

When does the NHS pay for care?

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

This booklet has been produced by the Alzheimer's Society and is also supported by Age Concern, Help the Aged and the Royal College of Nursing



Further information

The Alzheimer's Helpline

Telephone 0845 300 0336 (Monday to Friday 8.30am-6.30pm)

Email helpline@alzheimers.org.uk

Age Concern England

Free information line 0800 00 99 66 (Every day 7am-7pm)

Email ace@ace.org.uk

Help the Aged

Free SeniorLine 0808 800 6565 (Monday to Friday 9am to 4pm)

Email seniorline@helptheaged.org.uk

The health service ombudsman

Helpline 0845 015 4033

Email OHSC.Enquiries@ombudsman.gsi.gov.uk

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Contents

| | | |
|---------------------|--|-----------|
| Introduction | | 2 |
| Section 1 | Explains what continuing NHS health care is and who might be eligible for it | 4 |
| Section 2 | Explains how to make an effective complaint | 12 |
| | Flow chart of the application and appeal process | 24 |
| Appendix 1 | The history | 26 |
| Appendix 2 | Implications for people with dementia and their carers (A personal view by Barbara Pointon) | 30 |
| Appendix 3 | 'Free' nursing care and continuing NHS health care | 32 |
| Appendix 4 | Getting access to a patient's notes | 36 |
| Appendix 5 | Some commonly asked questions | 38 |

Introduction

This booklet explains what to do if you or the person you care for have been charged for care that you think should have been paid for by the NHS. It explains what continuing NHS health care is, how you might be able to get it, and how to complain if your request for continuing NHS health care is turned down.

Although this information focuses on people with dementia, much of it may be relevant to people with other conditions too.

The Alzheimer's Society is campaigning for people with dementia to be given access to fully funded NHS care, in the same way as people with other medical conditions. The current system discriminates against people with dementia.

Funding of care, whether in a person's own home, a hospital, a residential home or a nursing home, is complicated. Many people with dementia and carers are paying for care that should be paid for by the NHS. Some people have contacted the Alzheimer's Society, and the other organisations listed in this booklet, after reading about the findings of the health service ombudsman, who was concerned that the failings she had found in a number of cases could be widespread, possibly leading to people being wrongly charged. Most people want to know how to get their case reviewed and whether they may be eligible for a refund, with interest, of payments which they have made towards the cost of care.

You may have a case for a refund with interest if you or the person you care for has been receiving care since April 1996 and had to contribute towards the cost of that care. This is the case even if the person you were caring for has since died.

It is important to state up front that this information is not all easy to understand. This is because the system and the process that you have to go through is repetitive, time consuming and far from transparent. The criteria that explain who is entitled to fully funded continuing NHS health care, and who is not, are ambiguous and seem to be applied in an arbitrary fashion in different areas of the country. Reading the information in this booklet should help you to understand the review process and some of the information you should gather. It will not unfortunately tell you whether your case meets the criteria.

Do not be put off by the jargon and complexity. Read the parts that you think are most relevant to you.

Quick reference to the review and appeal process

The steps you will probably need to take are as follows:

- 1** Ask the primary care trust to review your case against the criteria for continuing NHS health care
- 2** If the trust says your case does not meet the criteria, consider whether you are satisfied with its explanation. If you are not satisfied, ask for an independent review of the decision
- 3** If the independent review finds that you do not have a case, contact the health service ombudsman
- 4** The ombudsman will then either investigate your complaint or tell you to go back to the local NHS complaints procedure

The Alzheimer's Society encourages anyone who thinks they have wrongly been charged for care to complain. It is important in individual cases and because we must highlight the injustice of people with dementia being wrongly charged for care. Along with Help the Aged, Age Concern England and the Royal College of Nursing (RCN) we also want to highlight the injustice of people whose primary need is a health need being wrongly charged for their care.

There is a flow chart explaining the steps you should take on page 24.

Section 1

What is continuing NHS health care?

Definitions

The government's guidance describes continuing care as follows:

'Continuing care (or long term care) is a general term that describes the care which people need over an extended period of time, as a result of disability, accident, or illness, to address both physical and mental health needs. It may require services from the NHS and/or social care. It can be provided in a range of settings, from an NHS hospital, to a nursing home, and people's own homes.'

The NHS is responsible for providing some continuing care and this is referred to as continuing NHS health care.

Continuing NHS health care is provided free of charge. The government's guidance defines continuing NHS health care as 'a package of care arranged and funded solely by the NHS. It does not include the provision by local councils of any social services...'

This means that someone awarded continuing NHS health care will not have any of their care provided by social services. It will all come from NHS staff.

These definitions are taken from Health Service Circular 2001/015: *Continuing care: NHS and local councils' responsibilities*. You can get the full government guidance on continuing NHS health care from the Department of Health website at

www.dh.gov.uk/assetRoot/04/01/22/80/04012280.pdf
or request a copy by writing to the Department of Health, PO Box 777, London SE1 6XH or by faxing 01623 724524.

People who meet the criteria for continuing NHS health care will have a complex condition that requires regular support. The guidance indicates that the cases in which this is most likely to apply are those where one or more of the following applies:

- 1 The nature, complexity or unpredictability of the individual's health care needs requires regular supervision by a member of the NHS multidisciplinary team, such as the

consultant, palliative care, therapy or any other member of the team.

