November 2007

Key Points:
• Replaces previous version dated August 2007 • Includes information on application of the National Framework for NHS continuing healthcare and NHS- funded nursing care

NHS continuing healthcare, NHS-funded nursing care and intermediate care

This factsheet is aimed at people aged 60 and over.

The factsheet outlines the situation for people living in **ENGLAND ONLY**.

Readers living in Scotland can obtain a similar Factsheet 37s, *Hospital discharge arrangements and NHS continuing health care services* available by phoning 0800 00 99 66 (free call), from the website: www.ageconcernscotland.org.uk; or by writing to Age Concern FREEPOST (SWB 30375), ASHBURTON, Devon TQ13 7ZZ.

Contact details for Age Concern Scotland are:
Causewayside House, 160 Causewayside, Edinburgh EH9 1PR, tel: 0845 125 9732 (lo-call rate).

If you require information about the charging rules in Wales, you may have received a supplementary sheet with this factsheet.
If you have not received this, a copy can be obtained by calling 0800 00 99 66 (free call).

Contact details for the national Age Concern office for Wales are:

Age Concern Cymru, Ty John Pathy, Units 13/14 Neptune Court, Vanguard Way, Cardiff CF24 5PJ, tel: 029 2043 1555 (national call rate); website: www.accymru.org.uk.

Contact details for the national office for Northern Ireland are:

Age Concern Northern Ireland, 3 Lower Crescent, Belfast BT7 1NR, tel: 028 9032 5055 (national call rate) Monday to Friday 10am - 12pm and 2pm – 4pm, website: www.ageconcernni.org.

Contents

1. Continuing care

You may need long term support from the NHS and/or social services because of a long term illness, following hospital treatment or because of a disability. This factsheet explains the help that can be provided by the NHS, to those aged 18 or over.

Health professionals often use certain terms when talking about the support that can be offered. These are briefly explained below.

Continuing care - is a general term describing care provided over an extended period of time to those aged 18 or older to meet physical and mental health needs that have arisen as a result of disability, an accident or illness. It may require services from the NHS and/or social services.

Continuing health and social care – is available in a range of settings and may involve services from the NHS and social services.

NHS continuing healthcare – this is a complete package of ongoing care arranged and funded by the NHS. It can be provided in any setting including but not limited to, a care home, hospice or the person's own home.

NHS-funded nursing care in a care home – is the funding provided by the NHS to homes providing nursing care, to support the provision of care from a registered nurse for their eligible residents. It was first introduced in October 2001.

Intermediate care – can be available for up to six weeks, free of charge. It is based around a care plan designed to maximise a person's independence. The aim is to enable a person to return to their own home after hospital treatment or by providing suitable services, to avoid the need for hospital admission.

In 2002:
Residential homes became known as 'care homes'.

Nursing homes became known as 'care homes registered to provide nursing' or 'care homes with nursing'. For ease of reading we will continue to refer to residential homes and nursing homes or cares home if it can be either.

1.1 Background

If you have long term care needs, you may be living in your own home or in a care home. You often require services from your local authority's social services department and / or the NHS.

In many cases it is 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.

Over the past thirteen years, the Health Service Ombudsman has been asked to investigate a large number of complaints about criteria used and processes followed when making such decisions. The legality of some decisions has been challenged in the courts.

It is against this background that the 'National Framework for NHS Continuing Healthcare and NHS-funded nursing care' has been developed for use in England from 1st October 2007. **From now on it will be referred to in the text as the 'Guidance'.**

If you would like to learn more about the key reports and events leading up to the development of the Guidance, see the Appendix to this factsheet.

2. NHS Continuing Healthcare

2.1 What is NHS continuing healthcare?

This is a package of care that can be arranged and funded by the NHS to meet physical or mental health needs which have arisen because of illness.[1]

You can receive care in any setting including your own home or a care home. If you live in your own home, the NHS pays for your assessed health and personal care needs. If you live in a care home, the NHS makes a contract with the care home to pay the full fees for your accommodation and care.

[1] The NHS Continuing Healthcare (Responsibilities) Directions 2007

The Primary Care Trust (PCT) in whose area your GP practice is located, is responsible for deciding your eligibility and if you are eligible, for arranging and funding your care.

2.2 What is the National Framework?

'The National Framework for NHS continuing healthcare and NHS-funded nursing care' was published by the Department of Health (DH) in June 2007 for implementation from 1st October 2007.

It is a guidance document setting out clear principles and processes to be followed throughout England for establishing a 'primary health need'. Having a primary health need means you are eligible for NHS continuing healthcare. It also clarifies the relationship between continuing NHS healthcare and the nursing needs of nursing home residents.

The Guidance aims to minimise local interpretation of eligibility and improve the clarity, transparency and consistency of the decision-making process by:

- introducing guidance to be followed by all PCTs in conjunction with their local authorities;
- launching a national assessment process supported by national assessment tools to inform those making decisions;
- introducing common paperwork to record evidence that will inform decision-making;
- eliminating the need for a separate determination of nursing needs, if it is agreed you are not eligible for NHS continuing healthcare and accommodation in a nursing home is your best option.

The three assessment tools, described later, have been produced to minimise variation in interpretation of your needs and to inform consistent decision-making.

