NHS Continuing Healthcare in England

Standard Note: SN/SP/6128
Last updated: 22 November 2011
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Section: Social Policy

NHS continuing healthcare means 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. Eligibility decisions for NHS continuing healthcare rest on whether someone's need for care is primarily due to health needs. For example, people who are eligible may have complex medical conditions that require highly specialised nursing support. This note is intended to help Members respond to queries from constituents about eligibility to NHS continuing healthcare.

As services provided by the NHS are free whereas those arranged by local authority social services are means tested, the outcome of any decision as to who has responsibility for providing care can have significant financial consequences for the individual concerned.

Since the early 1990s, the Parliamentary and Health Service Ombudsman has investigated a large number of complaints about local criteria used for making decisions about eligibility for NHS continuing healthcare. The legality of individual eligibility decisions has also been challenged in the courts on a number of occasions. In 2007 the Department of Health issued a *National Framework for NHS Continuing Healthcare*, to try and improve the consistency of approach taken by local NHS bodies, by providing a common framework for decision making and the resolution of disputes. A separate Library note, *Background to the National Framework for NHS Continuing Healthcare* (SN04643) is intended to help Members to understand the background to the introduction of the Framework through an account of the preceding guidance and case law.

The key Department of Health documents, and briefings from other organisations, are listed at the end of this note. The Department of Health guidance should be consulted for a fuller account of the rules and duties that apply to NHS bodies (currently primary care trusts (PCTs) are responsible for determining eligibility for NHS continuing healthcare but, subject to the passage of the *Health and Social Care Bill*, formal responsibility will transfer to Clinical Commissioning Groups in 2013).

Contents

1 What is NHS Continuing Healthcare?

NHS continuing healthcare is a package of care provided outside hospital, arranged and funded solely by the NHS, for people with ongoing healthcare needs. Services may be provided in any setting including, but not limited to, a residential care home, nursing home, hospice or a person's own home. The *National Framework for NHS Continuing Healthcare* (the National Framework)[1] uses the term NHS continuing healthcare to describe the situation where the NHS takes full responsibility for ongoing, sometimes long-term, care.

Primary legislation governing the health service does not explicitly define the duty of the NHS to provide continuing healthcare. It is from the broader requirements to provide a health service under sections 1 to 3 of the *NHS Act 2006* that the duty is derived. The Secretary of State has issued instructions, known as Directions, to the NHS that specify what sections 2 and 3 of the *NHS Act 2006* mean for PCTs when they determine eligibility for NHS continuing healthcare.[2]

The National Framework explains that the actual services provided as part of that package should be tailored to meet the specific health and social care needs of the individual, and should be seen in the wider context of best practice and service development for each "client group". Eligibility for NHS continuing health care is not based on having a specific medical condition and eligibility places no limits on the settings in which the package of support can be offered or on the type of service delivery.

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1 Department of Health, *The National Framework for NHS Continuing Healthcare and NHS-funded nursing care (revised July 2009)*

2 Regulation 1, *The NHS Continuing Healthcare (Responsibilities) Directions 2009*.

There is thus no specific set of services that must constitute NHS continuing healthcare. Services will depend on the needs of the individual in question and, whatever the services may be, people in receipt of NHS continuing healthcare continue to be entitled, like other people, to the usual range of NHS primary, community, and secondary care, and other NHS services.[3]

Someone may have a package of support provided or funded by both the NHS and the local authority, this is known as a 'joint package' of continuing care. Local authority social services have duties to provide welfare services, for example, residential accommodation "for people who, by reason of age, illness or disability, are in need of care and attention that is not otherwise available to them."[4]

How that division of responsibility is made between the NHS and local social services has been a major point of contention over the years and has repercussions for the respective expenditure of the NHS and the local social services authority. For individual patients it can mean the difference between a service that is provided free (if it is the responsibility of the NHS) and one that is means-tested (if it is the responsibility of the local authority).

