary team recommendation is that you are not eligible for NHS continuing healthcare, the multi-disciplinary team should indicate your need for registered nursing care based on information provided by the assessments. This information should be used when drawing up your care plan.

If a joint health and social care assessment is conducted it should identify your nursing needs. It may be useful to consider and document your needs based on the 'domains' featured in the decision-support tool.

Once it is agreed a place in a nursing home is appropriate, the PCT establishes a contract for NHS-funded nursing care with your nursing home and pays the home directly, based on information provided by the assessment.

6.2 **Review of NHS-funded nursing care needs**

Your nursing needs should be reviewed no later than three months after the decision was first made that you are not eligible for NHS continuing healthcare and at least annually as a minimum after that.

As part of each review, your potential eligibility for NHS continuing healthcare should always be considered by using the checklist.

If you fund your own place in a nursing home, you need to ensure you have a review of your needs three months after you first move in and annually thereafter. The care home manager should be aware of the PCT's arrangements for nursing care reviews.

6.3 **NHS-funded nursing care payments**

If you moved into a nursing home on or after 1 October 2007 you will be on the single band of nursing care. This is usually reviewed annually in April. From 1 April 2010 the weekly rate, paid directly to the nursing home, is £108.70.

If you moved into a care home before 1 October 2007, a three-band system operated: low – medium – high. Residents on the low and medium bands transferred on to the single band on 1 October.

Residents on the high band remained on this band if a review indicated that their needs continued to be equivalent to the high band, based on previous guidance. They continue to be eligible for a high rate (from 1 April 2010 it is £149.60) until:

- they are no longer resident in a nursing home
- they become eligible for NHS continuing healthcare
- death
- a review suggests they no longer need nursing care
- a review suggests their nursing needs no longer match high band criteria; in which case they transfer to the single band rate.

6.4 **If you are admitted to hospital**

If you are admitted to hospital, the PCT does not pay nursing care costs to the care home during your hospital stay. The NHS-funded nursing care guidance says PCTs may want to consider paying a retainer to help safeguard care home places of residents while in hospital. It also says any arrangements the PCT makes should not disadvantage residents who fund their own care home place.

6.5 Short stays in a nursing home

If you go into a nursing home on a temporary basis for a period of less than six weeks you will qualify for NHS funding. There is no need to carry out an assessment of nursing needs if it is known at the outset that the stay is for less than six weeks and you have already been assessed for nursing care in the community.

This might apply if you are having a trial period in the home, you are admitted to the home in an emergency because your carer is ill or for respite care.

7 Useful organisations

● Disability Benefits and Attendance Allowance helpline

Contact this helpline if you need to give notification of your eligibility for NHS continuing healthcare.

Tel: 08457 123456

● NHS Direct

NHS Direct is a 24-hour NHS helpline. It has details on areas covered by each SHA and PCT in England and local PALS.

Tel: 0845 46 47

● Office of the Public Guardian

The Office of the Public Guardian supports and promotes decision-making for those who lack capacity or would like to plan for their future under the Mental Capacity Act 2005.

Tel: 0845 330 2900

Website: www.publicguardian.gov.uk

● Parliamentary and Health Service Ombudsman

The Parliamentary and Health Service Ombudsman can investigate complaints about NHS care.

Tel: 0345 015 4033

Website: www.ombudsman.org.uk

8 Further information from Age Concern

Visit the Age Concern website, www.ageconcern.org.uk, or call our national Information Line on 0800 00 99 66 (free call) if you would like:

- to order copies of any of the Age Concern information materials mentioned in this factsheet
- to request information in large print
- further information about our full range of information products
- contact details for your nearest local Age Concern.

Books from Age Concern

Age Concern publishes a wide range of books for older people and those who care for and work with them. The following title may be of particular interest:

Your rights to money benefits 2009/10. All you need to know about the full range of benefits for the over 60s. £5.99 (available June 2009)

To order this book, or to view our full range of books, please visit our website www.ageconcern.org.uk/bookshop or call our book order line 0870 442 2120.

Age Concern and Help the Aged

Age Concern England and Help the Aged have joined together to form Age UK, a single charity dedicated to improving the lives of older people.

Age Concern and Help the Aged across the UK

To find out more about Age Concern and Help the Aged's work in Northern Ireland, Scotland and Wales, contact:

Age Concern Northern Ireland
Tel: 028 9032 5055
Website: www.ageconcernni.org

Scottish Helpline for Older People (Age Concern Scotland)
Tel: 0845 125 9732
Websites: www.olderpeoplescotland.org.uk

www.ageconcernscotland.org.uk

Age Concern Cymru & Help the Aged in Wales

Tel: 029 2043 1555

Website: www.accymru.org.uk

Support our work

Age Concern is the largest provider of services to older people in the UK after the NHS. We make a difference to the lives of thousands of older people through local resources such as our befriending schemes, day centres and lunch clubs; by distributing free information materials; and through our national freephone helpline – the Age Concern Information Line 0800 00 99 66.