- 2 The individual's needs require the routine use of specialist health care equipment under supervision of NHS staff.
- 3 The individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multidisciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team.
- 4 The individual is in the final stages of terminal illness and is likely to die in the near future.

What continuing NHS health care means in terms of funding

If someone is assessed as needing continuing NHS health care they do not have to pay any of the costs of their care. The NHS pays the whole cost. It applies whether the person is in a nursing home, a residential care home, a hospital or their own home. For example, someone in a nursing home who is assessed as needing continuing NHS health care will not have to pay any fees, although their benefits will be affected in the same way as if they were in hospital. Someone in their own home would not have to contribute towards respite care or home care fees.

However, there are limitations on what continuing NHS health care will pay for. Someone receiving continuing NHS health care will usually have limited choice about where they are cared for. If the care is in a care home and the NHS does not normally contract with that particular home, then 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 criteria for continuing NHS health care

To be eligible for continuing NHS health care, a person must have a complex medical condition that requires a lot of care and support, and/or very specialised nursing support. The general policy on who is entitled to continuing NHS health care will be explained in your local eligibility criteria. These can be obtained from your primary care trust or strategic health authority. The local NHS will normally use an

assessment tool to assess whether the criteria apply to particular people.

The assessment tool will typically look at issues such as:

- 1 **Motivation** – how motivated is the person?
- 2 **Clinical background** – what care and support has the person needed in the past?
- 3 **Medication** – medication use and the ability of the person to manage this themselves
- 4 **Mental health** – cognitive functioning including behaviour, dementia, disorientation and memory
- 5 **Safety** – is the person a risk to themselves or others?
- 6 **Personal care and physical well-being** – skin care and wound management
- 7 **Continence** – bladder and bowel care
- 8 **Mobility** – Is the person able to move around without help?
- 9 **Pain** – what help does the person require with pain relief?
- 10 **Eating and nutrition** – does the person have problems eating and drinking?
- 11 **Senses** – What ability does the person have to express themselves and understand communication?

To qualify for continuing NHS health care, a person will normally have a high level of needs in a number of the categories described by the local assessment tool. It is up to the local NHS to decide how many categories need to be fulfilled and a panel will normally look at whether individual cases meet the continuing NHS health care criteria. However, there has been a great deal of criticism of both the criteria used by health bodies and the application of the criteria in individual cases.

Assessments for continuing NHS health care

The NHS is responsible for making assessments for continuing NHS health care. If you are unsure whether an assessment has been made or if you want to ask for one, contact your continuing NHS health care co-ordinator in the local primary care trust. 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.

Care in a nursing home

Anyone living in a nursing home should automatically have been assessed for continuing NHS health care before going into the home. If they have not been awarded fully funded NHS care, you can generally assume that the NHS has decided that they do not meet the continuing NHS health care criteria. However, it is always worth checking this as in some cases assessments for continuing NHS health care are not carried out.

If a person in a nursing home has not been assessed as eligible for continuing NHS health care, they will often still be eligible for a contribution by the NHS towards the costs of their registered nursing care. This is known as the registered nursing care contribution. In England, there are three bands of payment that the NHS contributes towards the registered nurse costs of fees in a home providing nursing care.

The Alzheimer's Society and others have argued that it is difficult to understand why those assessed as needing the highest level of nursing care do not automatically get continuing NHS health care. (See Appendix 3 for more details.)

The experience of the Alzheimer's Society is that people moving into nursing homes are not automatically considered for continuing NHS health care and that their needs are not adequately identified. If an assessment has not taken place, you should ask for one by contacting the nursing home co-ordinator or social services.

Care in a residential home

People living in residential homes have not usually been assessed for continuing NHS health care. However, if someone has moved into a residential home after being in hospital it is possible that they will have been assessed for continuing NHS health care while in hospital.

Leaving a hospital

The government has issued new directions (February 2004) to the NHS stating who should be assessed for continuing NHS

Ask for a written copy of the assessment

Ask for copies of the assessment for continuing NHS health care. These are crucial in order to understand why a person has not met criteria and for use in appealing against decisions.

health care on leaving hospital. The directions state that before being discharged from hospital:

‘The NHS body must carry out such an assessment as it considers appropriate of the patient’s need for continuing care, in consultation, where it considers it appropriate, with the relevant social services authority.’

It also states that:

- carers must be consulted where appropriate
- the result of the decision must be recorded in the patient’s notes
- the NHS must inform the patient, if he or she is dissatisfied with the result of the assessment, about how to ask for a review.

This means that in future most people leaving hospital should have been considered for continuing NHS health care. However, the experience of the 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.

Care in your own home

The government’s guidance on continuing NHS health care states that it can be provided in someone’s own home. However, we know that very few people are granted fully funded care at home. This means that if a person is being cared for at home, they are unlikely to have been assessed for continuing NHS health care.

A case involving a man with Alzheimer’s disease who was being cared for in his own home recently went to the health service ombudsman. Malcolm Pointon was being cared for by his wife, Barbara, at home. The health service ombudsman recommended that he should be entitled to continuing NHS health care. This case should make it easier for people to get continuing NHS health care at home in the future. See Appendix 1 for more details and Appendix 2 for Barbara’s comments.