The Guidance, the three tools, the Directions supporting the Framework and a leaflet for patients and their family can be found on the Department of Health website at: http://www.dh.gov.uk/en/Policyandguidance/socialcare/socialcarereform/continuingcare/DH_079276.

2.3 Who is eligible for NHS continuing healthcare?

Eligibility is not dependent on and should not be influenced by your diagnosis, who cares for you or where your care is provided. You are eligible if a multi-disciplinary assessment of your needs indicates your primary need is a health need.

The Guidance sets out the principles and processes for establishing a 'primary health need'.

2.4 When should eligibility be considered?

Not everyone with ongoing health needs is likely to be eligible but there are times to make sure your eligibility has been considered.

a) if you have a rapidly deteriorating condition, which may be entering a terminal phase;
b) before you are discharged from hospital, particularly if it seems a permanent place in a care home may be necessary;
c) when your care needs are being formally reviewed on a regular, usually annual, basis;
d) if your physical or mental health deteriorates significantly and your current care package seems inadequate. This may occur while you are living at home or in a care home.

Directions supporting NHS continuing healthcare says that a PCT must take reasonable steps to ensure that an assessment for NHS continuing healthcare is carried out, following the process described in the Guidance and recording the decision, in all cases where it appears to the Trust

a) that there may be a need for such care or for a variation in the provision of such care; and

b) before any assessment to identify nursing needs of a person who is in or is about to go into a nursing home. [2]

[2] The NHS Continuing Healthcare (Responsibilities) Directions 2007

If you are waiting to be discharged from an acute hospital bed and it appears you may be eligible for NHS continuing healthcare, separate Directions cover the NHS Trust's duty to assess and follow the processes detailed in the Guidance.[3]

2.5 How is the eligibility decided?

The decision-making process and how to use the three tools produced to support it, is explained in the Guidance document. It is recommended that staff have attended training using national training materials before using the tools.

3. National Framework assessment and decision-making

3.1 Involving you and your carers

The Guidance reminds staff that:
"The process of assessment and decision-making should be person-centred. This means placing the individual, their perceptions of their support needs and their preferred models of support at the heart of the assessment and care-planning process."

"Assessments…..should be organised so that the person who is undergoing assessment and their family and/or carers understand the process, and receive advice and information to enable them to participate in informed decisions about their future care."

Staff should seek your consent before the process of assessing your eligibility begins. You can ask that your family's views and knowledge are taken into account and for any information collected during the assessment to be shared with them. You can choose a family member or other person to advocate on your behalf.

If it is determined that you lack capacity to consent, staff should check whether, under the *The Mental Capacity Act 2005 (applies in England and Wales),* you have made an Advance Decision or appointed someone as Lasting Power of Attorney to act on your behalf on health and welfare matters. If you have not, staff responsible for making decisions on your behalf must act in your 'best interests', having consulted those with a knowledge of and/or interest in your welfare.

[3] The Delayed Discharges (Continuing Care) Directions 2007

If it is determined you lack capacity to make major decisions about your health and personal welfare **and** do not have an appropriate relative or unpaid carer who can be consulted, the PCT must consider the appointment of an Independent Mental Capacity Advocate (IMCA) if they are proposing serious medical treatment or a change of accommodation.[4]

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

3.2 Fast track pathway tool

This can be used if you have a rapidly deteriorating condition that may be entering a terminal phase and therefore need urgent consideration of your eligibility for NHS continuing healthcare. Although usually used in hospital by a member of a multi-disciplinary team, it could be used in other settings.

The fast track decision will need to be approved by the PCT and where appropriate, the decision to fast track should be followed by a full assessment of your needs.

3.3 NHS continuing healthcare checklist tool

The checklist is used once it is agreed 'fast tracking' is unnecessary and you will not benefit from further NHS-funded treatment or rehabilitation.

Its purpose is to help health and/or social care professionals identify who is most likely to be eligible for NHS continuing healthcare and whether referral for a full consideration of eligibility is necessary. The decision to apply the checklist does not imply likelihood that you will be found eligible.

The intention is that a variety of professionals, not only those working in a hospital, could use this checklist. This might be a GP or nurse visiting a patient at home or in a residential home or a social worker who is carrying out a community care assessment.

[4] More information about the Mental Capacity Act 2005, acting in 'best interests', Advance Decisions, Lasting Powers of Attorney and IMCAs is available from the Office of the Public Guardian. See section 8.

If agreed by the local PCT, a registered nurse employed by a nursing home, may be offered training and use it. If family members believe their relative's condition has deteriorated significantly, they may like to use the checklist before approaching the PCT or social services.

The checklist is based on the Decision-Support Tool (D-ST). It features a statement describing the 'high' level of need for each of the eleven areas of need or "domains" identified in the D-ST. (See the next section).

Your needs are considered in relation to each statement. To complete the checklist, the assessor ticks one of three boxes. A tick in box A means your need "meets / exceeds the described need"; in box B means "nearly meets the described need" and in box C means "clearly does not meet the described need".

A full consideration of eligibility is recommended if there are:

- 2 or more ticks in box A;
- 5 or more ticks in box B;
- 1 tick in box A for the areas of need given 'priority' level in the D-ST (see below).

If you do not meet the above threshold, the assessor can still recommend a full consideration if they believe it appropriate.