If you would like to support our work by making a donation please call Supporter Services on 020 8765 7527 (national call rate, Monday to Friday 9.15am–5pm) or visit www.ageconcern.org.uk

Legal statement

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Please note that the inclusion of named agencies, companies, products, services or publications in this factsheet does not constitute a recommendation or endorsement by Age Concern and Help the Aged. While every effort is made to ensure accuracy, Age Concern and Help the Aged cannot be held responsible for errors or omissions.

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Appendix: Eligibility criteria for continuing NHS healthcare – a brief history (1995–2007)

The core duties to provide a national health service are found in the National Health Service Act 2006. These duties are imposed on the Secretary of State for Health although subsequent legislation means most of the functions are now carried out by SHAs and PCTs.

In 1995 the Department of Health issued *national* guidance for the first time, requiring health authorities in England to develop eligibility criteria for access to NHS funded continuing care.¹ The guidance was a broad framework allowing each of the 95 health authorities to develop its own local criteria. The criteria were to be applied by health authorities from April 1996.

In 1996 the Department of Health issued follow-up guidance to improve the quality of continuing care decisions.

In 1999, an important Court of Appeal judgment – known as the Coughlan judgment – ruled that eligibility criteria used by the health authority concerned in this case, were far too restrictive.

The Court found social services had been asked to take on healthcare responsibilities for a nursing home resident that went far beyond the duties imposed upon them by law under section 21 of the 1948 National Assistance Act (NAA).

The judge said social services can only be asked to provide nursing care that is:

- merely incidental or ancillary to the provision of accommodation which a local authority is under a duty to provide or
- of a nature which it can be expected to provide under section 21 of NAA 1948.

This is often referred to as the quantity/quality test. The over-riding factor is whether a person's need is primarily for healthcare – which is fully funded by the NHS – or social care – which is means tested and so charges may be applied.

¹ HSG 95 (8): LAC 95 (5) *NHS responsibilities for continuing healthcare needs*.

Following the judgment, the Department of Health issued further guidance,² asking health authorities to be sure their criteria complied with 1995 guidance and the Coughlan judgment. They also advised that past cases should be reassessed if criteria were found to be flawed.

In June 2001, new guidance replaced the 1995 guidance.³ It required all 95 health authorities, using this guidance, to agree joint continuing health and social care eligibility criteria with local councils. This guidance is the basis of eligibility criteria used before the National Framework was implemented in October 2007. Although it indicates the key issues to consider when establishing eligibility criteria, it does not indicate exactly how these issues should affect eligibility.

According to the 2001 guidance, the key issues to consider were:

- the nature or complexity or intensity or unpredictability of the individual's healthcare needs (and any combination of these) requires regular supervision by a member of the NHS multi-disciplinary team such as the consultant, palliative care, therapy or other NHS member of the team
- the individual's needs require routine use of specialist healthcare equipment under supervision of NHS staff
- the individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multi-disciplinary team
- the individual is in the final stages of a terminal illness and is likely to die in the near future
- a need for care or supervision from a registered nurse and/or a GP is not, by itself, sufficient reason to receive continuing NHS healthcare
- the location of care should not be the sole or main determinant of eligibility. Continuing NHS healthcare may be provided in a hospital, nursing home, hospice or the individual's own home

² HSC 1999 / 180 *Ex parte Coughlan follow up action continuing health care*

³ HSC 2001 / 015 *Continuing care: NHS and local councils' responsibilities*

- eligibility criteria or application of rigorous time limits for the availability of services by a health authority should not require a council to provide services beyond those they can provide under section 21 of the National Assistance Act 1948.

In April 2002, the 95 health authorities were replaced by 28 Strategic Health Authorities and 303 Primary Care Trusts. Consequently, the Department of Health asked each SHA to agree one set of eligibility criteria with local authorities in their area and to ensure these criteria were in use by all PCTs in their area by March 2003. Thus 95 sets of criteria were reduced to 28.

In February 2003 a Health Service Ombudsman (HSO) report – *NHS funding for long term care was published.*⁴ Relating to the period between 1996-2001, it drew attention to the pattern emerging from complaints investigated about eligibility criteria used by health authorities during this time.

The report found the complaints raised were justified. The health authorities concerned were using over-restrictive eligibility criteria that were not properly in line with Department of Health guidance or with the Coughlan judgment.

