Leading the fight against dementia

Alzheimer's Society

When does the NHS pay for care?

Guidance on eligibility for NHS continuing healthcare funding in England and how to appeal if it is not awarded

Version 4

This booklet is for people with dementia in England who need long-term support from the NHS and/or social services because of dementia, and their carers. It explains the help that the NHS in England may provide and/or pay for.

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No booklet can ever be a complete guide to the law, which also changes from time to time. Specialised, legal advice should always be taken if you are in doubt.

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Introduction

Provision of care in the UK is the responsibility of two organisations. The NHS provides healthcare and local authority social services provide social and personal care. This booklet is primarily about NHS care.

Services that the NHS provides are mostly free. However, you may have to pay for all or some of the services that have been arranged by your local authority social services, depending on your income and the amount of your savings. In other words they are means-tested. Therefore any decision as to whose responsibility it is to provide care can have significant financial consequences for you.

Guidance on eligibility for NHS continuing healthcare is subject to review and change. Please refer to the Alzheimer's Society website alzheimers.org.uk for the most up-to-date information.

The aims of this guide

The NHS supplies and pays for three types of care which take place outside of a hospital:

- primary care at home or in a residential care home, from health professionals, for example community nurses or community psychiatric nurses, podiatrists
- the nursing element of care in a nursing home
- NHS continuing healthcare (full provision and funding of care) in nursing homes, residential care or own homes.

This guide explains what NHS continuing healthcare is, how you might be able to get it, and what to do if your request for NHS continuing healthcare is turned down.

For more information about NHS primary care at home, please see Alzheimer's Society factsheet 454, How health and social care professionals can help. All factsheets are available to download from the Alzheimer's Society website at alzheimers.org.uk/factsheets.

For more information about NHS-funded nursing care in a nursing home (also called the nursing care contribution) refer to Alzheimer's Society factsheet 452, Assessments for NHS-funded nursing care.

We also want to highlight the injustice of people whose primary need is a health need being wrongly charged for their care.

Alzheimer's Society campaigns

Alzheimer's Society campaigns for people with dementia to be given access to fully-funded NHS care through its work including the promotion of information about NHS continuing healthcare, helping people to challenge decisions through the NHS continuing healthcare volunteer group as well as providing information.

Since the Health Service Ombudsman's report in 2003, many people have contacted Alzheimer's Society to find out how to get their case looked at again. Alzheimer's Society is still encouraging anyone who thinks they have wrongly been charged for care to complain. It is important, not only in individual cases, but also because we must highlight the injustice of people with dementia being unfairly charged for care.

Five key NHS publications

The government has published a number of documents to clarify its position on continuing care, and the processes necessary to obtain it. This document refers frequently to these main publications, all of which are available on the Department of Health's website. These are:

- National Framework for Continuing Healthcare and NHS-funded Nursing Care (revised July 2009)
  This publication deals principally with the process for establishing eligibility for NHS continuing healthcare and is referred to throughout this document as the Framework.

- NHS Continuing Healthcare Checklist (July 2009)
  This document is used to help identify people who may need a referral for a full consideration for NHS continuing healthcare. This does not indicate the likelihood that a person will necessarily be found to be eligible for NHS continuing healthcare.

- Decision Support Tool for NHS continuing healthcare (July 2009)
  Decision Support Tool (DST) supports the application of the Framework to individual cases by bringing together and recording/applying evidence in one document. It is used to help establish whether an individual is eligible for NHS continuing healthcare.

- Fast Track Pathway Tool for NHS continuing healthcare (July 2009)
  This document is the assessment tool for determining a person's eligibility for fast tracking to receiving continuing healthcare when that person is near the end of their life.

- NHS Continuing Healthcare Practice Guidance (March 2010)
  This publication is intended to support practitioners and others with responsibilities for NHS continuing healthcare in the implementation of the revised National Framework and in the use of associated tools.

Funding of care, whether in a person's own home, or a residential or nursing home, is complicated. Getting information can be difficult and the rules can be hard to understand. In the past they were applied differently in different parts of the country. The process of applying is time-consuming and often bewildering.

This guide, however, aims to help you understand the assessment and review process for NHS continuing healthcare and what kind of information you need to gather. It cannot, unfortunately, tell you whether your case meets the criteria.

Our guide applies to people living in England. Readers in Scotland, Wales and Northern Ireland should look at Appendix 4 for organisations that can give information about the rules there. In 2010, a National Framework for Wales was published, see 'References'.

Apply if you think that the person with dementia may be eligible

Try not to be put off by the complexity of the subject matter. Read the parts that you think are most relevant to you. Although this information focuses on people with dementia, much of it may also be relevant to people with other conditions.

However, it is important to understand that the NHS limits access to free care, ie NHS continuing healthcare through eligibility criteria and has rules that apply. Many people with dementia who do not meet the criteria will not be eligible. From July to September 2010, 51,088 people in England received fully paid care from the NHS, including people with all types of illness and not just dementia.

1 What is NHS continuing healthcare and how do you qualify for it?

Definitions

The government's definitions of continuing care and NHS continuing care are taken from The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care published in June 2007 (revised July 2009). Continuing care is described as:

> 'Care provided over an extended period of time, to a person aged 18 or over to meet physical or mental health needs that have arisen as a result of disability, accident or illness.'

The NHS is responsible for providing some continuing care and this is referred to as NHS continuing healthcare. NHS continuing healthcare is provided free of charge. An individual's continuing care could be solely provided by the NHS, or sit alongside some services provided by local authorities (LAs). The Framework goes on to describe this possible division in providers of continuing care services:

> 'An individual who needs 'continuing care' may require services from NHS bodies and/or from LAs. Both NHS bodies and LAs therefore have a responsibility to ensure that the assessment of eligibility for continuing care and its provision take place in a timely and consistent manner.'

Someone awarded NHS continuing healthcare will have all the care in that package provided by the NHS. This package will meet all assessed needs including what is normally called social care for people in their own home. In care homes this includes the residential costs and food. For those receiving continuing healthcare in their own home, it is possible that additional social care may be provided which must be paid for.

The criteria for NHS continuing healthcare

The criteria for assessing whether people are entitled to NHS continuing healthcare are set out in the Framework.

A National Framework is just that – a national policy that covers the whole of England. That should mean a reduction in the regional variations in assessments and an end to the inconsistency, whereby people find that the services that they can get depend on where they happen to live. An individual NHS primary care trust (PCT) – which may cover an area such as part of a county, a large town, or a section of a big city – is your first point of contact in requesting an assessment for NHS continuing healthcare. PCTs or, if the person is in hospital – medical staff, carry out the assessments, which should all follow the same procedure, set out in the Framework.

All care needs should be assessed in relation to the following four key indicators:

- nature – the type of condition or treatment required and its quality and quantity
- complexity – how symptoms interact to make care and management more difficult
- intensity – one or more severe needs requiring regular, sustained care
- unpredictability – the degree to which unexpected changes in the condition occur affecting level of risk and care needs.

Primary health need

To help decide which treatment and other health services the NHS should provide (and pay for) and which services local authorities may provide (and may charge for), the government has started using the concept of 'a primary health need' which comes from case law. Where a person's primary need is a health need, it is the NHS that is responsible for providing for all their needs, including accommodation, if that is part of the overall need, and so they are eligible for NHS continuing healthcare.

The guidance calls for 'a practical approach' to deciding who is eligible for NHS continuing healthcare, especially when it comes to working out which services the NHS should provide and which are the responsibility of the local authority. The primary care trusts (PCTs) use the Decision Support Tool to help determine whether there is a primary health need.

People approaching the end of their lives or those with a rapidly deteriorating condition that may be entering a terminal phase, may well be assessed as having a primary health need, and may urgently need NHS continuing healthcare funding, for example, to allow them to go home to die or to allow end-of-life support to be set up. In these cases people will be assessed using the Fast Track Pathway Tool.

However, doctors often are reluctant to or indeed cannot accurately say when a person with dementia is nearing the end of life, so this pathway is hard to achieve for people with dementia.

Determining primary health need

The diagnosis of a particular disease or condition does not in itself guarantee that someone will be entitled to funding for NHS continuing healthcare. It is only an individual's assessed healthcare needs that determine eligibility.

If this assessment shows that your primary need is a health one, you should qualify for NHS continuing healthcare. The Decision Support Tool (DST) aims to bring together and record a person's needs based on 12 'care domains':

1 Behaviour
2 Cognition
3 Psychological/emotional needs
4 Communication
5 Mobility
6 Nutrition – food and drink
7 Continence
8 Skin (including tissue viability)
9 Breathing
10 Drug therapies and medication: symptom control
11 Altered states of consciousness
12 Other significant care needs.

A person with dementia is assessed on their needs in each domain and the needs are scored as **low, moderate, high, severe or priority** needs. Not all the scores will apply in all domains. Each domain is explained in full in the notes that accompany the Decision Support Tool.

Core values

The Department of Health says there are a number of 'core values' that should underpin any assessment for NHS continuing healthcare. These include:

- The assessment and the decision-making process should be centred on the person.
- The assessment and decision-making process must be led by health needs, not by diagnosis.
- NHS continuing healthcare is available in any setting, as is access to the assessment process.
- All decisions will be culturally sensitive and client-centred.

- Before assessment for NHS continuing healthcare begins, full agreement from the individual being assessed should be obtained. If there is a question over the individual's ability to give consent, alternative consent should be sought in accordance with the Mental Capacity Act 2005 and the associated code of practice.
- The assessment should document and take into account the individual's wishes on how and where care is to be delivered.
- Assessments should be organised so that the person who is undergoing an 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.
- Decisions and the reasons for them should be transparent for individuals, carers, family and staff.

Needs are needs, wherever you are

PCTs are allowed to provide or fund NHS continuing healthcare in any setting such as a nursing home, a residential home, a hospice or the person's own home. Where the person is currently being cared for should not influence the assessment and neither should the nature of their relationship with the person giving care. The guidance says that decision-makers should not marginalise a need just because it is being successfully managed: well-managed needs are still needs.