Reasons why people with dementia may not be viewed as eligible for continuing NHS health care

There are various reasons why it has been difficult for people with dementia to meet the criteria for continuing NHS health

care. Some of these reasons also affect people with other conditions.

Dementia care regarded as social care

Historically, much of the care received by people with dementia has been classed by the government as social care. If someone with dementia needs help with washing, eating, dressing and using the toilet, this help is typically provided by a care assistant from social services. People are means tested for the care they receive from social services. The Alzheimer's Society argues that this care is an essential part of the health care package that someone with dementia receives, and that no one should be charged for it. If this care was provided by district nurses or other health care workers it would not be charged for. The government's charging policy is, therefore, based on who provides the care (NHS or social services) and not on what people's care needs are. This discriminates against those whose care would typically come from social services rather than the NHS.

Emphasis on physical care

When people are assessed for continuing NHS health care, assessments do not typically take into account people's mental health and/or psychological needs. Instead, they focus on the physical aspects of care and whether care comes from specific health care professionals. There has been little recognition of the mental health care that people with dementia need or of the fact that much of their health care is provided by social services care assistants, among others.

Helping someone to cope with the psychological and emotional impact of dementia is a skilled part of health care but has not been recognised as such in assessments for continuing NHS health care. The same is often true for people who have had sudden deteriorations in their health, caused by strokes, for example.

Stability and predictability

The criteria for continuing NHS health care place a strong emphasis on how stable the person's condition is and on the definition of stable. If someone's condition is classed as stable they are not likely to meet the criteria, and if they are classed as unstable they are more likely to meet the criteria.

For example, someone in the later stages of dementia may spend a lot of time in bed or in a chair, without the need for

constant medical attention from a health care professional. The criteria would judge the person to be stable, despite the fact that they are in the final stages of a terminal condition. Because they are regarded as stable they are less likely to be classed as needing continuing NHS health care.

If, on the other hand, someone behaves in a way that other people regard as challenging, they are more likely to be classed as unstable and, therefore, to meet the criteria.

Definition of being 'in the final stage of a terminal illness'

People who are near death are more likely to meet continuing NHS health care criteria.

In the past, health authorities have put limits on what they regard as an acceptable amount of time to be providing end of life care. For example, they might have said that if someone is going to die in the next eight weeks, care would be provided by the NHS. In fact, the Department of Health guidance says that no arbitrary time limit should be set.

This system discriminates against people with dementia because it has not always been recognised that dementia is a terminal condition that leads to death. People at the end stage of dementia can live at that stage of their condition for a long time.

The Coughlan judgment

It has always been difficult to understand who is entitled to continuing NHS health care and who is not. Part of the problem is that the criteria explaining who is eligible have been vague.

A appeal court case in 1999 resulted in what has become known as the Coughlan Judgment. The case concerned Pam Coughlan, who is physically disabled following an accident. The judgment attempted to draw up a definition of who is entitled to fully funded care. It said that if someone in a care home 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. (See Appendix 1 for more detail.)

The court said that Pam Coughlan's needs were too great to be met by social services and that they should be met by the NHS. It looked as though this would lead to the NHS paying

for the care of many more people with physical illnesses or dementia living in care homes.

Unfortunately, this is not what has happened. In fact, access to continuing NHS health care has remained very restricted.

The health service ombudsman's report

You may have seen some of the publicity that has followed the health service ombudsman's reports into continuing NHS health care. She found that some health authorities had been interpreting the criteria wrongly, with the result that people had been charged for care that should have been paid for by the NHS.

The ombudsman recommended that all health authorities should review their criteria to ensure that they were compliant with the Coughlan judgment. She also recommended that they look through the cases of people assessed for continuing NHS health care since 1996 to decide whether anyone had been wrongly charged for care.

Thousands of people have made complaints to the NHS about being charged for care in light of the Coughlan judgment and the ombudsman reports. Many of these are members of the Alzheimer's Society.

You may have also read in the Alzheimer's Society *Newsletter* about the case of Malcolm and Barbara Pointon, as mentioned on page 8 of this document. Barbara argued that Malcolm should be able to receive continuing NHS health care in their home, where she had been caring for him. Her complaint to the ombudsman was successful.

For more details of these cases see the appendices.

Section 2

How to get a review ... and make an effective complaint if you are not satisfied

This section explains how to get a review of your case for continuing NHS health care and make a complaint if you believe that you or the person you care for have been/are being wrongly charged for care. It applies equally to all people, not just those with dementia. Please see the relevant section below about where the person lives and receives care.

Care in a nursing home

A person living in a nursing home may not have had an assessment for continuing NHS health care, in which case you can request one.

However, residents should have had an assessment of their registered nursing needs. Depending upon the level of nursing care that the person requires, they should have been awarded some money to cover their nursing care. This is paid directly to the care home. If this has not happened, you should speak to social services or the nursing home manager about getting an assessment.

People are means tested for all costs in a nursing home apart from nursing care. In England, if you have assets of more than £20,000 you will have to pay all of the additional costs of care. If you have assets of between £12,250 and £20,000 there is a scale according to which you will have to contribute, depending upon your means. When you have below £12,250 of assets you do not have to contribute any of these assets towards the costs of care. However, if you have income from those assets and other income besides, you will have to contribute a proportion of it towards the costs of care. (All savings limits quoted are correct at April 2004). This system means that thousands of people with dementia or other conditions have to find tens of thousands of pounds a year to pay for care.