The report raised a number of issues, including:

- how giving health authorities the room to develop their own local criteria, could lead to variations in eligibility across the country and the equivalent of a postcode lottery
- how patients and carers can be left inadequately informed unless the guidance procedures used are published alongside eligibility criteria and patients told with reasons, why they do or do not meet the criteria
- the need to develop a clear, well-defined national framework and ensure staff have detailed guidance and procedures on the assessment of patients and the application of the eligibility criteria.

As a result of recommendations in the Ombudsman's report, all 28 SHAs were asked to establish an integrated set of eligibility criteria for NHS continuing care to operate across their territory. It also asked them:

⁴ *NHS funding for long term care* HC399 London. The Stationery Office. Also available on www.ombudsman.org.uk

- to take reasonable steps to identify cases arising since 1996 that may have been wrongly denied NHS funded care⁵
- to undertake a retrospective review of those cases
- to make appropriate recompense to the person or their estate where NHS funding had been wrongly denied.

The Department asked that retrospective reviews be completed by December 2003 and commissioned an independent review of progress in completing these tasks in nine SHA areas. It proved a larger task than anticipated. Cases were still outstanding in March 2005 and reimbursement of eligible cases was still to be completed.

Meanwhile, **in November 2003, the Ombudsman upheld a complaint made on behalf of Mr Pointon, a man with dementia cared for at home by his wife.** This complex case, which can be read in full on the HSO website, raised a number of issues around eligibility criteria and the assessment of individuals:

- the need to ensure criteria for funding NHS continuing healthcare at home are clearly defined
- the need to ensure assessment takes account of mental health and psychological as well as physical needs of patients with illnesses like dementia
- recognition that it is possible for the standard of care provided and co-ordinated by a carer to reach that which a nurse could provide.

The HSO said that this ruling should not be seen as implying that all patients with dementia should be eligible for fully funded care.

Reports published between December 2004 and April 2005

1. The Department of Health's Independent Review *Continuing health care: review, revision and restitution*, December 2004, looks at factors affecting the integration of eligibility criteria and the investigation and restitution process.⁶

⁵ It is not possible to investigate cases where a care home resident died before April 1996. This is the date when formal, written eligibility criteria based on national guidance became operative. There was no obligation to have written criteria before that time.

⁶ Report can be found at www.menaniehenwood.com

2. The Ombudsman's follow-up report *NHS funding for long term care: follow up report*, December 2004, gave an overview of the type of complaints received about the review process.⁷

The report highlights the need for clear and consistent national guidelines about who is eligible for funding, which are understandable to carers and professionals alike; accredited tools and good practice guidance to support the criteria; robust approaches to assessing need and ensuring there are enough people with the right skills to undertake assessment at local level.

The HSO also drew attention to apparent continuing misconceptions in some SHA areas about the distinction between NHS-funded continuing care and 'free' nursing care.

On 9 December 2004, just before the publication of the HSO follow-up report, the Department of Health announced it was commissioning the development of a national consistent approach to assessment for fully-funded NHS continuing care, ie the National Framework.

3. House of Commons Health Select Committee Report⁸

In this wide-reaching 60-page report published in April 2005, the Committee also supported the need for a single set of national eligibility criteria that take account of psychological and mental health as well as physical health needs.

They suggested that the criteria should be underpinned by a national standard assessment methodology and a single set of documentation to record the outcome and that confusion caused by similarities in the guidance issued for NHS continuing healthcare and NHS-funded nursing care should be addressed.

March 2006 – Grogan case

The High Court heard a challenge, on behalf of Mrs Grogan, who argued that she had been wrongly denied fully funded care.

⁷ The Ombudsman's follow-up report is here:

www.ombudsman.org.uk/improving_services/special_reports/hsc/care04/care04_cover.html

⁸ Go to www.parliament.uk/parliamentary_committees/health_committee.cfm

In his judgment, the judge criticised the lack of clarity in the 2001 guidance. He also criticised the local criteria which effectively gave no guidance on the test to apply to assess and weigh the nature or complexity or intensity or unpredictability and the impact of an individual's health needs in order to decide if they were eligible for fully funded care.

The DH issued further guidance following the Grogan judgment.⁹

June 2006 – Consultation document on the National Framework published

It proposed:

- a single policy on who should receive NHS funding – be it fully funded care or NHS funded nursing care
- one nursing band rather than the current three bands, in the case of those granted NHS-funded nursing care
- a standard process for assessing eligibility.

October 2006 – SHAs were reduced from 28 to 10 and PCTs from 303 to 152. Guidance was issued recommending that SHAs review their inherited criteria with a view to establishing a single set of criteria for their area but keeping the changes to a minimum, pending the publication of the National Framework.

June 2007 – National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care published for implementation from 1 October 2007.

9

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139934