2 How to get an assessment

Five steps to getting a continuing care assessment

1. Find out which is your local primary care trust (PCT).
2. Ask the PCT to assess the person for NHS continuing healthcare.
3. The Decision Support Tool has been developed to help support practitioners in the application of the National Framework. It portrays needs based on criteria, specifically 12 care domains. Ask the PCT to provide you with detailed information about the process involved.
4. Ask the PCT when they will begin the assessment process, and make the PCT aware that you wish to participate fully in the process yourself.
5. Ask the PCT to ensure you are given the opportunity to see the full Decision Support Tool before you comment on your perceptions of the patient's needs.

This booklet goes through these steps in detail. If you are not happy with the outcome then you can work through the appeal and review process.

Assessments can be requested wherever the person is cared for and reviews may also be requested at any time if his/her condition deteriorates, in which case this is a new assessment.

It is the responsibility of the NHS to assess need for NHS continuing healthcare. If you are unsure whether an assessment has been made or you want to request one, contact your local primary care trust and ask for the NHS continuing healthcare co-ordinator.

To find out the name of this co-ordinator, ask at your local GP surgery or speak to the local patient advice and liaison service, known as PALS. To get contact details for PALS, call NHS Direct on 0845 4647. Alternatively, you can find your local primary care trust at www.nhs.uk/servicedirectories where there is a link.

The assessment in brief

The assessment process may have two stages – an initial **screening** – roughly estimating your potential eligibility for NHS funding and a **full assessment**. However, for people who have a rapidly deteriorating condition and are considered to be near the end of their life, senior doctors or nurses may use the Fast Track Pathway Tool to enable care to be put into place urgently.

The initial screening will be carried out by a nurse, doctor, other qualified healthcare professional or social worker. If the outcome of the screening is that the NHS considers that the person may qualify for full NHS funding, there will then be a full assessment.

The full assessment is a comprehensive assessment of a person's physical, mental, psychological and emotional needs. This assessment includes contributions from all the health and social care professionals involved in the person's care (the multidisciplinary team), to build a comprehensive picture of needs.

The Framework makes it clear that:

- carers must be consulted where appropriate
- the result of any decision must be recorded in the patient's notes
- the NHS must explain to the person or their families how to ask for a review if they are not happy with the result of the assessment.

If the outcome of the screening is not referral for a full assessment, this decision should be clearly communicated to the patient as well as carers or representatives. A full assessment can still be requested from the PCT, who must fully consider this request as well as planning for the care of individuals with ongoing needs.

Whatever the outcome of the screening, there should be a case review after three months to reassess care needs and, if one was not recommended previously, whether a full assessment for NHS continuing healthcare should be carried out. After this, reviews should take place at least annually.

Multidisciplinary assessment

To carry out a full multidisciplinary assessment, an individual or individuals should be identified by the PCT to co-ordinate the process. They then take responsibility for this until the decision about funding has been made and a care plan has been written. A full multidisciplinary assessment of an individual's care needs, including all specialist and non-specialist assessments should be carried out by a multidisciplinary team

including both representatives from the NHS and the local authority or two professionals from different healthcare professions. Its task is to look at all possible evidence, and make a recommendation to the PCT as to whether an individual has a primary health need. Only under exceptional circumstances should this recommendation not be followed.

Following a comprehensive assessment, the Decision Support Tool is used to help determine whether someone is eligible for NHS continuing healthcare, and you may find it useful to compare these guidelines with the input from local authority representatives. There is a section in the Decision Support Tool allowing you to summarise what you see as the needs for care. Make sure you use this opportunity.

Consenting to the assessment

As with any examination or treatment, the individual being assessed should give their informed consent before the assessment begins. If there is a concern that someone may lack the capacity to do this, people doing the assessment should follow the code of practice linked to the Mental Capacity Act 2005 which came into effect in October 2007. See also Alzheimer's Society factsheet 460, Mental Capacity Act 2005.

A person may elect a family member or other person (who should be independent of the local authority or NHS) to advocate on their behalf. Even where this is not the case, anyone carrying out the assessment should take into account the views and knowledge of family members.

The Framework states, 'a carer providing regular and substantial care has a right to an assessment of their needs as a carer'. A carer's right to an assessment was established in The Carers (Recognition and Support Services) Act 1995, and extended further to acknowledge other commitments and responsibilities that should be considered in the assessment as part of The Carers (Equal Opportunities) Act 2004.

Top tip

It is recommended that you try and participate in assessment meetings and try to ascertain which documents have been used as evidence. For example, it may be extremely useful to take hospital notes into account. It is also advisable to go and see the records yourself rather than request them in the post as not all the relevant information may be sent to you.

When and where assessments can take place

Hospital

Assessments can take place in any settings. The new guidance says that before an NHS body, such as a hospital, passes the details of someone it wants to discharge from hospital to a local authority social services department, it:

> 'must take reasonable steps to ensure that an assessment of eligibility for NHS continuing healthcare is carried out in all cases where it appears to the body that the patient may have a need for such care, in consultation, where it considers it appropriate, with the social services authority appearing…to be the authority in whose area the patient is ordinarily resident.'[1]

In other words, a hospital should not discharge someone with dementia without considering the need for NHS continuing healthcare. 'Considering' involves screening, a possible full assessment, or even fast tracking. See **The assessment in brief**, on page 13, for what the hospital is being asked to do. Alzheimer's Society factsheet 453, Hospital discharge provides further information on the subject.

The Framework makes it clear that doing assessments in hospital wards does not always give a fair idea of how much care an individual really needs and says that it should be considered whether further NHS-funded therapy and/or rehabilitation might make a difference to the potential of an individual before a full assessment takes place.

The Framework also states that, if possible, 'NHS staff should get social services colleagues involved in these assessments'. In addition it warns that local authorities 'should not allow an individual's financial circumstances to affect a decision to participate in a joint assessment'.

This means that most people with dementia leaving hospital should have been considered for NHS continuing healthcare. However, the experience of Alzheimer's Society is that few people have this explained to them and few are told when or how they can ask to be reassessed.

1 Department of Health, The Delayed Discharges (Continuing Care) Directions, 2009

Care homes

Alzheimer's Society's experience is also that people moving into nursing homes are not automatically considered for NHS continuing healthcare and that their needs are not adequately identified. If an assessment has not taken place, you should ask for one by contacting the primary care trust. Assessments should be carried out annually in nursing homes when the registered nursing care is reviewed as an NHS continuing healthcare assessment should be carried out before a nursing assessment.

In the past it has often been assumed that people in residential homes are not eligible to receive NHS continuing healthcare. The assumption was based on the view that people with the most serious medical conditions and complex care arrangements would be cared for in a nursing home.

In fact, there are many people in residential homes with complex medical conditions who could be eligible for NHS continuing healthcare, although it is most likely to be a struggle to get it.

If a person is assessed as needing care in a care home, social services will carry out a financial assessment to decide how much that person will have to contribute towards the cost of their care. The local authority financial assessment takes into account both income and capital.

- Income includes money received regularly – for example, from pensions and benefits.
- Capital includes savings, investments and, in some cases, the value of the person's home.

The person with dementia is only assessed on their own income and capital or on their share of jointly held resources. You can ask the local authority to provide a written explanation of how it has worked out the person with dementia's contribution. It should be clear to you what has been taken into account. Before the move to the home takes place, check what the fees cover so that there can be no misunderstandings with the local authority or the home about any 'extras'.

Care in someone's own home

NHS continuing healthcare can be provided in someone's own home. However, we know that the highest proportion of people receiving NHS continuing healthcare are in nursing homes and far fewer are awarded it while living at home.

A person receiving care provided by the local authority in their own home will normally be means-tested by the local authority to see how much they must pay towards the cost of that care.

Most local authorities charge for care services although this is something about which they have discretion. Some set maximum amounts that a person can be charged and that maximum varies from area to area. A person may be charged for home care and/or respite care.

Someone with dementia might be eligible for NHS continuing healthcare funding to cover the costs of this care at home. The government says that people have always been eligible to receive NHS continuing healthcare funding in their own homes but in practice it has been very difficult for anyone to get NHS continuing healthcare in their own home.

As with people in residential care, it has been assumed that those with the most serious medical conditions would be cared for in a nursing home. Many people with complex needs, however, are being cared for at home.

When the Health Service Ombudsman reviewed the case of Malcolm Pointon, in her 2004 report, she found that Malcolm and his wife, Barbara, had wrongly been charged for care at home that should have been available on the NHS. (See Chapter 4 for more details of this important case). You may want to quote the Pointon case as an example in your correspondence if it's appropriate. The case study below also shows an example of someone awarded NHS continuing healthcare in their own home.

Case study 1 – Getting NHS continuing healthcare in one's own home

Mr B has Alzheimer's disease. He was admitted to the urology ward of a general hospital in January 2006 and discharged in September of that year. The PCT wanted to admit him to a nursing home where nursing care could be provided for him. Mr B's son appealed against this decision in order to get continuing healthcare provided for care in Mr B's own home. In the first instance, Mr B's assessment was made with local criteria when he was judged to be not eligible for continuing care.

Mr B's son appealed against the decision based on the way in which the criteria had been applied and a reassessment took place using the National Framework guidelines and the Decision Support Tool. At this time Mr B's son insisted that Mr B was observed over an extended period of time so that an accurate evaluation of his condition could be made. Continuing healthcare was granted to Mr B in June 2007 for care in his own home.

Difficulties for people with dementia

There are various reasons why it is difficult for people with dementia (and people with some other conditions) to meet the criteria for NHS continuing healthcare.

Dementia care regarded as social care

For care provided at home, people are expected to pay for care they receive from social services. If they cannot afford it, they will have to fill in a local authority form, called a means test, stating how much savings and income they have. After this means test, the local authority may fund some or all of the care. Each local authority has its own rules about the types of care it provides and how much it costs. This information is public so the local authority has to provide this information, if asked. There is further information about this on the Alzheimer's Society factsheet 469, When does the local authority pay for care?

The Decision Support Tool

This test of primary health need has become a key test for eligibility for NHS continuing healthcare in the wake of an important court case, known as Coughlan. It is recognised however that there are certain limitations to this test. For more information about Coughlan and another influential case, the Grogan judgment, see Chapter 4, page 38. The national Decision Support Tool (DST) has been developed in order to minimise the variation seen in assessments with the aim of providing a mechanism by which the primary health need test can be consistently applied.