Care in a residential home

People entering a residential home are means tested for all their care costs. In England, if you have assets of more than £20,000 you will have to pay all of the costs of care. If you have assets of between £12,250 and £20,000 there is a scale according to which you will have to contribute, depending upon your means. When you have below £12,250 of assets you do not have to contribute any of these assets towards the costs of care. However, if you have income from those assets and other income besides, you will have to contribute a proportion of it towards the costs of care. This system means that thousands of people with dementia or other conditions have to find tens of thousands of pounds a year to pay for care.

In the past it has often been assumed that people in residential homes are not eligible to receive continuing NHS health care. This is not necessarily true, although it will be even more of an uphill struggle.

The false assumption was based on the view that people with the most serious medical conditions and complex care arrangements would be in a nursing home. In fact, there are many people in residential homes with complex medical conditions. The health service ombudsman's office has told the Alzheimer's Society that they expect to see more cases related to people in residential homes.

Care in someone's own home

If a person is receiving care at home, they will normally be means tested. Local authorities have discretion about whether to charge but most do. Some have set maximum amounts that a person can be charged but the maximum varies from area to area. A person may be charged for home care and/or respite care.

The person with dementia might be eligible for continuing NHS health care funding to cover the costs of this care at home, but this is not easy to get.

The government has said that people have always been eligible to receive fully funded care in their own homes. But historically it has been very difficult for anyone to get continuing NHS health care in their own home. The Society has examples of people with very complex conditions living in their own homes who have been told that they do not meet the criteria for continuing NHS health care.

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

The Pointon case, which was reviewed by the ombudsman, found that Barbara and Malcolm Pointon had wrongly been

Barbara Pointon's top tips

Barbara Pointon, who made a successful complaint to the health service ombudsman, has put together a list of tips for people wanting to make a complaint. Read through them before you begin making a complaint.

- Get a copy of your local primary care trust's policy and eligibility criteria for continuing NHS health care for people with dementia and for people with physical/sensory disabilities.
- Go to meetings with your case set out as you see it. This will give you a checklist to refer to. Make sure others at the meeting also have a copy. It can be useful evidence for later.
- Ask what exactly the assessment is for at the beginning of the meeting – personal/nursing care, or eligibility for continuing NHS health care. This confusion characterises the whole case. Ensure that you are very clear on the purpose of any health or social services assessment.
- Politely put your grievances in writing and copy your letter to a manager of the person you are dealing with. You never know when it will come in useful. Save all paperwork and copies of letters.
- Bring in professional backing (for example, a GP) – and in writing.
- Ask someone neutral but knowledgeable, such as a person from your local branch of the Alzheimer's Society, if they would be willing to observe any meetings you have, take notes and provide moral support.
- Public law is very complicated. Unless you know the ropes, consider employing a solicitor who is very experienced in this area if you get to the complaints stage. A solicitor is able to support major points of your complaint with detailed reference to the law and/or to Department of Health guidance.
- For complex issues, tape recording a meeting provides the most accurate record.
- Ask Data Services (this is what they were called in my case – ask the local trust who you should speak to) for an Access to Records form so that you can obtain copies of the patient's medical records concerning the decisions in question. (A fee may be charged).
- Keep the ombudsman and your MP informed.
- If stalemate is reached, bring in an independent expert witness.

charged for care at home that should have been available on the NHS. You can quote this case as an example in your correspondence. See Appendix 1 for more details and Appendix 2 for Barbara's comments.

Who do the health service ombudsman's recommendations apply to?

The recommendations of the health service ombudsman are relevant to all people who have been cared for since 1996. This is true even if the person being cared for has died. In some areas the NHS has trawled through its records to look for cases, but to be on the safe side it is best to bring your case to the attention of the NHS and ask for a review (see below).

How do I tell whether my case might be eligible for continuing NHS health care?

You might already be in a position to tell whether your case might meet the criteria for continuing NHS health care from reading the information in this document. Whether you are or not, the steps suggested below will help you to be more informed about how to make the strongest case possible.

Assess the evidence

Before requesting a review of your case it is important to understand whether you might have a case. You don't want to waste your time, so it is worth doing some research.

Get a copy of the local continuing NHS health care eligibility criteria by calling your local primary care trust or strategic health authority or by looking on their website. To get the contact details for your primary care trust, look in the telephone book or call NHS Direct on 0845 4647.

Look through the criteria and think about whether the condition of the person to whom the complaint refers complies with the criteria. Also look at the brief details of the Coughlan judgment in Appendix 1.

It will help you make a strong case if you have as much documentary evidence as possible. Ask for social services and health records, and look for copies of old assessments and reports showing the level of needs. Care plans and notes from the person's care home may also be useful.

Now you should be in a position to decide whether to ask for a review.