2 The National Framework

2.1 Publication

The *National Framework for NHS Continuing Healthcare* was published in June 2007[5] and became mandatory from 1 October 2007. Instead of each Strategic Health Authority (SHA) having its own rules for determining eligibility, the National Framework introduced a national approach for the NHS in England, with a common process and national "tools" to support decision making.[6] The Secretary of State issued Directions requiring PCTs, SHAs and local authorities to comply with key aspects of the new policy. The relevant Directions, as updated in 2009, are:

- *NHS Act 2006, Local Authority Social Services Act 1970: The NHS Continuing Healthcare (Responsibilities) Directions 2009*

The following Directions also contain relevant provisions:

- *The Delayed Discharges (Continuing Care) Directions 2009*
- *The National Health Service (Nursing Care in Residential Accommodation) (Amendment) (England) Directions 2009*

As well as dealing with the arrangements for NHS continuing healthcare, the National Framework simplified the arrangements for *NHS-funded nursing care* (that is, care provided by a registered nurse in a nursing home for someone not otherwise funded by the NHS - sometimes known as the Registered Nursing Care Contribution). The National Framework made clear that in all cases, individuals should be considered for eligibility for NHS continuing healthcare before a decision is reached about the need for NHS-funded nursing care.

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3 The National Framework paragraph 107.

4 The basic legal framework governing the social services is summarised on pages 6 and 7 of the National Framework, which also describes the legal framework governing the NHS.

5 Written Ministerial Statement : HC Deb 26 June 2007 20-21WS and Department of Health Press Notice, "Streamlining the system for NHS continuing care," 26 June 2007:

6 See the final page of the note for a list of the current associated documents.

Following a Government commitment to review the National Framework after one year, a revised Framework was published in July 2009. The revised document says that the main change concerns fast track treatment for people with a rapidly deteriorating condition entering a terminal phase. If an appropriate clinician considers a person to have a *primary health need* arising from such a situation and has given a completed *Fast Track Pathway Tool* to the PCT, that PCT is required to determine that the person is eligible for *NHS continuing healthcare*, until such time as a full assessment is completed using the standard *Decision Support Tool*. The revised document also includes some changes to processes, for example, in relation to obtaining a review of an initial screening decision, but the main basis of eligibility was not changed.

2.2 Who is eligible? The *primary health need* test

The central criterion for receipt of NHS continuing healthcare, set out in the National Framework, is whether a person's primary need is a health need:

> Where a person's primary need is a health need, they are eligible for continuing NHS healthcare. Deciding whether this is the case involves looking at the totality of the relevant needs. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed needs – including accommodation, if that is part of the overall need.[7]

The Framework document expands on this, saying that as there should be no gap in the provision of care, the *primary health need* test is partly dependent on the limits of a local authority's responsibilities. This, it says, means that the test should be applied in such a way that a decision of ineligibility is only possible where, taken as a whole, the nursing or other health services required by the individual satisfy the definition of what a local social services authority might provide, as established by the *Coughlan* judgement[8]. In other words, a decision of ineligibility is only possible where the health services:

> a) are no more than incidental or ancillary to the provision of accommodation which LA social services are, or would be but for a person's means, under a duty to provide; and
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> b) are not of a nature beyond which an LA whose primary responsibility it is to provide social services could be expected to provide.

The National Framework adds that there are limitations to this test as neither the PCT or local authority social services can dictate what the other agency should provide. In addition, the *Coughlan* judgment itself, on which the criterion was based, focused only on general and registered nursing needs. A practical approach to eligibility was therefore required, including situations in which the 'incidental or ancillary' test was not applicable because, for example, the person would be cared for in their own home.

Certain characteristics of need – and their impact on the care required to manage them - might help determine whether the 'quality' or 'quantity' of health services required was more than the limits of a local authority's responsibilities. These characteristics are listed in the National Framework as:

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7 National Framework, paragraph 25

8 The significance of the *Coughlan* judgement is explained in a separate Library note, *Background to the National Framework for NHS Continuing Healthcare* (SNSP.....). The impact of the judgement is also summarised in Annex B of the National Framework.

Nature: This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.

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

Complexity: This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/ or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.