The summary sheet on the DST gives some clear examples of where eligibility for NHS continuing healthcare would be recommended:

- a level of **priority** needs in any one of the four domains that carry this level
- a total of two or more incidences of identified **severe** needs across all care domains.

It goes on to indicate that:

- 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, **may well also indicate a primary health need**.

The DST says that in these cases:

> 'the overall need, the 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 for NHS continuing care should be made.'[2]

It also goes on to state that all factors impacting on care needs must be taken into account including the interactions between needs, overall need and risk assessment evidence.

The Decision Support Tool can be seen as arbitrary because some needs are rated more severe than others, eg psychological and emotional needs and communication needs do not have a severe rating, but behaviour and altered states of consciousness do. There are no definitive values which ensure that continuing care is awarded. It is possible that someone could be assessed with a large number of 'moderate' needs but this would not indicate a primary health need. The Framework does make it clear, however, that both the quality and quantity of care should be taken into consideration, for example a large amount of low-level nursing care could indicate that someone cannot be left unsupervised and in reality needs 24 hour care. However, this in itself does not necessariy mean that the person will qualify for continuing care.

Results of the assessment

The primary care trust (PCT) that has arranged the assessment should inform you of its decision with a clear explanation of the reasons for it.

The PCT should tell you verbally and in writing once a decision is reached, within 28 days of referral. Remember that this decision relates to the condition of the person with dementia at that time of the assessment; this may change. You should have been involved in the assessment and there is also a section for you to complete in the Decision Support Tool.

If you disagree with a decision you can say so. Ask for all the papers, including the DST, so that you can show where you disagree with the scoring. Your request, along with any additional information you provide, should be given due consideration.

2 Department of Health, Decision Support Tool for NHS continuing healthcare, 2009

After the assessment

If NHS continuing healthcare is not awarded

If NHS continuing healthcare is not awarded, someone in a nursing home will get the NHS contributions to nursing care. For social care needs in residential care homes and nursing homes, national rules apply on means testing. Care in someone's own home is subject to individual local authority charges. More information can be found on Alzheimer's Society factsheets 451, 452 and 469.

There should be no gap in the provision of care, with people needing care that neither the NHS nor the local authority will pay for. If the primary health need test is applied, people should only be turned down for NHS continuing healthcare where, taken as a whole, the nursing or other health services required by the individual are judged to be 'merely incidental or ancillary' to the provision of the accommodation that local authority social services have a duty to provide, and are not beyond the type of service that a local authority (whose main responsibility is to provide social services) could be expected to provide.

If NHS continuing healthcare is awarded

Someone assessed as needing NHS continuing healthcare does not have to pay any of the costs of that care. The NHS pays the whole cost. It is provided in any setting whether the person is in a nursing home, a residential care home, a hospice or their own home. Someone in a nursing home who is assessed as needing NHS continuing healthcare will not have to pay any fees. However, receiving NHS continuing healthcare affects eligibility for other benefits in the same way as if they were in hospital. Disability Living Allowance and Attendance Allowance benefits will be affected and you should notify the Disability and Carers Service (DCS). State pension payments will continue as before, however pension credit can be affected in certain circumstances such as when an additional amount for severe disability has been paid previously. If you have any queries about benefit entitlements contact your local benefits office.

With regards to the care setting, someone receiving NHS continuing healthcare will usually have limited choice about where they are cared for. If the existing care is in a care home and the NHS does not normally contract with that particular home, it may require discussion with your PCT's care co-ordinator and representatives from the care home in order to ensure that the care needs identified will be met. The NHS might wish to move the person to a home in which it has beds. However, the NHS should take the person's psychological needs into account, as well as the risk to health of moving the person. The Framework makes this clear in paragraph 41.

Alzheimer's Society's position on charging for care

The current system of charging for care hits people with dementia hardest. This is because the majority of care that people need is classed as 'social care'. Unpaid carers, for example family or friends, provide the majority of care for people with dementia. However, if someone with dementia is living at home and needs help with eating, washing, dressing and using the toilet, it is usually social care staff provided or arranged by local authority's social services who provide such support.

It may be that the best option is a move to a care home where the person with dementia will receive support from care assistants employed by the care home. Social care is means-tested. As a result, people with dementia are paying substantial amounts for essential care that they need. If doctors or nurses provided this care, it would be free of charge on the NHS.

Alzheimer's Society argues that it is wrong that people with dementia are affected so badly by the current charging for care system. Despite the amount that people pay, the quality of care that people receive is often very poor. We are campaigning for a new care system that delivers a better deal for people with dementia. Any new system must clearly and fairly share the cost of care between the individual and state and deliver high quality care.

To find out more about our campaign to end the current system of charging for care, see alzheimers.org.uk/nhscontinuingcare

3 Reviewing assessments and the complaints procedure

Four steps to challenging an assessment decision

You will probably need to take these steps if you think you are being (or have been) wrongly charged for care that, in your view, should have been provided by NHS continuing healthcare. It is important to remember that, in order to challenge a decision, you need to have grounds such as questioning the application of the Framework to an individual's case and/or the procedure followed by the PCT, ie it is not just your view that the decision made was wrong.

There are two stages to any requests for a review. Firstly, at PCT level through a local review process which, along with timescales, should be publicly available. It is important to note that different PCTs may have a different local review process, eg some PCTs refer cases to a neighbouring PCT. You should ask for further details from your PCT to clarify their local resolution process. The second stage is a request to the strategic health authority which may then refer the case to an independent review panel.

1 If you are dissatisified with the PCT's decision about NHS continuing healthcare ask the PCT to reconsider the decision – this will often be done at a PCT review panel. If the PCT has conducted a review and says that, according to the criteria, the person is not eligible for NHS continuing healthcare, you may not be satisfied with its explanation. Take your case to the PCT review panel for the next stage in contesting the decision.
2 If the PCT review panel finds that you do not have a case, you may then request an independent review from the strategic health authority (SHA). The SHA independent review panel (IRP) will seek information from family members and professionals involved in the case.
3 If the SHA independent review is unsuccessful, the final recourse available is to contact the Health Service Ombudsman.
4 The Ombudsman will either investigate your complaint or advise you to use the local NHS complaints procedure.

The following chapter goes through these steps in detail, and a flowchart explaining the process is on page 36.

Available support

Taking on the NHS can seem a daunting undertaking – which is why Alzheimer's Society has launched a support group to help people challenge decisions, when they believe that they have wrongly been denied access to NHS continuing healthcare. The NHS continuing care volunteer support group is run by Alzheimer's Society volunteers. These are people who have won NHS continuing healthcare cases after challenging the system. All the volunteers have personal experience of continuing care cases and can offer sound advice.

If you think that you have been wrongly turned down for NHS continuing healthcare and want information on how to challenge the decision, you can contact the group – email NHSCC@alzheimers.org.uk or call Alzheimer's Society National Dementia Helpline 0845 3000 336. Members of the NHS continuing care volunteer support group are all volunteers who have successfully obtained NHS continuing care funding. They offer practical support and information based on their own experience. They do not offer legal advice. The volunteers' time is given freely to help others and they offer support specifically to individuals who are challenging NHS continuing care funding decisions themselves. Whilst you do not need to engage a solicitor to do this you may decide to do so. We are sorry but our limited resources mean we cannot provide any additional support to those approaching a solicitor or other advisors. The Patient and Liaison Service may also be able to advise you. Visit their website at www.pals.nhs.uk

Appealing against an assessment result

This chapter explains how to get a review of your case for NHS continuing healthcare. It also tells you how to make a complaint if you believe that you or the person you care for have been/are being wrongly charged for care. It applies to everyone, not just those with dementia.

First things first – getting a detailed assessment

It is the responsibility of the NHS to assess need for NHS continuing healthcare. If you are unsure whether an assessment has been made or you want to request one, contact your local primary care trust and ask for the NHS continuing healthcare co-ordinator. To find out who this is, ask at your local GP surgery or speak to the patient advice and liaison service, known as PALS. To get contact details for PALS, call NHS Direct on 0845 4647. See Chapter 2, How to get an assessment, for more details.

What is a review?

Review is a word that gets used a lot in relation to assessments and can mean different things.

Periodic reviews

First, the Framework says that three months after an initial assessment or screening in hospital with the checklist, there should be a review, to ensure that a person's needs have not changed. The review may show either that they still need NHS continuing healthcare, or that they now need NHS continuing healthcare, when previously the need for this was rejected.

Case Study 2 – Maintaining NHS continuing healthcare at periodic review

Mrs F has Alzheimer's disease. Having been awarded NHS continuing healthcare for 15 hours' care per day in her own home, her first periodic review was carried out in 2008. As a result of this, the PCT proposed to cut the number of hours provided to her by two hours per day. Mrs F's husband appealed against this decision on the basis that her condition had not improved (and was actually marginally worse) nor had it become more predictable since the previous assessment.

At the review panel meeting, Mrs F's husband invited representatives from social services to be present in order to hear their opinion on the proposals, ie that they should take over aspects of Mrs F's care. The PCT put forward reasons for this proposed cut in care. These included the fact that deterioration was an inevitable feature of Mrs F's condition and that her case did not reflect the level of needs included in other cases which had been considered, ie care being provided to Mrs F was not equitable with that being provided to other people.

The SHA upheld the appeal saying that eligibility of criteria should depend on 'individual clinical need not equity of cost'. The social services professionals also made it clear that they could not take on the aspects of care proposed for them.

Change of circumstance review

Some people's needs may be changing quite rapidly and they may need a review more often. On the whole, once a review undertaken three months after the initial screening has confirmed the person's needs, s/he should be reviewed afresh at least once a year – this is the minimum standard outlined by the Framework. A person can request a review of their assessment at any time if their circumstances change considerably.

Review of an assessment decision

This review is one that you might request if you are not happy with the outcome of an assessment or screening of someone's needs for NHS continuing healthcare. You ask the PCT to carry out this review of their own decision and decision-making process. We explain this in more detail on page 26.

Independent review

The next stage in the review process is an independent review, conducted by a strategic health authority (SHA) independent review panel. If you are not satisfied with the findings of the primary care trust's own review – see above – then you can ask for a SHA independent review and we explain this on page 30.

Finally, you may come across reviews and review panels in another channel that the NHS offers for challenging its decisions – the complaints procedure.