How to ask for a review

You need to ask for a review of your case against the continuing NHS health care criteria. You can do this by writing to the chief executive of your primary care trust and asking for a review. You can get the details of who to write to by calling NHS Direct on 0845 4647. Or you can speak to

| | |
|--|--|
| | |
| Date | Your address etc |
| Dear <i>[name of chief executive of trust]</i> | |
| I wish to request a review of <i>[my mother's]</i> continuing care. | |
| I believe that <i>[my mother, Helen Smith]</i> , has been wrongly charged for care that should have been paid for by the NHS. | |
| I am complaining in light of the health service ombudsman's report into continuing NHS health care, which found that people have been wrongly charged for care. | |
| As you will be aware, the health service ombudsman found that many health authorities have not ensured that their continuing NHS health care criteria are compliant with the 1999 Coughlan judgment. I believe that this may apply to <i>[my mother's]</i> case. | |
| <p>Insert here the details of the person on whose behalf you are complaining. For example:</p> | <p><i>[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.]</i></p> |
| <p>Add the following sentence if the person being cared for is in a residential home or their own home:</p> | <p>You will also be aware that the Department of Health has stated that people can receive continuing NHS health care whether they are in a nursing home, residential care home, or their own home.</p> |
| The basis of my request is that having looked at both the local continuing NHS health care criteria and the findings of the Coughlan judgment, I believe that <i>[my mother]</i> meets the criteria. | |
| <p>_____</p> | |
| Please progress this review and update me as soon as possible. | |
| Yours sincerely Geoffrey Smith | |

social services or your nursing home co-ordinator about getting a review for continuing NHS health care.

The strategic health authority is responsible for the conduct of continuing NHS health care independent reviews, but you will need to ask the primary care trust to reconsider first.

Your letter to the chief executive might look something like the one on the opposite page.

Consider copying your letter to your MP at the House of Commons, London SW1A 0AA.

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. 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. This was not accepted in the case in the Pointon investigation. 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?

Predictability – It is often argued in cases of people with dementia that once the condition is advanced, their needs are predictable and, therefore, can be managed without health care input beyond the occasional visit from the district nurse. Is this true? You will need to itemise issues that require an immediate response and are unpredictable. For instance, does the person have panic attacks, convulsions, fits? Are they at risk of choking when they eat?

Quantity of health care needs – As the Coughlan judgment stressed, criteria should not be applied to prevent someone from getting continuing NHS health care because their needs are not for highly specialised care. It is helpful to document everything that the person requires during an average 24-hour period and include that information with your request for a review. Obviously,

also include information on any specialist needs.

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 – Are there additional issues that need to be taken into account as well as the fact of incontinence, 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 older 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.

The trust's response

The trust will respond to your letter, although this may take a long time. Telephone the trust to ask whether it has made any progress if you have not heard anything within a month.

If the trust decides that your case has merit it may call a review panel. See section 'If your case goes to the independent review panel' on page 20 for details.

However, if the trust responds by saying that it has reviewed your case and believes that the person does not meet the continuing NHS health care criteria, you must decide whether or not you are satisfied with this answer.

If you are satisfied to let the issue rest, the process ends here.

If you wish to take your review further, see the section 'What to do if the trust says you do not have a case' below.

What to do if the trust says you do not have a case

You should keep going to the next stage in the review process until you are satisfied with the findings or until you do not wish to devote any more energy to the complaint.

If you are not satisfied, you should now request that your case goes before a continuing NHS health care independent review panel. In your request you must explain your reasons for disagreeing with the trust's initial decision.

Write another brief letter to the person from the 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 local continuing NHS health care criteria and the Coughlan judgment and believe that you have wrongly paid for care that should have been available on the NHS. Write briefly about the complexity of the person's condition. You might want to pick up any issues that you mentioned in your original request for a review that you feel have not been picked up or have been ignored.

The 2004 directions given to health authorities by the government place responsibility for the review panel stage on the strategic health authority (SHA). However, some areas operate a panel at primary care trust (PCT) level as well, which must be attended before the SHA panel can be accessed.

Dear Complaints Officer

Thank you for your letter of 21 March in which you informed me that the 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.

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 [*your local MP*], House of Commons, London SW1A 0AA

CC Andrew Chidgey, Campaigns Officer, Alzheimer's Society, Gordon House, 10 Greencoat Place, London SW1P 1PH

Example of a letter requesting an independent review

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 model letter in this document, and consider the notes about why people are often refused funding for care.

You may not be allowed to attend. It is at the discretion of the panel.

If the trust decides not to grant you an independent review panel

The trust may decide to grant you an independent review panel. See section 'If your case goes to the independent review panel' below for details on how to proceed.

If the trust says that it will not grant an independent review panel, write to the health service ombudsman and ask her to follow up your complaint. The address is:

Health Service Ombudsman
Millbank Tower
Millbank
London SW1P 4QP

The health service ombudsman may decide to send the complaint back to another local panel. In this case, see the

section on complaints on page 22. Alternatively, the ombudsman may decide to investigate the complaint. If this is the case, you will be advised on how to proceed. As part of this process, you will be interviewed about the complaint.

If your case goes to the independent review panel

The case will be considered by a chair person and two panel members – one from a local authority (council) from the same strategic health authority area but not involved in the case, and the other from a local primary care trust not involved in the case.

The chair person will decide on how to conduct the independent review panel but according to the current guidance, they should have access to the views of the person requiring continuing NHS health care and their carers, and to independent clinical advice.