The PCT should inform you of their decision (in writing if appropriate) with a clear explanation of the reasons for it and make a record of it. If you disagree with a decision not to recommend a full consideration, you can request this. Your request, along with any additional information provided, should be given due consideration. Also see section 3.10 Ongoing Reviews.

3.4 Multi-disciplinary assessment

Once it is confirmed a full consideration is needed, the PCT should appoint a co-ordinator(s) to co-ordinate the multi-disciplinary assessment (M-DA) of your needs and the remainder of the process until a decision is reached and your care plan written.

The M-DA should, where possible, take account of your perception of your needs and how you would like to be supported, involving your family or carers as appropriate. It should involve relevant health and social care professionals, so that all your health – physical, mental, psychological and emotional – and social care needs, including well managed needs, are identified and recorded.

Involving NHS staff and social services in your assessment should ensure more effective and consistent decision-making and streamline the process of care planning.[5] A commentary on the Guidance has been prepared by Association of Directors of Adult Social Services (ADASS) and Local Government Association (LGA) to assist social services in working closely with NHS staff.[6] As when conducting their own assessments, social services should not allow your financial circumstances to affect their decision to participate.

3.5 Decision-support tool

The aim of the D-ST is to bring together and evaluate the needs identified during your M-DA. It takes account of the nature, intensity, complexity and unpredictability of an individual's needs. These may, in combination or alone, demonstrate a primary health need because of the quality and/or quantity of care required to meet them. Needs that do not easily fit into the tool should still be recorded and taken into account. The completed tool is not meant to determine eligibility but to support the process of establishing a primary health need.

Eleven areas of need or "domains" are described in the D-ST. A domain has statements representing some or all of the following levels of need: 'no need', 'low', 'moderate', 'high', 'severe' and 'priority'.

[5] The NHS Continuing Healthcare (Responsibilities) Directions 2007 say it is the duty of the PCT as far as reasonably practicable, to consult with the local authority before making an eligibility decision and that they shall, as far as reasonably practicable, provide advice and assistance.
[6] Commentary and Advice for Local Authorities on the National Framework http://www.adass.org.uk/publications/guidance/guidance.shtml

The domains are:

- Behaviour ►►
- Cognition ►
- Psychological and emotional needs
- Communication
- Mobility►
- Nutrition – food and drink ►
- Continence
- Skin and tissue viability ►
- Breathing ► ►
- Drug therapies and medication: symptom control ►►
- Altered states of consciousness ► ►

►► = priority level of need
► = severe level of need
In four of the domains the highest level is 'priority'; in four others it is 'severe' and in the remaining three it is 'high'.

The D-ST has a section allowing you, or your carer if appropriate, to summarise your perception of your care needs.

If you would like an idea of what the D-ST looks like and to read the statements relating to each domain, ask the PCT co-ordinator for a copy. In some Strategic Health Authority (SHA) areas, sections may be added to the pages of each domain. This is to allow supporting evidence to be included in the tool itself, rather than as attachments. Copies of the D-ST are available on the DH website.[7]

3.6 Reaching a decision

Where possible, the person co-ordinating the process should liaise with the multi-disciplinary team members (MDT) to complete the tool and match your level of need as closely as possible with the statements for each domain. [8]

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[7] http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/IntegratedCare/Continuingcarepolicy/DH_073912

[8] The multi-disciplinary team is a team of at least two professionals, usually from both health and social care backgrounds.

You or your main carer or advocate can be invited to be present during the MDT's assessment of eligibility. There is a section on the D-ST to record whether or not you or your main carer or advocate were present, or not invited, or declined to attend and whether you / they have seen and agree with the completed D-ST.

The user notes accompanying the D-ST say in paragraph 16 that "a clear recommendation of eligibility would be expected in each of the following cases:

- **priority** need in any of the four domains carrying this level or
- a total of two or more incidences of identified **severe** needs across all domains."

Para 17 of the user notes says: " 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

this can also indicate a primary health need. In these cases, the overall need and interactions between needs in different care domains, and the evidence from risk assessments, should be taken into account in deciding whether a recommendation of eligibility should be made. It is not possible to equate a number of incidences of one level with a number of incidences of another level, for example, "two moderates equals one high".

Para 18 says:

"If needs are recorded as **"low"** or **"no need"**, this would indicate ineligibility. However, because low needs can add to the overall picture, influence the continuity of care necessary, and alter the impact that other needs have on an individual, all domains should be completed."

Therefore using information from the D-ST, user notes and their experience and professional judgement, the multi-disciplinary team (MDT) reach a decision and make their recommendation to the PCT.

If their recommendation is that you are not eligible for NHS continuing healthcare, they should enter your need for registered nursing care on the D-ST. (See section 6)

Although the final decision rests with the PCT, the Guidance says that only in exceptional circumstances and for clearly stated reasons should the MDT's recommendation not be followed.

The Guidance recognises that many PCTs use a panel to ensure consistency in decision-making. However it cautions against these panels having a gate-keeping function or being used as a financial monitor. Because the eligibility decision should be independent of financial constraints, finance officers should not be members of any decision-making panel.

3.7 What happens if you are eligible?

The PCT should tell you verbally and in writing once a decision is reached - in most cases within two weeks of a referral for full consideration. This is not necessarily a permanent decision as your condition may change. Ongoing reviews are built into the process. (See section 3.10)

If your eligibility has been decided using the fast track tool, the guidance reminds PCTs that careful decision-making is essential to avoid undue stress that could result from moving in and out of eligibility within very short periods.