Unpredictability: This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to 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 either a fluctuating, unstable or rapidly deteriorating condition.[9]

Each of these characteristics may, alone or in combination, demonstrate a *primary health need*. In order to minimise variation in the interpretation of these characteristics, the Department of Health has published a Decision Support Tool, which is outlined in the section on *Assessment Process* below).

As well as describing the characteristics on which eligibility should be based, the Framework includes a section on what **not** to base eligibility. It lists the following examples:

- the person's diagnosis;
- the setting of care;
- the ability of the care provider to manage care;
- the use (or not) of NHS- employed staff to provide care;
- the need for/presence of 'specialist staff' in care delivery;
- the fact that a need is well managed;
- the existence of other NHS-funded care; or
- any other input-related (rather than needs-related) rationale.

In addition, the Framework says that the possibility of deterioration should generally be taken into account. In particular, where an individual has a rapidly deteriorating condition that may be entering a terminal phase, this would be a *primary health need* because of the rate of deterioration. The Department of Health has published a Fast Track Tool to help decide eligibility where this may be the case (see section on *Assessment Process* below).

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[9] The National Framework page 10.

2.3 Assessment Process

Getting an assessment

The NHS choices website provides advice about getting an assessment for NHS continuing healthcare. It says:

> PCTs are responsible for assessing eligibility for NHS Continuing Healthcare and NHS-funded Nursing Care, as well as ensuring that the national eligibility criteria are used consistently. They also identify, arrange and fund all the services required to meet your needs:
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> - if you qualify for NHS Continuing Healthcare, or
> - for the healthcare part of a joint care package.
>
> The PCT for your area can provide more information on the eligibility criteria and assessment process. If you think you have care needs that should be assessed, or if someone you care for has needs that you think should be assessed, you should contact your PCT.
>
> You can get contact details for PCTs by calling NHS Direct on 0845 4647 or visiting the NHS Choices website. When you contact your PCT, ask to speak to the co-ordinator for NHS Continuing Healthcare.[10]

The Directions specify circumstances where eligibility must be considered and place a general duty on PCTs to take reasonable steps to ensure that an assessment of eligibility is carried out in all cases where it appears to the PCT that there may be a need for *NHS continuing healthcare*. A couple of specific circumstances where an assessment should be carried out are set out below (these are not the only ones mentioned).

- When patients are discharged from hospital: where the NHS is intending to refers someone to social services for help with social care needs, it should first carry out an assessment for NHS continuing healthcare.
- Before any decision is made by the NHS to make a registered nursing care contribution when a person goes into a care home that provides nursing care.

The National Framework sets out principles and values that should be applied to the process of assessment, for example, obtaining the patient's consent, what happens when the patient does not have capacity to consent, and making patients aware of advocacy services that might be available. The Framework then describes the process of establishing eligibility, much of which is covered in the Directions to PCTs, which also contain requirements for local authorities to co-operate in the procedure.

If the NHS is commissioning, funding or providing any part of the care, a case review should be undertaken no later than three months after the initial eligibility decision, in order to reassess care needs and eligibility for NHS continuing healthcare, and to ensure that those needs are being met. Reviews should then take place annually, as a minimum. These reviews are separate from the dispute resolution reviews described in part 3 of this note.

Screening: *The Checklist*

The first step for most people is a screening process where a nurse, doctor other qualified healthcare professional or social worker applies the *Checklist* to see if the individual needs a

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[10] *NHS Choices website: What is NHS continuing healthcare?*

full assessment of eligibility.[11] Whatever the outcome of the *Checklis*t process, the decision, including the reasons why the decision was reached, should be communicated clearly and in writing to the individual and (where appropriate) their representative.

Where the outcome is not to proceed to a full assessment of eligibility, the written decision should also contain details of the individual's right to ask the PCT to reconsider the decision. The PCT should give such requests due consideration and provide a clear, written response as soon as is reasonably practicable. The response should also give details of the individual's rights under the NHS complaints procedure.