Unfortunately, the rules state that the complainant does not have an automatic right to attend the independent review panel.

The panel may ask the person with dementia (if appropriate) or their carer whether they are willing to be interviewed by the panel. If this happens, the person can take a representative (a carer, advocate or friend) with them. However, the panel does not meet in public and you will not necessarily be invited to attend it.

If you are not invited, ask whether you can attend. If the panel refuses to let you attend, ask whether you can send them a written view.

The guidance states that you are not allowed to bring a solicitor acting in an official capacity.

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 continuing NHS health care.

The best way to do this is to compare the individual's health needs with the eligibility criteria. Look again at the list of aspects to consider in the letter on page 17 and write down

what you want to say. Run through what you intend to say before the meeting.

Try to get copies of notes about the person's care from their GP and from social services. See Appendix 4 for further information about this.

Consider taking someone with you to provide moral support and back up what you have heard. It might be useful to take some notes about what the panel says.

The panel will probably not give you a decision about your appeal immediately but will write to you after discussions about the review.

The panel decision

If the panel agrees that the person being cared for should receive continuing NHS health care, they will make this recommendation to your primary care trust or strategic health authority. You should then discuss the repayment with the primary care trust or strategic health authority, including interest due on any money already paid.

If the panel decides that your case is not valid, you have to decide whether you are satisfied with this outcome or whether you want to proceed to the next stage.

If you want to proceed further, contact the health service ombudsman at:

Health Service Ombudsman
Millbank Tower
Millbank
London SW1P 4QP

The ombudsman may decide to send the complaint back to another local panel, in which case you should see the advice above again. Alternatively, the ombudsman may decide to investigate the complaint. If this is the case, you will be advised on how to proceed.

The health service ombudsman tells you to go through the local NHS complaints procedure

This can be quite disheartening. The system is repetitive and bureaucratic. However, try to persist with it if you can. Read the section below about how to make an official complaint.

Making an official complaint

The first step is to ask for a review of your case by making an official complaint.

Do this by writing 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 this time you must state in your letter to the chief executive that you wish to make an official complaint.

There are people who can help you make your complaint. For example:

Citizens Advice Bureau

Get their contact details from your telephone book

Alzheimer's Society

Call the Alzheimer's Helpline on 0845 300 0336 for contact details of your local branch (Monday to Friday 8.30am-6.30pm)

Community law service

Telephone 0845 608 1122 or visit www.justask.org.uk

Independent complaints advocacy service (ICAS)

Call your local GP surgery or hospital and ask for the patient advice and liaison service (PALS). You can ask PALS how to contact ICAS.

Writing the letter

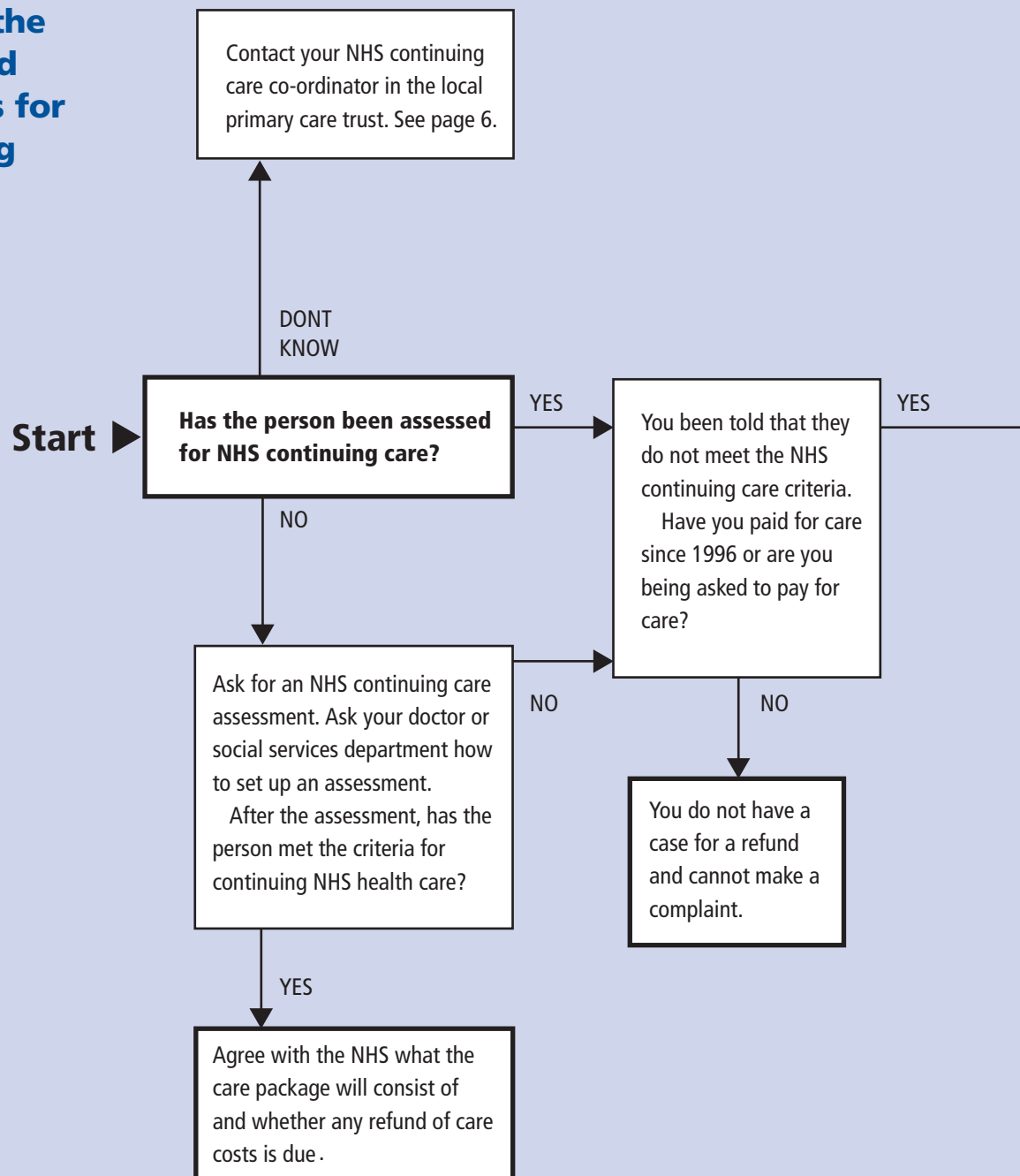
You can use a version of the first letter you wrote requesting a review but you may want to adapt it, given what you have learnt in the process of the review.