The PCT must provide a care package it thinks appropriate to meet your needs. Your preferences and those of your relatives on how and where your care will be provided should be taken into account, together with the risks associated with different types of care and fairness of access to PCT resources. The final decision rests with the PCT.

Your care can be provided in a range of settings, including:

In a nursing home

You do not have the right to choose either the location ie, the town or actual nursing home. The PCT may already have a contract with one or more local nursing homes but your assessed needs will determine whether these homes 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 your funding PCT.

If agreed you can live in a home in a different PCT area, you will need to register with a GP. Once you have done this, your primary care eg, GP services, and any treatment unrelated to the reason for your placement becomes the responsibility of your GP's PCT. Your nursing home fees remain the responsibility of the PCT that initially agreed your placement.

If you are living in a nursing home when the decision to grant fully funded care is made, you need to discuss with the PCT whether you can remain there. This is particularly relevant if your home is more expensive than the NHS would normally pay to meet needs such as yours. The risks and benefits to you of a change of location or support should be considered. The effect on your physical and mental health should be taken into account before a decision to move you is confirmed.

If your current care home cannot meet your needs, you will need to discuss your options with the PCT.

In a hospice

This may be appropriate if you are in the final stages of a terminal illness. However government policy is, where possible, to allow you to be at home at this time if you prefer it.

In your own home

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

If you were living at home prior to being awarded continuing NHS healthcare, you may have received Direct Payments from social services to meet your social care needs. 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. When deciding whether to do this they should, where possible, take account of your preferences.

Subject to their eligibility criteria and charging policy, it may be appropriate for your local authority to arrange services in addition to those provided by your PCT. These might be services for you or that would allow your carer to maintain their caring responsibilities. Knowing your circumstances, your PCT and local authority should consider this when agreeing your care plan.

If you receive care at home and later wish to move to a house outside your funding PCT area, you will need to discuss the implications of this with your funding PCT.

Moves within 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.

3.8 What happens if you wish to challenge a decision?

You should approach the PCT if you disagree with their decision because you are dissatisfied with:

a) the procedure followed in reaching the decision;
b) the application by the PCT of the D-ST in the decision-making process.

The first step, unless it will add unnecessary delay in resolution, is usually the PCT's local resolution process. This may involve a review panel from their own or a neighbouring PCT.

When local procedures are exhausted, you should be told you can apply in writing to the appropriate Strategic Health Authority (SHA) for an independent review (IR) of the decision.

Independent support at the independent review stage

If you would like an independent advocate to help you at the IR stage, your local PALS (Patient Advice and Liaison Service) will be able to give details about the Independent Complaints and Advocacy Service (ICAS). An ICAS is available in every PCT area to provide independent support to anyone making a formal complaint about NHS services. Your local Age Concern may also be able to help with advocacy. NHS Direct can tell you how to contact your local PALS or ICAS service. See Section 8.

The independent review process[9]

An independent review is **not** an option if you or your family or carers wish to challenge:

- The content of criteria used;
- The type and location of any offer of NHS funded continuing care services;
- The content of any alternative care package offered;
- The treatment or any other aspect of the services they are receiving or have received

Any of the above would be dealt with by the complaints procedure.

Following a request for a review, the SHA must notify, in writing, the standing chairman or reserve standing chairman that a request has been received. The SHA may then refer the matter to an independent review panel (IRP) for advice. Annex E of the Guidance covers IRP procedures.

The main Guidance gives key principles that should be followed by an IRP regarding:

- evidence gathering;
- involvement of the individual and their family or carer (giving them input at all stages);
- allowing all parties to submit their views in writing or attend the IRP;
- the need for a full record of panel deliberations and clear, evidenced written decisions.

Annex E also says "the PCT should continue to fund appropriate care while the review process is being conducted. Any existing care package, whether hospital care or community health services, should not be withdrawn under any circumstances until the outcome of the review is known."

You or your family should receive a reasoned, written decision from the SHA of the outcome of the IR.

[9] The NHS Continuing Healthcare (Responsibilities) Directions 2007 explain the duties of SHAs to consider requests for a review and the composition of the review panel. The Framework guidance explains the key principles for resolving disputes at PCT and SHA level.

If the original decision is upheld, you should be told you can refer your case to the Healthcare Commission and ultimately the Parliamentary and Health Service Ombudsman. See section 8.

3.9 Effect on state benefits

If you are living in a care home and claiming Disability Allowance (DLA) or Attendance Allowance (AA) when you are awarded continuing NHS healthcare, you should notify the Disability Benefits and Carers Service (DBCS). [10] Your benefit will cease on the 29th day after the PCT began to fund your care or sooner if you have recently been in hospital.

If you are living at home and claiming DLA or AA but will need to move into a care home, you should notify DBCS. Your benefit will cease on the 29th day after the PCT began to fund your care or sooner if you have recently been in hospital.

If you are awarded NHS continuing healthcare and will receive care in your own home, you should continue to receive AA or DLA.

Being awarded NHS continuing healthcare does not affect your state pension.

Pension Credit, guarantee credit, can be affected if you lose AA, as AA can influence the amount of pension credit you receive.