NB: spot the difference

The strategic health authority is responsible for the conduct of NHS continuing healthcare **independent reviews**, but that is the next stage. For the time being you are asking the primary care trust to reconsider by conducting its own **review**.

The Health Service Ombudsman's recommendations and you

The role of the Health Service Ombudsman is to provide a service to the public by undertaking independent investigations into complaints that government departments, a range of other public bodies in the UK, and the NHS in England have not acted properly or fairly or have provided a poor service.

The report of the Health Service Ombudsman in 2003 including the recommendation that efforts are made to recompense patients who were wrongly charged for care initially applied to everyone who has been cared for since 1996, even if that person has died. See page 41 for further information on retrospective funding.

The strength of your evidence

Before requesting a review it is important to consider carefully whether you might have a case. Doing some research may save you wasting your time.

If you have not already done so, get a copy from the PCT of the Decision Support Tool. To get the contact details for your primary care trust, look in the phone book or call NHS Direct on 0845 4647.

It will help you make a strong case if you have as much documentary evidence as possible. Ask for social services and NHS patient records. We explain how to get access to a patient's notes in Appendix 4. If you are asking for a review going back over a long period of time, look for copies of old assessments and reports showing the level of needs. You will also need to have the relevant SHA eligibility criteria and the old 2001 guidance. Care plans and notes including any daily progress records from the person's care home – whether nursing or residential – may also be useful.

Tips for a positive result

- Try to ascertain which documents have been used as evidence. Have the hospital notes been taken into account, for example?
- Go and see the records yourself at the hospital rather than request them in the post. If you request them via post you may not be sent all the information available.

Contacting the primary care trust for a review

Write to the chief executive of your primary care trust to ask for the review. You can get the chief executive's name and address by looking at the PCT's website or by calling NHS Direct on 0845 4647. Or you can speak to social services or your nursing home co-ordinator about getting a review for NHS continuing healthcare. A sample letter is shown on page 28.

Ask the PCT for a review of need for NHS continuing healthcare and to reconsider the way the criteria that have been applied to assess your case as not eligible for NHS funding.

The primary care trust's response

The primary care trust should respond promptly to your letter. In the majority of cases, the first step will be a local resolution process which will usually take the form of a PCT review panel. Sometimes, a PCT may refer to a neighbouring PCT in order to maintain impartiality in the decision-making process. If you have not heard anything after one month, phone the trust to ask about progress.

The PCT may decide that it will call an independent review panel (IRP): go to page 32 for details of what happens after the panel decision.

If the primary care trust says you have no case

If you are not satisfied with the findings of the primary care trust's own review, you should now request that your case goes before a strategic health authority (SHA) independent review panel. Remember, you can disagree with the procedure followed in reaching the decision, and/or the application of the Decision Support Tool to your case, by the PCT.

This panel will consider the case and make a recommendation to the PCT. The panel's main task is to assess whether the PCT has correctly applied the National Framework for NHS continuing healthcare, and has followed the processes set out in this guidance. Based upon its review of the circumstances surrounding the case, the IRP can then make a recommendation on the validity of the PCT's decision.

However, the trust could respond by saying that it has conducted its review and still believes that the person does not meet the NHS continuing healthcare criteria. If you are not satisfied, read on.

An independent review is **not** an option if you wish to challenge:

- the actual criteria used for the assessment
- 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. We explain the complaints procedure on page 33.

Composing a letter to your PCT

Your letter to the primary care trust's chief executive might look something like the one shown below.

Date
Your address etc

Dear [name of chief executive of NHS trust]

I wish to appeal the decision of [my mother's] continuing care assessment.

I believe that [my mother, Helen Smith], has been wrongly refused NHS continuing healthcare.

Below are the reasons I think the wrong conclusion has been reached. I attach the relevant documents. [Include this sentence if you are able to include documents supporting your argument]

Insert here the details of the person on whose behalf you are complaining. For example:

[My mother is in the late stages of Alzheimer's disease and is cared for at the Devon Cliffs nursing home/residential home/in her own home. She can no longer communicate, is doubly incontinent and has mobility problems.]

Add this sentence if the person being cared for is in a residential home or their own home:

You will be aware that the Department of Health has stated that people can receive continuing NHS Continuing Healthcare whether they are in a nursing home, residential care home, or their own home.

The basis of my request is that I believe [my mother] meets the criteria.

Please progress this review and update me as soon as possible.

Yours sincerely
Geoffrey Smith

Explain here why you think the person meets the criteria. Be brief – details about the person's condition should be in their notes. Some aspects that may be important in cases of people with dementia (they may apply in other conditions as well) include the following, although this is not an exhaustive list. You will be able to think of other aspects that apply to your particular case.

Psychological needs

Health professionals often argue that once a person with dementia has become too ill to display behaviour that is difficult to manage, they no longer have any psychological needs.

The Health Service Ombudsman did not accept this argument in her investigation into the case of Malcolm Pointon (see page 43). Think carefully about psychological needs, for instance:

- Does the person have panic attacks or fits?
- How do these affect his/her needs?
- Does the person forget to eat unless they are carefully persuaded?
- Is s/he easily frightened and do everyday care tasks have to be carried out in particular ways to take account of psychological factors?
- Does the person suffer from hallucinations?

Predictability

It is often argued that once dementia is advanced, needs are predictable and, therefore, can be managed with the occasional visit from the district nurse as sufficient healthcare (except in nursing homes). Is this true? Make a list of issues that require an immediate response and are unpredictable. These may include the types of psychological needs described above.

Quantity of healthcare needs

As the Coughlan judgment stressed (see page 39), no one should be prevented from getting NHS continuing healthcare on the grounds that they do not require highly specialised care. Record the care that the person requires during an average 24 hour period.

Medication

What level of monitoring of medication is needed? Are there issues about side-effects of medication that also require monitoring? Are there complicated issues around administering medication?

Incontinence

Along with incontinence, are there additional issues that need to be taken into account, such as a susceptibility to urinary tract infections etc?

Mobility issues

Transferring a person with dementia using a hoist is a more complex and difficult operation than transferring a frail person who understands what is happening and can co-operate as far as physically possible. You could argue that moving a person with dementia requires skilled care beyond the basic manual handling training that you would expect from any professional care assistant.

Requesting an independent review from the strategic health authority

When you ask for an independent review your letter must explain your reasons for disagreeing with the primary care trust's initial decision. Write another brief letter to the person from the primary care trust who responded to you, stating that you are not satisfied that your case has been adequately reviewed and that you wish to move to an independent review of the case. You should state that you have read the National Framework for NHS continuing healthcare 2009 and the associated assessment 'tools'. Say you believe that you are wrongly paying or have paid for care that should have been available on the NHS. We show a sample letter below.

Write briefly about the complexity of the person's condition. You might want to pick up on any issues that you mentioned in your original request for a review that you feel have not been picked up or have been ignored.

Example of a letter requesting an independent review

Dear Chief Executive

The [name of primary care trust] trust has reviewed the case of [my mother, Helen Smith, who lives at the Devon Cliffs nursing home.]

I am not satisfied with this finding and wish to request an independent review of the case.

Put here your reasons for not being satisfied with the original decision not to fully fund care. You might want to refer back to the information in the first sample letter on page 28, and consider the notes about why people are often refused funding for care.

Please let me know if and when a review of my case will take place and give me details of when I can attend.

Yours sincerely,
Geoffrey Smith

cc Campaigns Officer, Alzheimer's Society,
Devon House, 58 St Katharine's Way, London E1W 1LB

Once the SHA has received your request for an independent review, it will convene a panel to review the case, or refuse to grant an independent review panel (see page 33).

The independent review panel

The key task of an independent review panel is to decide whether the primary care trust has correctly applied the criteria in the Framework, and has followed the processes set out in this guidance. The Framework says that the panel should ask the views of the person's family or carer and should have access to independent clinical advice. They should also have access to the views of key parties involved in the case including the individual requiring NHS continuing healthcare, health and social services staff, and any other relevant bodies or individuals. It is open to key parties to put their views in writing or to attend.

An individual requiring NHS continuing healthcare may have a representative present – a relative or carer or advocate – to speak on his or her behalf if they have difficulty in presenting their own views, says the guidance. The panel should be satisfied that any such representative is accurately representing the person's views and that there is no conflict of interests or wishes.

If you would like an independent advocate to help you at this stage, ask your local PALS (Patient Advice and Liaison Service). NHS Direct (see page 12) can tell you how to contact your local PALS.

The guidance tells the panel to make sure that it keeps families and carers informed about when things are going to happen and how long they are expected to take. It also stresses that until the outcome of the review is known, the existing care package should not be withdrawn under any circumstances.

Making the most of your evidence to the panel

It is important to make a strong case if you are attending a meeting with a review panel. Explain why you think the person should be receiving NHS continuing healthcare. The best way to do this is to compare the individual's health needs with the eligibility criteria and the care domains of the DST.

Look again at the list suggested for the letter on page 28–29. Write down what you want to say and practise saying it before the meeting. Try to get copies of notes about the person's care from their GP and from social services. See Appendix 3 for more about this.

Even if you think you can manage without an independent advocate, consider taking someone with you to provide moral support and back up what you have heard. It might also be useful to take some notes of what the the panel says and the questions they ask. This is another role that a friend or supporter might take on for you.

The panel decision

The panel will write to you after discussions about the review.

Good news

If the panel agrees that the person being cared for should receive NHS continuing healthcare, they will make this recommendation to your primary care trust. Look at the Department of Health guidelines on redressing continuing healthcare cases at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicy AndGuidance/DH_073094

Whatever the initial decision, there should be a case review after three months to reassess care needs and, if one was not recommended previously, whether a full assessment for NHS continuing healthcare should be carried out. After this, reviews should take place at least annually.

Bad news

If the original decision is upheld and the panel decides that your case is not valid, you have to decide whether you are satisfied with this outcome or whether you feel you have a good enough case to proceed to the next stage. The panel should tell you that you can refer your case to the Health Service Ombudsman.

If the SHA refuses you an independent review panel

If the original decision by the PCT is upheld and an independent review panel is refused, this would be very unusual. The Framework says that this can only be done if the SHA considers that the ‘individual falls well outside the eligibility criteria or where the case is very clearly not appropriate for the panel to consider’.