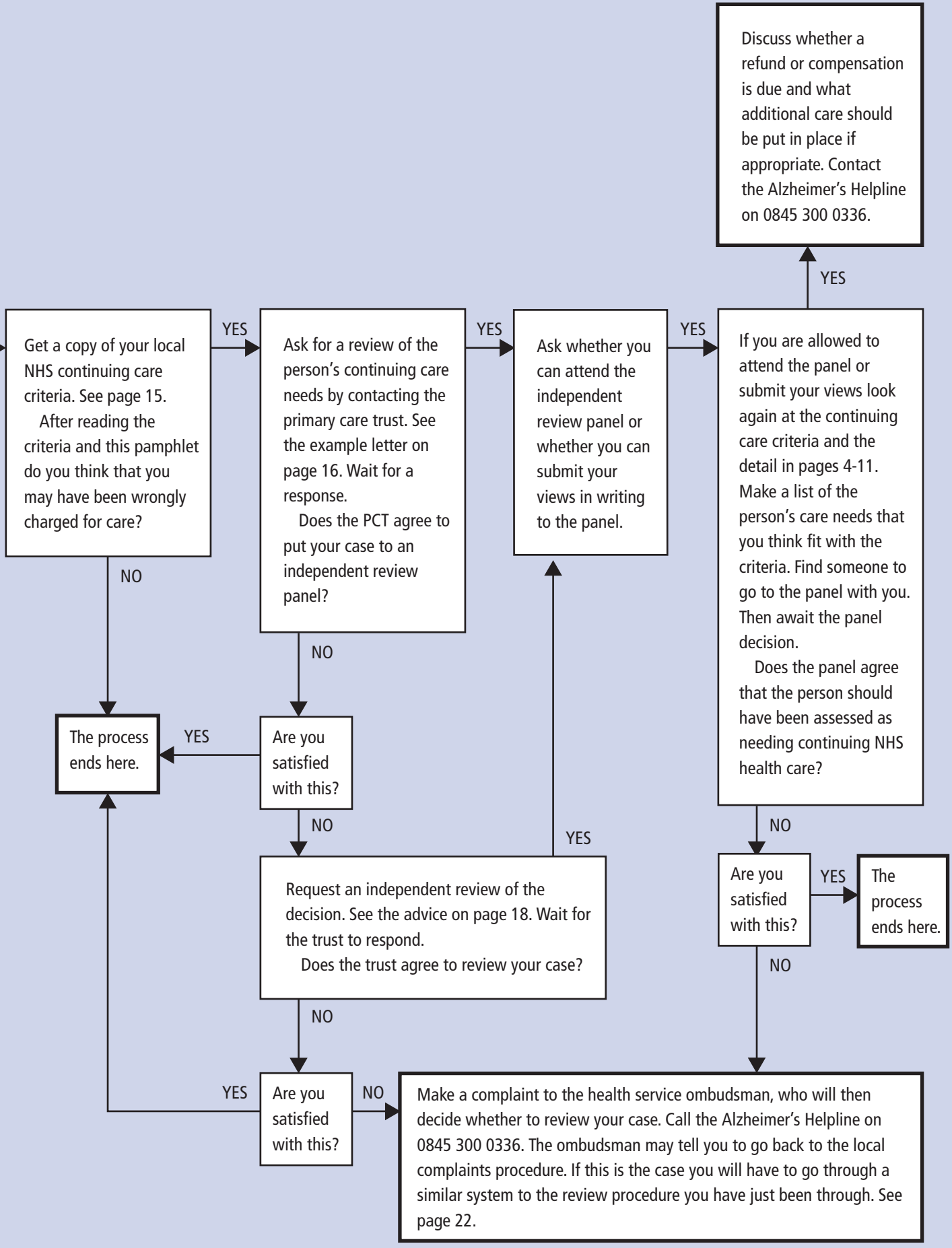
Ensure that you mark the request 'official complaint'. If you do not, your case may be reviewed for a long time before you get into the actual complaints procedure.