3.10 Ongoing reviews of eligibility decisions

If, after considering your eligibility for NHS continuing healthcare, the NHS is providing any part of your care package, a case review should be undertaken no later than three months following the original decision.

This review is to reassess your care needs and eligibility for NHS continuing healthcare and to ensure your needs are being met. You should have such a review even if you did not receive a full assessment following application of the Checklist.

Reviews should then be held on, at least, an annual basis.

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[10] If you claim AA or DLA and need to go into hospital or are awarded NHS continuing healthcare, you should inform the Disability Benefits and Carers Service Warbreck House, Warbreck Hill, Blackpool, Lancs FY2 0YE. Tel: 08457 123456.

4. Your care package if not eligible

If you are not eligible for NHS continuing healthcare, your needs may be met through a joint health and social care package. Your PCT and social services will need to agree where their funding responsibilities lie. You will be means tested for services that are the responsibility of social services.

The following NHS services may be provided in their own right or alongside a social care package:

- Care provided by a registered nurse in a nursing home (see section 6);
- Care from a GP and other members of the practice team;
- Assessment involving doctors and registered nurses;
- Rehabilitation and recovery services;
- Respite health care services;
- Palliative care.

GP practice and other NHS staff working in the community

You should receive the same primary and community health services in a care home or sheltered housing as you receive when living in your own home.

You should also have access to a dentist or optician. A charge may be made for NHS dental treatment or glasses you need. If for health reasons you cannot visit their premises, no additional charge should be made for a home visit by a practitioner offering NHS treatment. If specialist equipment is needed, you may have to visit their premises.

Rehabilitation and recovery services

These services aim to promote recovery and maximise independence and often start while you are in hospital. They may continue for weeks or months and might include speech therapy - to help with speech or swallowing; physiotherapy - to help mobility or dexterity and occupational therapy – to identify suitable aids and home adaptations and make sure you can use them safely. Intermediate care is intended to fill a similar role but is strictly time limited. See Section 7.

Respite health services

In most cases, local councils are responsible for arranging respite care. Respite services are usually provided if you are cared for at home by a relative or close friend. They are often provided when your usual carer is ill or to give them a break.

However the NHS has responsibilities for respite *health* care, that is, if you require or could benefit from rehabilitation services during a period of respite care.

If you do not meet your PCT's eligibility criteria for respite *health* care, your local authority may still arrange respite care. In this case you may be asked to pay towards the cost. If the local authority arranges your care in a nursing home, the NHS should take responsibility for paying for the registered nursing care element of your stay. See Section 6.

Crossroads, a voluntary, charitable organisation, can offer respite care in your own home - either with or without involvement of social services. You may be asked to pay for this service. See Section 8.

Specialist healthcare services

If you are assessed as needing it you are entitled to receive, whether you live in your own home or a care home:

- occasional ongoing specialist medical advice or treatment;
- specialist care such as continence advice (including continence products you are assessed as needing), stoma care, diabetic advice or community services such as physiotherapy, speech and language therapy and chiropody;
- specialist equipment that it would be unreasonable to expect your care home to provide.

Palliative care services

If you have a progressive disease that is not curable, you and your family may be offered support from several members of a multi-disciplinary team. This may initially be on an intermittent basis and possibly more frequently as your disease progresses.

Palliative care services are designed to keep you comfortable and ensure the best quality of life for you and your family. They may include controlling and managing pain and other physical symptoms and providing emotional support during your illness and around the time of your death.

See Section 8 for details of charitable organisations that can provide support to cancer patients and their families.

5. Challenging eligibility decisions made prior to 1st October 2007

If you believe that you or a relative may have been wrongly denied NHS continuing healthcare prior to 1st October 2007 – because of a failure to consider eligibility or due to an incorrect decision - you can request a review of the case. The review will be based on the eligibility criteria operating during the period in question.

However if your case involves an eligibility decision made before April 2004, or which involves a period of time mainly before April 2004, you would need to submit your case immediately, explaining why you have not raised it before.

A cut off date of 30 November 2007 for cases covering the above periods was announced in July 2007 by the NHS Chief Executive, following consultation with the Health Service Ombudsman. He advised SHAs and PCTs of the wish to begin to draw to a close the retrospective review process started in 2004 and asked them to publicise the above cut off date. Although not ruling out that there may be exceptional circumstances which meant that some cases could not be submitted before this date, he advised that in the absence of such circumstances, cases should be returned to the applicant explaining the reason why.

To help you decide if it may be appropriate to request a review covering a period after April 2004, the appendix at the back of this factsheet gives brief details on principles behind guidance operating since 2001. Call NHS Direct if you do not know which PCT to contact to request a review.

Ask the PCT for a copy of the eligibility criteria that would have been used at the time. If, having read them, you believe you or your relative fit the criteria, write to the Chief Executive of the PCT explaining your reasons for requesting an assessment and/or review of the case.

The request can relate to someone currently living in a care home or to a deceased relative. It could be a person who is/was self funding their care. It could also be someone who is/was supported by the local authority following a means test. Individuals supported by the local authority contribute income from their state pension and any occupational pension towards the cost of their care.