You are entitled to write to the Health Service Ombudsman and ask for your complaint to be looked at. At this point, you could also send a copy of your letter to your local MP at House of Commons, London SW1A 0AA.

The Health Service Ombudsman

The Ombudsman will write to acknowledge your complaint within two working days. They will give you a reference number which will help with any future communication with its Ombudsman. The Ombudsman may decide to investigate the complaint and if this happens, the process will be explained to you. The Health Service Ombudsman recommends that first you call the helpline to check that you have a case and have followed the correct channels for a resolution. The Health Service Ombudsman helpline number can be found on page 55. You will be interviewed about the complaint.

If the Ombudsman decides not to investigate your complaint further they will explain to you why they have come to that decision.

In some circumstances, the Ombudsman may ask a PCT to review a case again. This might be at the start of an assessment if an obvious mistake was found in the way processes were carried out or after an investigation if maladministration was discovered.

If the Ombudsman tells you to complain

Sometimes the Ombudsman tells people to go through the local NHS complaints procedure. This is not the same as asking the primary care trust for a review of the person's need for NHS continuing healthcare, nor is it the same process as the independent review panel. The complaints procedure deals with all kinds of complaints about the NHS, not just NHS continuing healthcare.

You will probably feel you have been sent back to square one and this can be quite disheartening. Here's how to make an official complaint.

The NHS official complaints procedure

There is now a standard complaints procedure throughout the NHS. This is detailed online here: www.nhs.uk/choiceintheNHS/rightsandpledges/complaints/pages/NHScomplaints.aspx

The letter of complaint

Write to the chief executive of the primary care trust in which the person is being cared for. The process is essentially the same as when you first wrote to the primary care trust to request a review, except that you must specifically state that you are making an official complaint.

You can use a version of the first letter you wrote requesting a review (see page 28). You may want to adapt it, incorporating things you have learnt in the process of the review. Be sure to state that you are making an official complaint.

This ensures that your letter is dealt with according to the NHS complaints procedure.

Keep a copy of this letter and all correspondence that follows from it. From now on, you should follow the process using the notes in this document in exactly the same way as you did with your request to the primary care trust for a NHS continuing healthcare review.

Eventually you will get to the Ombudsman again, who will either investigate your case or advise you what to do next.

Your views, your experience

We hope our guide helps you pick your way along this path and smooths out some of the complexities. If you have found it useful or you can see how it could be better, do please get in touch with us at the address at the front of the guide. We would like to hear your views.

We would also like to hear your experiences. Please tell us if you have challenged the NHS on any of its decisions about eligibility for NHS continuing healthcare. We would like to hear from you, whether you have been successful or not in getting funding for NHS continuing healthcare.

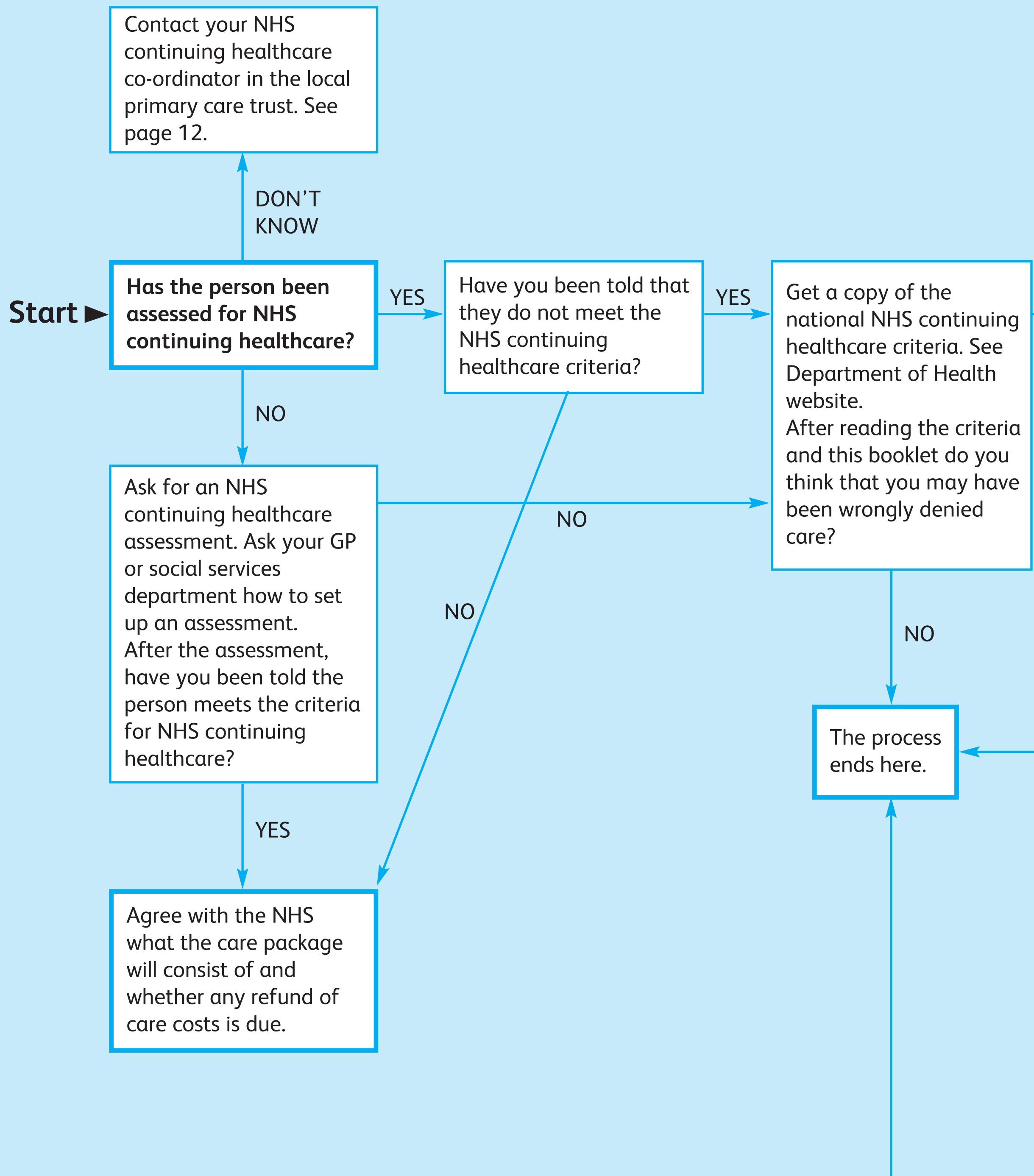
Finally, we recognise that working through these procedures and all this paperwork can be daunting. We hope it goes well for you and we wish you luck.

Top ten tips on preparing your case for NHS continuing healthcare

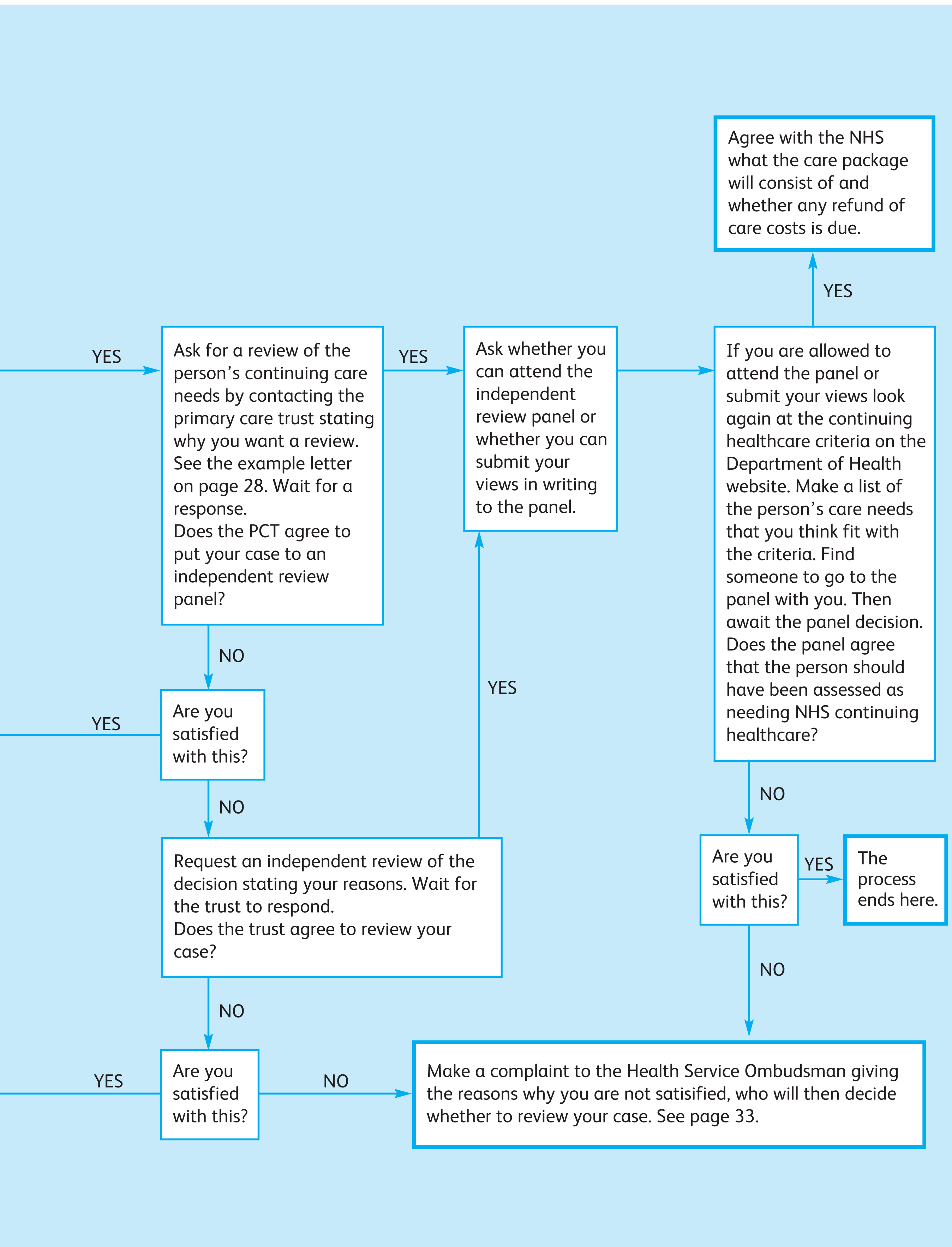
These hints and tips are based on the experience of members of Alzheimer's Society NHS continuing care volunteer support group (see page 23).