Full Assessment: *The Decision Support Tool*

If the person has passed the screening test, the next step is a full assessment (in some cases an individual may be referred directly for a full assessment, in which case the full assessment would be the first stage). The assessment should be carried out by a multidisciplinary team and, irrespective of the setting, the PCT has responsibility for coordinating the process until a decision is reached.

The aim is to capture the nature, complexity intensity and/or unpredictability of a person's needs (see section 2.2 on the *primary health need* test above). In order to do this, the *Decision Support Tool*[12] provides a framework for recording the person's needs in 12 generic areas. The 12 areas are: behaviour, cognition, psychological and emotional needs, communication, mobility, nutrition (food and drink), continence, skin (including tissue viability), breathing, drug therapies and medication (symptom control), altered states of consciousness, other significant care needs. For each domain, the assessment records: low, moderate, high.

However, the *Decision Support Tool* is not an assessment in itself; it is meant to be a way of applying the *primary health need test* by bringing together evidence in a single format in order to improve consistency and evidenced-based decision. It is not intended to directly determine eligibility and "Professional judgment should be exercised in all cases to ensure that the individual's overall level of need is correctly determined."

Once the multidisciplinary team has reached agreement, it should make a recommendation to the PCT on eligibility. Only in exceptional circumstances and for clearly articulated reasons, should the PCT reject the multidisciplinary team's recommendation and a decision not to accept the recommendation should never be made by one person acting unilaterally.

The Framework says that many PCTs use a panel to ensure consistency and quality of decision making but that a panel should not fulfil a gate-keeping function. Nor should it be used as a financial monitor.

The time between the *Checklist* (or other notification of potential eligibility) being received by the PCT and the funding decision should, in most cases, not exceed 28 days. In acute settings it may be appropriate for it took take much less than this. When there are valid and unavoidable reasons for the process taking longer, timescales should be clearly communicated to the person, and (where appropriate) their carers and/or representatives.

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11 *Healthcare Checklist (September 2009)*
12 *Decision Support Tool (September 2009)*

Terminal Care: *The Fast Track Pathway Tool*

The *Fast Track Pathway Tool*[13] is designed for assessing individual who need urgent attention because they have a rapidly deteriorating condition that may be entering a terminal phase with an increasing level of dependency. The Tool needs to be completed by an "appropriate clinician" who should give the reasons why the person meets the conditions required for the fast-tracking decision.

The 'appropriate clinician' is defined as someone who is, pursuant to the *NHS Act 2006*, responsible for an individual's diagnosis, treatment or care and who are medical practitioners (such as consultants, registrars or GPs) or registered nurses. Clinicians should have an appropriate level of knowledge or experience of the type of health needs, so that they are able to comment reasonably on the situation. They can be clinicians employed in voluntary and independent sector organisations that have a specialist role in end of life needs (for example, hospices), provided that they are offering services pursuant to the *NHS Act 2006*.

Where a recommendation is made for an urgent package of care via the fast-track process, this should be accepted and actioned immediately by PCTs. The framework says that it is not appropriate for individuals to experience delay in the delivery of their care package while disputes over the use of the *Fast Track Pathway Tool* are resolved. As mentioned in section 2.1, this is one of the areas where there has been a change since the first version of the National Framework was published in 2007.

2.4 Individual choice of care arrangement and limits on choice

The National Framework says that "the package to be provided is that which the PCT assesses is appropriate for the individual's needs".[14] However, practice guidance states that the PCT should take full account of the individual's own views of their needs and their preference as to how they should be met and that they "should be given as much choice as possible, particularly in the care planning process."[15]

PCTs have powers to offer personal health budgets for NHS continuing healthcare, either as a notional budget or a real budget held by a third party. Direct payments for NHS continuing healthcare can currently only be offered by PCTs that are pilot sites approved by the Secretary of State. In October 2011, Andrew Lansley announced that, subject to the evaluation of these pilots, by April 2014 everyone who is eligible for NHS continuing healthcare will have the right to ask for a personal health budget including a direct payment (although granting one would be at the discretion of the NHS commissioning body).[16]