Redress

The Health Service Ombudsman has received complaints raising the issue of redress for financial losses suffered by those who were wrongly denied NHS continuing healthcare. A special report addressing this issue was published by the Ombudsman's office in February 2007.[11] In response, the Department of Health issued new guidance. [12]

This guidance reminds PCTs of their responsibilities concerning maladministration and redress; reminds them that they are empowered to make ex-gratia payments where appropriate; advises them how to calculate interest payments redress; reminds them about the powers of local authorities regarding deferred payments, introduced on 1st October 2001, which enable care home residents to avoid having to sell their home immediately to pay for care.

6. NHS-funded nursing care

NHS-funded nursing care is the funding provided by the NHS to care homes providing nursing, to support the provision of nursing care by a registered nurse for those assessed as eligible.[13]

Definition of nursing care

This is the time a *registered nurse* spends providing nursing care and monitoring and supervising care delegated to a non-registered nurse such as a care assistant.[14] It does *not* cover time spent by a non-registered nurse on nursing tasks.

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[11] Retrospective Continuing Care Funding and Redress
http://www.ombudsman.org.uk/improving_services/special_reports/hsc/care07/index.html

[12] NHS Continuing healthcare: continuing care redress
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073094

[13] NHS-funded nursing care. Practice Guidance 2007.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078827

[14] Nursing care as defined in Section 49 The Health & Social Care Act 2001

6.1 Assessment and funding

Prior to introduction of the National Framework:

- it was necessary to carry out a separate determination of nursing needs if you were to receive care in a nursing home. (There was also the likelihood of this being carried out without having first considered your eligibility for NHS continuing healthcare.)
- nursing needs were identified as being in one of three bands: low, medium or high. For the year beginning April 2007, the PCT payment for the low band was £40 per week; medium band: £87 per week and high band £139 per week.

Since the introduction of the National Framework on 1st October 2007:

- assessment of nursing needs is integral to the process of deciding eligibility for continuing NHS healthcare, with a requirement that a decision about the latter must be made first. (See section 3.6)
- a single payment for nursing care of £101 per week is made for all nursing home residents assessed as eligible after this date. Respite care in a nursing home also attracts this rate.

NHS-Funded Nursing Care – practice guidance re-affirms that alternative ways of providing care and support, other than admission to a nursing home, should always be considered as part of the care planning process.[15]

6.2 Transitional arrangements

Advice was issued to PCTs explaining transitional arrangements for those residents already in a nursing home on 1st October 2007.

If in a nursing home on 1st October 2007
Nursing needs would be in the low, medium or high band.

Residents on the low or medium bands
From 1st October, care homes to receive the flat rate of £101 per week for each resident on the low or medium band.

[15] NHS-funded nursing care –practice guide 2007 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078827

Residents on the high band
PCTs to continue to pay £139 per week from 1st October unless on reassessment:

- you are found eligible for NHS continuing healthcare (the full cost of your care will then be the PCT's responsibility);
- your nursing needs have diminished to the extent that if the old guidance relating to nursing bands were applied, you would only be eligible for either the low or medium bands (the PCT will then pay the single rate of £101 from 14 days following notification of the outcome of the reassessment);
- you no longer have nursing care needs.

If you disagree with the decision made following reassessment you can ask the PCT for a review of the decision and if necessary, an independent review as explained in section 3.8.

6.3 If you are admitted to hospital

If you have to be admitted to hospital from your care home, the PCT does not pay nursing care costs during that period. NHS-funded nursing care – practice guidance says PCTs should provide for retainers to be paid to care homes to safeguard your care home place so you can return when discharged from hospital.

6.4 Care home fees and NHS payments for nursing care

Regulations introduced in September 2006 require residential homes and nursing homes to specify in their service user's guide the 'total fees payable' (for nursing homes, this means fees payable before account is taken of any nursing contribution paid by the PCT); the arrangements for paying such fees; and the arrangements for charging and paying for any additional services.[16]

These regulations also require **nursing and residential homes** to:

- give notice of changes to fee levels, if it is practicable, at least one month in advance, together with a statement of reasons for any increase;

[16] *The Care Standards Act (Establishments and Agencies) (Miscellaneous Amendments) Regulations 2006*

- specify whether services, terms and conditions and fees vary according to the source of funding for a person's care. The aim being to alert prospective residents to seek further information – for instance whether fees paid by those funded by the local authority differ from those paid by people funding their own care.

The **National Minimum Standards for Care Homes for Older People** require that residents have a written contract or statement of terms and conditions with the care home. This should include the care and services covered by the fee, the level of the fees and any additional services available at extra cost.

"Fair Terms for Care" is a consumer booklet produced by the Office of Fair Trading (OFT) to help you decide whether the terms of a care home contract are fair. Contact details for the OFT can be found in Section 8.

7. Intermediate care

Intermediate care services are designed *either* to help maximise your independence for example by promoting your recovery after hospital treatment *or* to prevent unnecessary admission to hospital. [17]

Definition of intermediate care

Intermediate care must meet the following criteria:

- be targeted at people who would otherwise face unnecessarily prolonged hospital stays or an inappropriate admission to acute in-patient care, long term residential care or continuing NHS in-patient care;
- be provided on the basis of a comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery;
- have a planned outcome that typically enables you to maintain or regain the ability to live at home;
- be time limited - normally no longer than six weeks and frequently as little as one to two weeks or less;
- involve cross-professional working, with a single assessment framework, single professional records and shared protocols.

[17] HSC 2001/ 01: LAC (2001) 1 Intermediate care. LAC (2003) 14 Changes to local authority charging regime for community equipment and intermediate care services.