1. Create a medical history for the person you care for. Ideally this should be on one page, and should be regularly updated.
2. Good record keeping is essential. Record the date, time, contact person and brief summary of all conversations with staff from your PCT, hospital, GP, care home, social services etc about the needs of the person you care for.
3. Request medical records from various bodies involved in the care of the person, eg the hospital or the GP. Social services may have carried out assessments and these can contain useful information. Ask to see any reports that the local authority have on the person.
4. When applying for, or challenging, a decision on NHS continuing healthcare it is often best to put your case in writing and keep a record of all correspondence.
5. File all the information you gather. For example, you might want to get a folder and file information under different headings, such as care home notes, nursing home notes, NHS continuing healthcare assessments, care plans, letters and your comments.
6. Read the Department of Health National Framework for continuing care and use it to do your own assessment of the person's needs.
7. Try to attend all assessments or appeal/review hearings, for example by the primary care trust or strategic health authority.
8. Get people to support your case, such as your GP or MP.
9. Be aware that the Parliamentary and Health Service Ombudsman is the final arbiter if you have exhausted the local complaints system. It is important to have good records in order to make an effective case to the Ombudsman.
10. If you think you have a strong case for continuing care be persistent. It can be difficult and frustrating but many people with dementia have successfully secured NHS continuing care funding and help is at hand.

Flowchart of the application and appeal process for NHS continuing healthcare



For information or advice at any stage contact Alzheimer's Society National Dementia Helpline on 0845 3000 336.


Agree with the NHS what the care package will consist of and whether any refund of care costs is due.
YES
YES
Ask for a review of the person's continuing care needs by contacting the primary care trust stating why you want a review. See the example letter on page 28. Wait for a response. Does the PCT agree to put your case to an independent review panel?
YES
Ask whether you can attend the independent review panel or whether you can submit your views in writing to the panel.
If you are allowed to attend the panel or submit your views look again at the continuing healthcare criteria on the Department of Health website. Make a list of the person's care needs that you think fit with the criteria. Find someone to go to the panel with you. Then await the panel decision. Does the panel agree that the person should have been assessed as needing NHS continuing healthcare?
NO
YES
Are you satisfied with this?
YES
NO
Request an independent review of the decision stating your reasons. Wait for the trust to respond. Does the trust agree to review your case?
NO
Are you satisfied with this?
YES
The process ends here.
NO
NO
YES
Are you satisfied with this?
NO
Make a complaint to the Health Service Ombudsman giving the reasons why you are not satisified, who will then decide whether to review your case. See page 33.

4 History and retrospective funding

This section offers a short history of government guidance regarding provision of health and social care in previous decades. When considering this history in regard to your own case, please look carefully at the dates as guidance and legal precedents change often.

The 1980s and 1990s

During the 1980s many people who had previously been cared for in NHS hospitals were transferred to private nursing homes using funds from social security payments. Numbers of long-stay NHS hospital beds declined rapidly during this period.

The NHS and Community Care Act 1990 introduced changes in social care and healthcare. One effect of these changes was that people with dementia were more often looked after in care homes allocated by social services. Residents had to pay some or all of their costs, depending on the amount of their savings and income.

Government guidance 1995

In 1995 the Department of Health issued guidance, requiring the then health authorities to produce – by April 1996 – formal written criteria for NHS continuing healthcare.

The criteria had to set out the kinds of health needs that a person must have in order to be eligible to receive NHS continuing healthcare. Before April 1996 there was no obligation to have written criteria. It became possible to ask the NHS to investigate cases involving someone whose death took place before April 1996. Before that date there was no written evidence of the criteria applied to any case.

The new formal criteria, however, did little to help. Very few people living outside hospitals were considered eligible for NHS continuing healthcare. People living in nursing homes, care homes, and in their own homes, saw little improvement.

The Coughlan judgment 1999

A clearer definition of the line between the responsibility of the NHS for people's long-term care and that of social services was also needed. A decision about who provides care can have significant financial consequences for individuals with long-term health needs and their families. The 1999 Coughlan judgment affected the way the law was interpreted and how the NHS and local authority social services took on this responsibility.

Pam Coughlan is physically disabled as a result of a car accident. She is tetraplegic, doubly incontinent, has a partially paralysed respiratory tract and suffers from headaches. The North and East Devon Health Authority decided to close the nursing home it ran and where Pam Coughlan lived, receiving her care from the NHS. It said that social services would have to be responsible for her future care.

Pam Coughlan challenged this decision and in 1999 her case went to the Court of Appeal. The court had to consider where the line should be drawn between long-term care that is the legal responsibility of the NHS and long-term care that is the legal responsibility of social services.

The Court of Appeal was critical of the 1995 government guidance – see page 38. It decided that social services could provide nursing care, but only 'in connection with' accommodation. This is limited to nursing care that is:

- Merely incidental or ancillary to the provision of the accommodation that a local authority is under a duty to provide (the quantity test) or
- Of a nature which it can be expected to provide under section 21 of the 1948 National Assistance Act which only envisaged that local authorities would provide social care (the quality test).

The Court of Appeal's judgment was that Pam Coughlan's needs were too great to be met by social services and that they should be met by the NHS. If someone in a care home, said the court, has nursing needs that are specialised or are more than 'incidental and ancillary' to their personal and social care needs, their care should be fully-funded by the NHS.

Health bodies should not force social services authorities to provide a greater level of healthcare than they are legally able to.

Health and Social Care Act 2001 Section 49

The Health and Social Care Act 2001 was designed to improve the performance of the NHS, extend direct payments for social services users and provide a fairer system of funding for long-term care including measures to reduce the need to sell one's home on entering residential care. Section 49 confers responsibility for providing nursing care directly to the NHS, excluding nursing care from community care services. It is reproduced below.

Exclusion of nursing care from community care services

(1) Nothing in the enactments relating to the provision of community care services shall authorise or require a local authority, in or in connection with the provision of any such services, to –

(a) provide for any person, or
(b) arrange for any person to be provided with,

nursing care by a registered nurse.

(2) In this section, 'nursing care by a registered nurse', means any services provided by a registered nurse and involving –

(a) the provision of care, or
(b) the planning, supervision or delegation of the provision of care,

other than any services which, having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse.

Government guidance up until 1 October 2007

Up until 1 October 2007 the rules for deciding who was entitled to NHS continuing healthcare were applied differently in different parts of the country. Many of the criteria were vague or ambiguous.

After the Coughlan case, the government revised its 1995 guidance and in 2001 the Department of Health issued new guidance about the responsibilities of local authorities and the NHS (Health Service Circular 2001/015: Continuing Care: NHS and local councils' responsibilities).

It told strategic health authorities that they were responsible for the eligibility criteria for NHS continuing healthcare in their areas. The guidance stressed that:

- The eligibility criteria or application of rigorous time limits for the availability of services by health authorities should not require a local council to provide services beyond those they can legally provide.
- The nature or complexity or intensity or unpredictability of the individual's healthcare needs (and any combination of these needs) required regular supervision by a member of an NHS multidisciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team.
- The individual's needs required routine use of specialist healthcare equipment under the supervision of NHS staff. (However, the Ombudsman's office has noted that reliance on the term 'specialist' to make funding decisions is too restrictive.)
- The individual had a rapidly deteriorating or unstable medical, physical or mental health condition and required regular supervision by a member of the NHS multidisciplinary team.
- The individual was in the final stages of a terminal illness and likely to die in the near future.
- A need for care or supervision by a registered nurse and/or GP was not by itself sufficient reason to receive NHS continuing healthcare.
- The location of care should not be the sole or main determinant of eligibility. NHS continuing healthcare could be provided in an NHS hospital, nursing home, hospice or the individual's own home.

Retrospective funding

It is possible to make a claim for NHS continuing healthcare retrospectively. This can go back to the date when the person was charged for care if you can prove that, at this time, you were unfairly charged. However, if this is a new claim, the case cannot be considered or backdated to before 1 April 2004, unless you can prove exceptional circumstances why the case should be considered. If an application has previously been made, the case can be considered before April 2004. If the time that is being claimed for is before 1 October 2007 – when the Framework was established – the case will be reviewed under the old local eligibility criteria.

Backdating

It is important to be aware of how the 2007 Framework (revised 2009) fits together with the pre-1 October 2007 local criteria, when reviews are being requested for the person needing care. If, for instance, someone was assessed by the local PCT's local criteria before 1 October 2007 as not needing NHS continuing healthcare, but when they are reassessed, using the national criteria of primary health need, they are found

to be eligible for NHS continuing healthcare, there is the question of whether the costs that they have already paid be refunded from the date when they were previously refused NHS continuing healthcare. The Framework poses this question. It stresses that, if the assessment was done properly and the criteria used at the time were lawful, the person should not be reimbursed.

However, the Framework says, if their needs have not changed, it should be *considered* [our italics] whether their funding should be backdated to the implementation of the Framework on 1 October 2007.

The guidance tells PCTs that when they review decisions made before 1 October 2007 – when the national Framework and its decision-making tools came into effect – they should use the most relevant, lawful criteria. These may therefore be local criteria that the PCT was using up until 1 October 2007, although the PCT must be sure that their criteria fit in with the changes introduced in the wake of the Coughlan and Grogan court judgments. Think about whether the condition of the person fits the criteria. Also look at the brief details of the Coughlan and Grogan judgments in Chapter 4 on pages 39 and 43.

It can be argued that the current national framework is a better method of assessing health needs and should be used when reviewing cases. The PCT criteria that were used before 1 October 2007 were flawed because they did not separate community care assessments from registered nursing care assessments.