The practice guidance provides some additional information about the limits that can be put on individual choice where, if followed, this would result in the PCT paying for a more expensive care arrangement, and the circumstances under which a PCT can decline to provide care in the preferred setting of the individual (see para 11.7). This section is set out below and notes that cost has to be balanced against other factors in the individual case, such as an individual's desire to continue to live in a family environment:

> In many circumstances there will be a range of options for packages of support and their settings that will be appropriate for the individual's needs. The starting point for agreeing the package and the setting where NHS continuing healthcare services are to

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13 *Fast Track Pathway Tool for NHS continuing healthcare (September 2009)*
14 The National Framework, paragraph 100
15 *NHS continuing healthcare practice guidance* (April 2010)
16 Department of Health press release, 5 October 2011

be provided should be the individual's preferences. Individuals will not always be aware of the models of support that it is possible to deliver (for example, they may assume that it is only possible to receive support in a care home). Those involved in working with individuals to plan their future support should advise them of the options and the benefits and risks associated with each one. PCTs should be aware of the models of support offered by partners and by other PCTs and of evidence about their benefits and risks so that the options offered are maximised and that generalised assumptions are avoided.

In some situations a model of support preferred by the individual will be more expensive than other options. PCTs can take comparative costs and value for money into account when determining the model of support to be provided but should consider the following factors when doing so:

a) The cost comparison has to be on the basis of the genuine costs of alternative models. A comparison with the cost of supporting a person in a care home should be based on the actual costs that would be incurred in supporting a person with the specific needs in the case and not on an assumed standard care home cost.

b) Where a person prefers to be supported in their own home, the actual costs of doing this should be identified on the basis of the individual's assessed needs and agreed desired outcomes. For example, individuals can sometimes be described as needing 24-hour care when what is meant is that they need ready access to support and/or supervision. PCTs should consider whether models such as assistive technology could meet some of these needs. Where individuals are assessed as requiring nursing care, PCTs should identify whether their needs require the actual presence of a nurse at all times or whether the needs are for qualified nursing staff or specific tasks or to provide overall supervision. The willingness of family members to supplement support should also be taken into account, although no pressure should be put on them to offer such support.[27] PCTs should not make assumptions about any individual, group or community being available to care for family members.

c) Cost has to be balanced against other factors in the individual case, such as an individual's desire to continue to live in a family environment (see the Gunter case in box below).

Gunter Case

In the case of *Gunter vs. South Western Staffordshire PCT*, a severely disabled woman wished to continue living with her parents whereas the PCT's preference was for her to move into a care home. Whilst not reaching a final decision on the course of action to be taken, the court found that Article 8 of the European Convention of Human Rights had considerable weight in the decision to be made, that to remove her from her family home was an obvious interference with family life and so must be justified as proportionate. Cost could be taken into account but the improvement in the young woman's condition, the quality of life in her family environment and her express view that she did not want to move were all important factors which suggested that removing her from her home would require clear justification.[17]

The Alzheimer's Society notes that "the highest proportion of people receiving NHS continuing healthcare are in nursing homes and far fewer are awarded it while living at

[17] *Ibid.*

home."[18] The practice guidance provides information on the respective responsibilities of PCTs and local authorities when a person is supported in their own home.[19]

3 Dispute resolution

The formal responsibility for informing individuals of the decision about eligibility for NHS continuing healthcare, and their right to request a review, lies with the Primary Care Trust (PCT). There are two possible levels at which a review of an eligibility decision (as distinct from a screening decision, for which see the section on the *Checklist* above) may take place:

- a local review process at PCT level; and
- a request to the Strategic Health Authority (SHA), which may then refer the matter to an Independent Review Panel.

If the Independent Review Panel upholds the original decision and there is still a challenge, the next stage is referral to the Health Service Ombudsman.

It is up to each PCT to agree a local review process, including timescales, which should be made publicly available and a copy should be sent to anybody who requests a review of a decision. The local review process may include referral of the case to another PCT for consideration or advice, in order to provide greater patient confidence in the impartiality of the decision making.