You and where appropriate your carer should be involved in drawing up your care plan, which should also indicate the support you are likely to need once this period of care finishes.

Exceptionally, intermediate care may be considered for slightly longer than six weeks. In this case, a review date within the six week period should be an integral part of the care plan.

There is no charge for any of the health and/or social care services offered as part of an intermediate care package provided for up to and including 6 weeks.

Services that may be offered

Rapid response teams - These teams may be based in the community but usually have close links with the hospital accident and emergency department or the ambulance service. They can provide, often on a 24-hour basis, rapid assessment of your needs and if necessary initiate rapid access to short-term nursing support, personal care at home or community equipment. Their prime aim is to avoid an unnecessary stay in hospital.

Hospital at home - intensive support in your own home, including investigations and treatments not normally available through your GP or community based staff.

Residential rehabilitation - a short term programme of therapy in a care home which may include physiotherapy to maximise mobility and minimise the likelihood of falling; speech therapy to help with speech and swallowing; occupational therapy to identify the most appropriate aids and gain skills and confidence in using them.

Day rehabilitation - similar to support offered in residential rehabilitation but provided in a day hospital or day centre.

Supported discharge - a short term programme of personal and/or nursing care to support your recovery at home. Community equipment and housing based support may also be included. A lower level of support is likely to be sufficient once this active rehabilitation phase is complete.

Intermediate care must involve active therapy, treatment or an opportunity for recovery. It is not intended to be used while you are simply waiting for a care home place to become available or for home care services to be put in place.

8. Further information

Alzheimer's Society, Devon House, 58 St Katharine's Way, London E1W 1JX. Helpline: 0845 300 0336 (lo-call rate), website: www.alzheimers.org.uk. Provides information about all types of dementia and supports people, their families and carers. The Society produces a range of factsheets and also a booklet 'When does the NHS pay for care?' For a copy of this booklet, together with the joint publication 'Guide to Fully Funded NHS Care' send a large (A4) addressed envelope with stamps to the value of 70p (1st class) or 60p (2nd class) postage.

Crossroads Caring for Carers, 10 Regent Place, Rugby, Warwickshire CV21 2PN, tel: 0845 450 0350 (lo-call rate), website: www.crossroads.org.uk. Crossroads has around 180 schemes throughout England and Wales. Look on their website or contact their office to see if there is a scheme in your area. The range of services provided by each scheme depends on local need and funding available.

Healthcare Commission (The), Finsbury Tower, 103-105 Bunhill Row, London EC1Y 8TG, tel: 020 7448 9200, complaints helpline: 0845 601 3012 (lo-call rate), website: www.healthcarecommission.org.uk. The Healthcare Commission is the regulator for NHS, private and voluntary healthcare in England. It can also be called upon if the independent review stage does not resolve a dispute around eligibility for NHS continuing healthcare or NHS-funded nursing care.

Hospice Information, Help the Hospices, Hospice House, 34-44 Britannia Street, London WC1X 9JG, tel: 0870 903 3903 (national call rate) or 020 7520 8232, website: www.hospiceinformation.info/index.asp. Hospice information is a partnership between St Christopher's Hospice and Help the Hospices and offers an enquiry service to the public and professionals on UK and international palliative care.

Macmillan Cancer Relief, 89 Albert Embankment, London SE1 7UQ.Cancerline 0808 808 2020 (free call), website: www.macmillan.org.uk. Macmillan can provide expert support in the form of Macmillan nurses and other health professionals. It has a patient's grants service and can also provide information and emotional support through Cancerline, its freephone helpline.

Marie Curie Cancer Care, 89 Albert Embankment, London SE1 7TP, tel: 020 7599 7777, website: www.mariecurie.org.uk. Marie Curie Cancer Care provides help for cancer sufferers and their families in their own homes and through their hospices.

NHS Direct, 0845 46 47 (lo-call rate) is a 24 hour NHS helpline. It can give details on areas covered by each SHA and PCT in England. It can also give contact details for your local PCT and Patient Advice and Liaison Service (PALS) and details of the NHS complaints procedure.

Office of Fair Trading, Fleetbank House, 2-6 Salisbury Square, London EC4Y 8JX, tel: 020 7211 8000, consumer helpline 08457 22 44 99 (lo-call rate), website: www.oft.gov.uk. The booklet 'Fair Terms for Care' can be ordered by writing to OFT, PO Box 366, Hayes UB3 1XB or by calling 0800 389 3158 (free call).

Office of the Public Guardian, Archway Tower, 2 Junction Road, London N19 5SZ, Customer Services 0845 330 2900 (lo-call rate) supports and promotes decision making for those who lack capacity or would like to plan for their future within the framework of the *Mental Capacity Act*. A series of guidance booklets, including one to help friends and family understand the implications of the Act are available on their website: http://www.publicguardian.gov.uk/ or by calling customer services.

Parliamentary and Health Service Ombudsman (The), Millbank Tower, Millbank, London SW1P 4QP, tel: 020 7217 4051, helpline: 0845 015 4033 (lo-call rate), website: www.ombudsman.org.uk. Reports published by the Ombudsman can be found on the website by selecting the section headed 'Publications'. If purchased by calling the helpline, a charge will be made.