Health Service Ombudsman's report 2003

In February 2003 the Health Service Ombudsman published another report about NHS funding for long-term care, after having investigated four cases. In one case, she found that the individual (Mrs N) did have NHS continuing healthcare needs, although the health authority had assessed Mrs N's need for nursing care as merely incidental or ancillary to the provision of accommodation or of a nature one could expect social services to provide. The Ombudsman compared Mrs N's case with that of Pam Coughlan and decided that Mrs N's needs were similar in that both were immobile and both were doubly incontinent. They were dissimilar in that Mrs N did not have breathing difficulties, but she was peg fed.

The Health Service Ombudsman stated that no authority could reasonably conclude that Mrs N's need for nursing care was merely incidental or ancillary to the provision of accommodation or of a nature one could expect social services to provide. Like Pam Coughlan, she needed services of a wholly different kind. In all four cases, the Ombudsman decided that the eligibility criteria that had been used were unlawful. This was because they were over-restrictive and they forced social services to provide more healthcare than they were legally allowed to provide.

The Health Service Ombudsman made a number of recommendations. She recommended that strategic health authorities should revise their eligibility criteria to make sure that they were lawful. She also told the strategic health authorities and primary care trusts to review current and past cases of individuals who ought to have been receiving NHS continuing healthcare and to reimburse them (or their estates, if they had died in the meantime).

The Pointon investigation 2004

Since 2003, the Health Service Ombudsman has investigated many more complaints about unfair eligibility criteria and unfair assessments.

In 2004 the Ombudsman upheld a complaint from Mrs Pointon, wife and carer of Malcolm Pointon a man with advanced dementia who was being cared for at home (and has since died).

The Ombudsman concluded that:

- the local eligibility criteria had been applied in a way that excluded the likelihood of the NHS providing continuing healthcare at home
- the assessment had focused on physical needs at the expense of psychological needs
- the assessment had failed to recognise that the standard of care provided by Mrs Pointon was equal to the care that a nurse could provide.

The Health Service Ombudsman (2004), Case No. E.22/02-03 Complaint against: The former Cambridgeshire Health Authority and South Cambridgeshire Primary Care Trust. You can get a copy of the Ombudsman's report by visiting www.ombudsman.org.uk/pdfs/pointon.pdf or by calling the Ombudsman's helpline on 0345 015 4033.

The Grogan case 2006

Mrs Grogan, resident of a nursing home, challenged a decision not to award her NHS nursing care. The judgment in her favour influenced the government to put in place a national policy for NHS continuing healthcare and NHS-funded nursing care.

In January 2006, in the high court, Mrs Grogan challenged the eligibility criteria used by Bexley Care Trust to refuse her NHS-funded nursing care.

Mrs Grogan argued that assessors in Bexley were only granting fully-funded NHS care when needs were assessed as being greater than the criteria for needing the highest Registered Nursing Care Contribution (RNCC) band and this in effect denied all but people needing constant nursing care from getting fully-funded NHS care. The Bexley assessors were applying a far higher test than that set out by the Court of Appeal in the case of Coughlan. It caused confusion and made no sense to those who were applying the tests.

The court agreed with Mrs Grogan and found that:

- NHS professionals had been led to believe that if a person's needs could be met *within* the RNCC bands then they were not eligible for fully-funded NHS care
- The eligibility criteria in the area where Mrs Grogan lives were 'fatally flawed' which in legal terms means unlawful because:
  - the health authority had not set out the Coughlan 'primary need' test or the limits of social services responsibilities in full
  - the health authority had linked fully-funded NHS healthcare eligibility to the RNCC bands.

The court criticised the Department of Health for failing to produce clear guidance and direction to the NHS. The judgment also stressed that:

a) any person whose needs were the same as, or exceeded those of Ms Coughlan, should be entitled to fully-funded NHS care
b) the actual identity of the person undertaking the nursing care did not dictate who should fund the service, as many nursing tasks were being done by non-registered staff (for example, healthcare assistants, and personal care assistants)
c) the health agency (for example, the PCT) should look at the totality of the person's needs to see whether the person has a primary need for healthcare, and thus meets the Coughlan test for fully-funded NHS care
d) social services should also look carefully at the totality of a person's needs before agreeing to take responsibility for them and so means-test them, because they might actually be the responsibility of the NHS and legally beyond the scope of social services.

Appendix 1
Some commonly asked questions

Q Is it true that people with dementia get free care?

A No one gets free care because of the nature of their medical condition, whether they have dementia or another condition. People with dementia may qualify for free NHS continuing healthcare if they have a high degree of healthcare needs.

Q Is a person with dementia entitled to a review of a decision that s/he is not entitled to NHS continuing healthcare?

A If you consider that you have wrongly been asked to pay for care that you think should be paid for by the NHS, as NHS continuing healthcare, you can indeed ask your local primary care trust to review its decision.

If you are asking the PCT to reconsider a decision made since 1 October 2007, the guidance in this booklet will help you work through the process step by step. If you feel that you have been wrongly paying for care since before that date, things get more complex. That is because, up until 1 October 2007, primary care trusts made decisions about who was eligible for NHS continuing healthcare using their own local criteria of eligibility. This does not mean you cannot challenge the decision, but the criteria may be different. They still need to have been lawful, however, and to have been fairly applied.

Have a look at the current national criteria, introduced on 1 October 2007 – we outline them in Chapter 1. To find out how to challenge the primary care trust's decision and any past decisions, go to Chapter 3.

Q Do I need a solicitor?

A The aim of this booklet is to help you conduct your own case. People have found solicitors helpful, but there is nothing to stop you taking all these steps yourself.

If you are considering a judicial review, however, you should contact a solicitor with expertise in these cases.

Q Are there different types of reviews?

A Yes and this can be confusing. Review is a word that gets used a lot and can mean different things.

First, the Department of Health's guidance says that there should be a review, to ensure that a person's needs have not changed three months after an initial assessment or screening of health needs, and then at least annually.

The second kind of review is one that you might request if you are not happy with the outcome of an assessment or screening of someone's needs for NHS continuing healthcare. You ask the primary care trust to carry out this review of their own decision and decision-making process. We explain this in more detail on page 27.

The third kind of review is an independent review, conducted by an independent review panel. If you are not satisfied with the findings of the primary care trust's own review – see above – then you can ask for an independent review and we explain this on page 31.

These are the types of review relevant to a NHS continuing healthcare case. Further reviews and review panels exist in another channel that the NHS offers for challenging its decisions – the complaints procedure (see page 33).

Appendix 2
‘Free’ nursing care and NHS continuing healthcare

In 1997 the government set up the Royal Commission on Long Term Care, to consider and advise on how to fund the care of older people. In 1999 the Royal Commission recommended that the costs of caring for older people should be split three ways:

1. **Housing costs**
   These should be means-tested so that the level individual older people should pay would depend on their financial means.
2. **Living costs – for example, food, electricity, clothing and transport**
   The Royal Commission said that help towards these costs should also be means-tested.
3. **Personal care costs**
   These are costs associated with someone’s disability, and involves someone having to do tasks of a personal nature such as washing or dressing the person. The Royal Commission did not distinguish between ‘social’ and ‘nursing’ care, but did say that tasks such as housework and shopping would not count as personal care. It recommended that all personal care costs should be fully-funded whether somebody was living in a care home or in their own home.

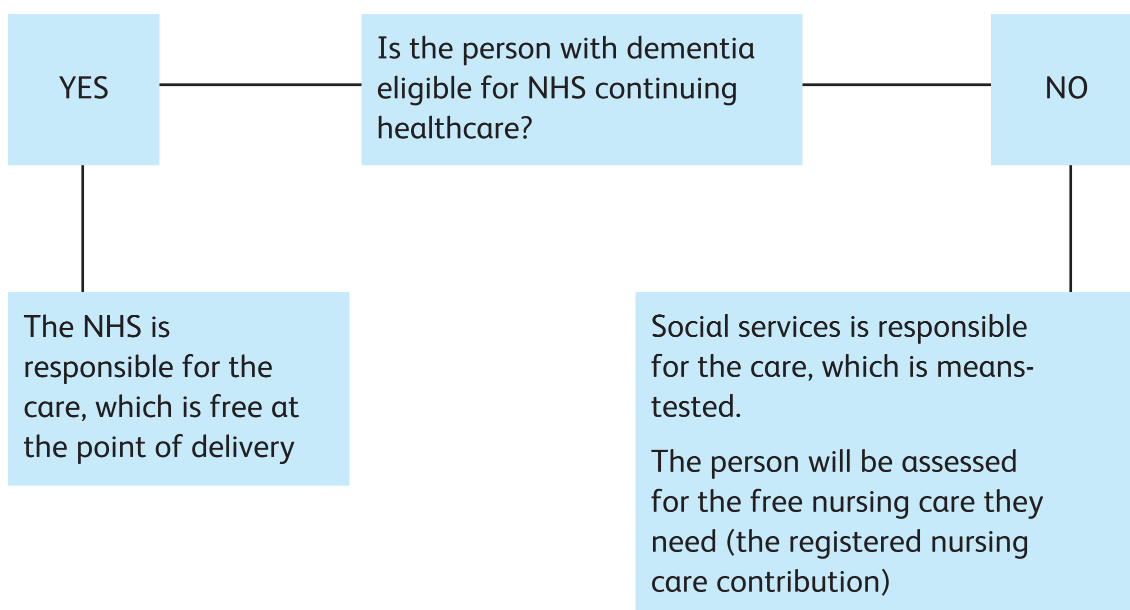
The Scottish parliament adopted these recommendations. In England, instead of adopting the recommendations of the Royal Commission, the government introduced what it calls ‘nursing care’. This is a contribution by the NHS, to meet solely the costs of the nursing ‘provided, delegated, monitored or supervised by a registered nurse’, that makes up part of a care package for people in nursing homes only. NHS-funded nursing care is paid by the NHS to these homes. In homes not registered to provide nursing care, this care is provided by a visiting nurse, not employed by the home.

Please see page 21 for Alzheimer’s Society’s position on charging for care.

NHS continuing healthcare: yes or no?

Is the person with dementia (or other condition) eligible for NHS continuing healthcare? If the answer is 'yes', the NHS pays the whole cost. This applies whether the person is in a nursing home, or anywhere else. Someone in a nursing home who is assessed as needing NHS continuing healthcare will not have to pay any fees.

If the answer is 'no' and the person with dementia (or other condition) has been assessed as not eligible for NHS continuing healthcare, that person could be entitled to financial assistance with the cost of their nursing care.