If a person has been unable to resolve the matter through any local dispute resolution procedure s/he may apply to the relevant SHA for an independent review of the decision if s/he is dissatisfied with:

a) the procedure followed by the PCT in reaching its decision as to the person's eligibility for NHS continuing healthcare; or

b) the application of the eligibility criteria for NHS continuing healthcare (i.e. the primary health need test).

Once local procedures have been exhausted, the case should be referred to the SHA's Independent Review Panel, which should consider the case and make a recommendation to the PCT. If using local processes would cause undue delay, the SHA has discretion to agree that the matter should proceed direct to an Independent Review without completion of the local process.

The Framework says that because Independent Review Panels have a scrutiny and reviewing role, it is not generally appropriate for any party to be legally represented at an IRP hearing although individuals may be represented by family, advocates, advice services and others in a similar role. It also says that although the role of the Independent Review Panel is advisory, its recommendations should be accepted by the PCT in all but exceptional circumstances.

The Framework sets out principles to be followed both locally and by Independent Review Panels (gathering of available evidence etc.). Annex E of the Framework provides further

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[18] *When does the NHS pay for care? Guidance on eligibility for NHS continuing healthcare funding in England*, Alzheimer's Society (2011).

[19] *NHS continuing healthcare practice guidance* (April 2010), paragraph 11.8

details of procedures to be followed in relation to Independent Review Panels. There are also provisions regarding disputes between PCTs and local authorities.

An individual's right under existing NHS complaints procedures and his or her existing right to refer a case to the Health Service Ombudsman is not affected by the Independent Review Panel procedures. In particular, where an individual is dissatisfied with issues other than the process followed or the application of the criteria, the Framework says that the matter should be considered via the complaints procedure.

4 Refunds guidance

NHS continuing healthcare: refunds guidance (March 2010) sets out the approaches to be taken by PCTs and local authorities when a decision is awaited on eligibility for NHS continuing healthcare or there is a dispute following a decision. It explains responsibilities for providing services during these periods and for refunding the costs of services provided.

If someone disputes a PCT's initial eligibility decision and this decision is revised following further consideration or as a result of a recommendation by an Independent Review Panel, the PCT should reimburse any costs incurred by the local authority or individual concerned. Ex-gratia payments from PCTs should aim to restore an individual's 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.

Disputes about PCT decisions on whether to provide reimbursement, or on the amount it intends to provide, can be addressed through the standard NHS complaints procedure.

5 Key guidance documents

The following Department of Health guidance, together with the Directions from the Secretary of State mentioned in the text of this note, should be consulted for a fuller account of the rules and duties of NHS bodies to provide NHS continuing healthcare.

- The National Framework for NHS Continuing Healthcare and NHS-funded nursing care (revised July 2009): This sets out principles and processes for establishing eligibility.
- Healthcare Checklist (September 2009): This is a screening tool to help establish who might need a full assessment of eligibility.
- Decision Support Tool (September 2009): This is a detailed questionnaire to help assess eligibility.
- Fast Track Pathway Tool for NHS continuing healthcare (September 2009): This is for urgent assessments of those with rapidly deteriorating, possibly terminal, conditions.
- NHS continuing healthcare practice guidance (April 2010): This provides a practical explanation of how the Framework should operate on a day-to-day basis and cites examples of good practice.

- Training materials for the revised National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (December 2009): These training materials have been developed to support local training on specific issues.

- NHS continuing healthcare: refunds guidance (March 2010): This sets out the approaches to be taken by PCTs and local authorities when a decision is awaited on eligibility for NHS continuing healthcare or there is a dispute following a decision. It explains responsibilities for providing services during these periods and for refunding the costs of services provided.

There are several introductory sources that constituents may find useful, for example:

- *NHS continuing healthcare and NHS-funded nursing care*, NHS public information booklet;

- NHS Choices website: *What is the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care?*;

- Age Concern factsheet 20, *NHS continuing healthcare and NHS-funded nursing care* (September 2010); and

- *When does the NHS pay for care? Guidance on eligibility for NHS continuing healthcare funding in England*, Alzheimer's Society (2011).