9. Further information from Age Concern

The following factsheets/guide may be of use:

Factsheet 10	*Local authority charging procedures for care homes*
Factsheet 37	*Hospital discharge arrangements*
Factsheet 41	*Local authority assessments for community care services*
Factsheet 46	*Paying for care and support at home*
Guide	*A guide to fully funded NHS care – joint publication with Alzheimer's Society, Help the Aged and Royal College of Nursing (*you can request a copy of this guide from any of the organisations involved in its publication).

The following books may be useful:

Age Concern England's annual publication *Your Rights to money benefits – Price £5.99* gives more information about pensions, benefits and other kinds of financial help.

Your Rights to Health Care – Price £7.99, this easy-to-read book provides information about the main entitlements to health care for older people, particularly NHS services provided in England. Although aimed at the older person, Your Rights to Health Care is essential reading for anyone coming into contact with the NHS, particularly NHS services provided in England, and who is concerned about their rights and entitlements.

Both are available from Age Concern Books. To order, please telephone our hotline (9am-7pm Monday to Friday, 10am-5pm Saturday): **0870 44 22 120** (national call rate), or visit our **website: www.ageconcern.org.uk/bookshop** (secure online bookshop).

If ordering by post, please send a cheque or money order, payable to Age Concern England, for the appropriate amount plus p&p to Age Concern Books, Units 5 & 6, Industrial Estate, Brecon, Powys LD3 8LA.

(**Postage and packing**: mainland UK and Northern Ireland: £1.99 for the first book, 75p for each additional book up to a maximum of £7.50. Free on orders over £250. For customers ordering from outside the mainland UK & NI: credit card payments only; please telephone the hotline for international postage rates or **email: sales@ageconcernbooks.co.uk**).

If you would like

- to find your nearest Age Concern
- any additional factsheets mentioned (up to a maximum of 5 will be sent free of charge)
- a full list of factsheets and/or a book catalogue
- to receive this information in a different format

phone 0800 00 99 66 (free call) or write to Age Concern FREEPOST (SWB 30375), Ashburton, Devon TQ13 7ZZ. For people with hearing loss who have access to a textphone, calls can be made by Typetalk, which relays conversations between text and voice via an operator.

Age Concern factsheets and other information materials can be downloaded free from our website at: www.ageconcern.org.uk. To receive a free e-mail notification when new and updated factsheets are published, please either contact the Factsheet Subscription Service on tel: 020 8765 7200 by email: factsheet.subscriptions@ace.org.uk, or sign up on-line.

Age Concern provides factsheets free to older people, their families and people who work with them. If you would like to make a donation to our work, you can send a cheque or postal order (made payable to Age Concern England) to the Personal Fundraising Department, ACE Freepost CN1794, London SW16 4BR.

Find out more about Age Concern England online at www.ageconcern.org.uk

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No factsheet can ever be a complete guide to the law, which also changes from time to time. Therefore please ensure that you have an up to date factsheet and that it clearly applies to your situation. Legal advice should always be taken if you are in doubt. *(Age Concern England is unable to give financial or legal advice).*

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Appendix: Eligibility criteria for continuing NHS health care – 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[18]. 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 health care 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*.
The judge said it can only be nursing care which 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 overriding factor is whether a person's need is primarily for health care – which is fully funded by the NHS – or social care – which is means tested and so charges may be applied.

[18] HSG 95 (8): LAC 95 (5) NHS responsibilities for continuing health care needs.

Following the judgment, the Department of Health issued further guidance[19], 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[20].
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 health care 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 health care 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 multidisciplinary 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 health care;
- the location of care should not be the sole or main determinant of eligibility. Continuing NHS health care may be provided in a hospital, nursing home, hospice or the individual's own home;
- 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 sect 21 of the *National Assistance Act 1948*.

[19] HSC 1999 / 180 Ex parte Coughlan follow up action continuing health care
[20] HSC 2001 / 015 Continuing care: NHS and Local Council's responsibilities

In April 2002, the 95 health authorities were replaced by 28 Strategic Health Authorities (SHA) and 303 Primary Care Trusts (PCT). 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 the SHA 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.[21] 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.

[21] NHS funding of long term care HC 399 London: The Stationery Office. Also available on the website: www.ombudsman.org.uk.

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

- to take reasonable steps to identify cases arising since 1996 that may have been wrongly denied NHS funded care; [22]
- 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 9 SHA areas. It proved a larger task than anticipated. There were few cases still outstanding in March 2005, and reimbursement of eligible cases was still to be completed in some SHA areas.

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 continuing NHS health care 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.

[22] It is not possible to investigate cases where a care home resident dies 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.

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. [23]

2. 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. [24]

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 9th December 2004, just prior to the publication of 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*. i.e. the National Framework.**

3. House of Commons Health Select Committee Report[25]

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.

[23] Report can be found on website: www.melaniewood.com
[24] HSO follow up report is available on: www.ombudsman.org.uk/improving_services/special_reports/hsc/care04/care04_cover.html
[25] Report can be found on website: www.parliament.uk/parliamentary_committees/health_committee.cfm

They believed 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 continuing NHS health care 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. 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.[26]

June 2006 – Consultation Document on the National Framework was published

It proposed:

- a single policy on who should receive NHS funding – be it fully funded care or NHS funded nursing care;
- there should be 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.[27]

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

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[26] Guidance can be found at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139934

[27] Guidance at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139934