A registered nurse assessment will determine eligibility for registered nursing care contribution. See Alzheimer's Society factsheet 452, Assessments for NHS-funded nursing care and factsheet 431, Benefits rates and income/savings thresholds.

Appendix 3
Getting access to a patient's notes

Rules about patient confidentiality and data protection make it difficult to get access to medical or social services notes that are not your own. As a rule, if someone decides that they wish you to have access to their files they should always write a clear instruction giving their consent.

Often, however, people with dementia are incapable of giving such consent. In effect someone in these circumstances has no legal right of access to their records and cannot give someone else consent to see them either. The Data Protection Act 1998 details rights to access of information. The Information Commissioner can also advise about access to data. Call 0303 123 1113 or visit the website www.ico.gov.uk

Power of attorney

Under a registered Enduring Power of Attorney (EPA) an attorney can only access the person's medical notes for financial reasons. If the attorney thinks that the person is entitled to NHS continuing healthcare, this should be considered to be a financial reason.

EPAs have been replaced by Lasting Powers of Attorney (LPA). LPAs were created by the Mental Capacity Act (2005) and came into force from 1 October 2007.

Although existing EPAs, created before 1 October 2007, continue to operate, they only apply to finance and property matters. Anyone with an existing EPA can also make an additional LPA for personal welfare decisions under the Act.

LPAs give more protection and options. There are two types:

- property and affairs LPA
- personal welfare LPA

Each has its own separate form.

A personal welfare LPA is helpful in getting access to notes. It gives authority to make decisions about health and personal welfare, such as day-to-day care, medical treatment, or where the person should live.

Recent advice to doctors states clearly that personal welfare LPAs can ask to see information about the person they are representing when that person lacks mental capacity, 'provided that it is relevant to the decisions the attorney has a legal right to make'. Before disclosing any information, the holder of the information should make sure that the attorney has the official authority.

The LPA gives the donor of the power a choice of conferring broad or limited powers to make decisions on their behalf, and a choice of who to appoint – for example relatives can be appointed to make welfare decisions,

A personal welfare LPA only ever takes effect when the donor lacks capacity to make decisions.

When there is no power of attorney

Some NHS bodies and social services departments are willing to release a personal file to the main carer, particularly if that carer is a close relative. However, when a dispute arises and you then request to see such files, you may be met with sudden concern about confidentiality.

The reasons given for refusing access usually involve either or both of the following:

- there is no legal right of access for anyone other than the patient
- the authority has a duty of confidentiality to the person.

This is not, however, the whole story. The law requires the public and private interests in maintaining confidentiality to be weighed against the public and private interests in disclosure. The nature of those interests and where the balance lies depends on the specific circumstances of any particular case.

It is probably best to make a simple request for access initially because the authority may be prepared to grant access without challenging any of this.

However, if access is refused, the picture changes. It has been argued that if a carer seeks access to social services or health records on behalf of someone lacking capacity, for the purpose of considering bringing a potential review on their behalf, access should

be given if there is no suggestion of harm to any person. These principles were established in the Stephens case, described on page 52.

The Mental Capacity Act

The Mental Capacity Act (2005) has taken on board many of the issues that arise when people lack mental capacity. A guide to the Act specifically mentions dementia as one of the things that could cause mental incapacity.

The new law says that anyone making decisions for a person who lacks capacity must do so in their 'best interests' and the guide explains how to judge what these might be. It offers reassurance that you will not be liable for your action, provided you have a reasonable belief that the person lacks capacity and that the action you are taking is in the best interests of the person who lacks capacity.

What is more, the Act requires health and social service staff to consult anyone caring for the person or interested in their welfare (for example family, friends and unpaid carers) when deciding on best interests.

It should be much easier now for carers to access medical notes and social services records of people with dementia, even if that person has not had the opportunity to formally appoint a Lasting Power of Attorney.

As a last resort: deputies

If the person you care for has not appointed or is unable to appoint an attorney, and they need certain decisions made on their behalf which can only be decided by a court case, then you will need to apply to the Court of Protection to become a deputy. A deputy is someone appointed by the Court of Protection to deal with a specific issue or range of issues to help a person who lacks capacity and who has not got an attorney.

The Court of Protection decides whether it thinks you are suitable to be a deputy. The Court will also decide if a deputy is needed, or whether it can just make an order to cover the particular decision that needs making. Although you apply to the Court of Protection to become a deputy, in most cases the application can be decided on the information given in the forms, without any formal hearing. The Office of the Public Guardian (see contact details on page 52) is responsible for supervising and supporting deputies. There will be fees for the costs of the application process and for ongoing supervision.

More information

The government produced several booklets about the Mental Capacity Act and making decisions. They are available from the Office of the Public Guardian, which is part of the Ministry of Justice:

- Making decisions…about your health, welfare or finances. Who decides when you can't?
- Making decisions: A guide for family, friends and other unpaid carers
- Making decisions: A guide for people who work in health and social care
- Making decisions: A guide for advice workers
- Making decisions: An Easyread guide
- Making decisions: The Independent Mental Capacity Advocate (IMCA) service

To read or download them online go to www.publicguardian.gov.uk and click on 'forms and booklets', then 'additional publications and newsletters'. For print copies of these booklets, contact The Office of the Public Guardian. Tel 0300 456 0300.

The Stephens case

S's son was subject to guardianship under the Mental Health Act 1983. S was considering whether to exercise her powers as the nearest relative to discharge her son from guardianship, but had been warned by the local authority that if she did so it would apply to remove her as the nearest relative.

S asked for access to her son's records so that she could obtain advice on whether or not to seek discharge. At first the local authority said that they could not release the records because they had no authority to do so. Her son, in their view, did not have capacity to consent. S judicially reviewed this decision and was unsuccessful but took her case to the Court of Appeal.

By the time the case reached this stage, the local authority had offered access to specific documents to experts instructed by S to advise on the guardianship issue. However, S wanted access herself. The court (by a majority of two to one) held that the local authority had failed to carry out the necessary balancing exercise between the public and private interests in disclosure.

Regarding best interests, the court paid particular attention to Article 6 (the right to a fair trial) and the need for S to have access in order to be able to obtain full legal advice before embarking on a course of action which, it appeared, would inevitably lead to court proceedings. There was no suggestion that letting S have access to the records would harm S's son or any

other person, nor that S’s son was in any sense objecting to letting his mother see his records. The balance was firmly in favour of disclosure to S and was ordered by the court.

This case illustrates the principles of ‘best interests’. In other words, where it is in the best interests of the person lacking capacity for the medical records to be disclosed it is right that they are.

Appendix 4
Further information and support including NHS continuing healthcare in Wales, Scotland and Northern Ireland

Further information and support

Alzheimer's Society
Devon House
58 St Katharine's Way
London E1W 1LB

Alzheimer's Society National Dementia Helpline
T 0845 3000 336 (Monday to Friday 8.30am–6.30pm)
E helpline@alzheimers.org.uk
W alzheimers.org.uk

Alzheimer's Society NHS continuing care volunteer support group
T 0845 3000 336
E NHSCC@alzheimers.org.uk
W alzheimers.org.uk/nhscontinuingcare

Age UK
York House
207–221 Pentonville Road
London N1 9UZ
T 0800 169 6565 (Advice line open 8am–7pm)
E contact@ageuk.org.uk
W www.ageuk.org.uk

Citizens Advice Bureau (CAB)
Various locations
W www.citizensadvice.org.uk
Your local CAB can provide information and advice in confidence or point you in the right direction. To find your nearest CAB look in the phonebook, ask at your local library or look on the website (above). Opening times vary.

Community Legal Advice
T 0845 345 4345
W www.communitylegaladvice.org.uk

Counsel and Care
Twyman House
16 Bonny Street
London NW1 9PG
T 0845 300 7585
W www.counselandcare.org.uk

NHS Direct
Helpline 0845 4647
W www.nhsdirect.nhs.uk

Office of the Public Guardian
PO Box 15118
Birmingham B16 6GX
T 0300 456 0300
E customerservices@publicguardian.gsi.gov.uk
W www.publicguardian.gov.uk

Parliamentary and Health Service Ombudsman
Millbank Tower
Millbank
London SW1P 4QP
T 0345 015 4033 (Helpline)
E phso.enquiries@ombudsman.org.uk
W www.ombudsman.org.uk

Information on NHS continuing healthcare in Scotland

Age Scotland
Causewayside House
160 Causewayside
Edinburgh EH9 1PR
T 0845 833 0200
W www.agescotland.org.uk

Alzheimer Scotland
22 Drumsheugh Gardens
Ediburgh EH3 7RN
T 0131 243 1453
0800 808 3000 (24 hour helpline)
W www.alzscot.org

Scottish Helpline for Older People
T 0845 125 9732
W www.olderpeoplescotland.org.uk

Information on NHS continuing healthcare in Wales

NHS Wales
W www.wales.nhs.uk

Age Cymru
Ty John Pathy
13–14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ
T 029 2043 1555
E enquiries@agecymru.org.uk
W www.ageuk.org.uk/cymru

Information on NHS continuing healthcare in Northern Ireland

Alzheimer's Society Dementia Helpline (Northern Ireland)
T 028 9066 4100

Health and Social Care in Northern Ireland
W www.healthandcareni.co.uk

References

Continuing NHS Healthcare: National Framework for Implementation in Wales (2010)
wales.gov.uk/docs/dhss/publications/100614chcframeworken.pdf

Department of Health (2009), The Delayed Discharges (Continuing Care) Directions, HMSO, London.

Department of Health (2009) The NHS Continuing Healthcare (Responsibilities) Directions, HMSO, London.

Department of Health (2009), The National Framework for NHS continuing healthcare and NHS-funded Nursing Care, HMSO, London. Available online at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_103162

The above document supersedes HSC2001/15 and LAC2001(18) NHS and local councils' responsibilities and NHS continuing healthcare: action following the Grogan judgement (2006).

Department of Health (2007), NHS continuing healthcare and NHS-funded nursing care – public information leaflet ref 298653, HMSO, London.

The Parliamentary and Health Service Ombudsman (2003), NHS funding for long term care 2nd report – session 2002–2003, The Stationery Office, London.