Keep a copy of this letter and all future correspondence on the issue.

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 for a continuing care review. Eventually you will get to the ombudsman again and she will either investigate your case or advise you what to do next.

Flow chart of the application and appeal process for NHS continuing care





Appendix 1

The history

The 1980s and 1990s

During the 1980s many people who had previously been cared for by the NHS were transferred to nursing homes using social security payments. Numbers of long stay hospital beds declined rapidly during this period. The NHS and Community Care Act 1990 introduced changes in social care and health care. One of the effects of these changes was that people with dementia were more often looked after in care homes arranged by social services. They were funded either partly or entirely by the care home resident, depending on how much money the person had.

Government guidance 1995

Following a critical report by the health service ombudsman, the Department of Health first introduced guidance in 1995. There was concern that the NHS had withdrawn too far from being responsible for people with long term health needs. This guidance required the former health authorities to produce eligibility criteria for continuing NHS health care by April 1996. The purpose of eligibility criteria was, and still is, to set out the kinds of health needs that a person must have in order to be eligible for continuing NHS health care.

This did little to help. Most people who were not patients in a hospital setting (inpatient care) were not considered to be eligible for continuing NHS health care.

The Coughlan judgment 1999

This was an important court case in the late 90s. 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 she lived in, saying that social services would have to be responsible for her future care. Pam Coughlan challenged this decision and her case went to the court of appeal, which had to decide 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 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 National Assistance Act which only envisaged that local authorities would provide social care (the quality test).

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

Current government guidance

In the Coughlan case, the court of appeal was critical of the 1995 government guidance. Two years later, the government replaced the old guidance with Health Service Circular 2001/015: *Continuing care: NHS and local councils' responsibilities*. This is still in force. You can see the full document by going to the Department of Health website at www.dh.gov.uk/assetRoot/04/01/37/84/04013784.pdf or you can request a copy by writing to the Department of Health, PO Box 777, London SE1 6XH or by faxing 01623 724524.

Strategic health authorities are now responsible for the eligibility criteria for continuing NHS health care in their areas.

Some important points from the new guidance include:

- 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 health care needs (and any combination of these needs) requires 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 require routine use of specialist health care equipment under the supervision of NHS staff.

- The individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multidisciplinary team.
- The individual is in the final stages of a terminal illness and is likely to die in the near future.
- A need for care or supervision by a registered nurse and/or GP is not by itself sufficient reason to receive continuing NHS health care.
- The location of care should not be the sole or main determinant of eligibility. Continuing NHS health care may be provided in an NHS hospital, nursing home, hospice or the individual's own home.

Health service ombudsman's report 2003

The next stage in the debate was the publication of the health service ombudsman's report in February 2003 (NHS funding for long term care 2nd report – session 2002-2003.) The ombudsman investigated four cases. In one case, she found that the individual (Mrs N) did have continuing NHS health care needs. She compared the 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 were unlawful. This was because they were over-restrictive and they forced social services to provide more health care than they were legally allowed to provide.

The health service ombudsman made a number of recommendations. These included a recommendation that strategic health authorities revise their eligibility criteria to make sure that they were lawful and that they and primary care trusts review current and past cases and reimburse individuals (or their estates) who ought to have been receiving continuing NHS health care.

This review process is currently underway.

For a full copy of the report visit the ombudsman's website at www.ombudsman.org.uk/hsc/document/care03/index.htm or call the helpline on 0845 015 4033.

The Pointon investigation 2004

Since her report, the health service ombudsman has investigated many complaints on the same subject. The ombudsman upheld a complaint from Mrs Pointon, wife and carer of a man with advanced dementia cared for at home. The ombudsman concluded that:

- The local eligibility criteria were applied in a way that made it practically impossible to provide continuing NHS health care at home
- The assessment focused on physical needs at the expense of psychological needs
- The assessment failed to recognise that the standard of care provided by Mrs Pointon was equal to the care that a nurse could provide.

A full copy of the ombudsman's report on the Pointon case can be obtained from the health service ombudsman's website at www.ombudsman.org.uk/hsc/document/pointon.pdf or by calling the helpline on 0845 015 4033.

Appendix 2

Implications for people with dementia and their carers

A personal view by Barbara Pointon

- When you care for someone at home, you tend to think that the only financial support available is that given by social services, and that it is means tested. Therefore, you may get very little financial help or none at all. You may be thinking of handing over to a nursing home sooner than you would have done had you received more support. If, however, the patient meets your primary care trust's eligibility criteria for continuing NHS health care for people with dementia (plus maybe the criteria for people with physical and/or sensory disabilities) he or she could be eligible for free care.
- However, the eligibility criteria, and therefore the assessments, are often skewed towards physical care (of the drips, drains and dressings variety) and the person with dementia does not qualify, even under the 'dementia' category. This ombudsman's report breaks new ground by recommending that the criteria should recognise patients' psychological, as well as physical, needs.
- Check why and against which criteria any assessment for funding is being made and make sure that psychological needs are included in that assessment. You know what you have to deal with as a carer – things such as the need for vigilance in case of harm, perplexing behaviours, mood changes, getting lost, visual/spatial problems, delusions, severe confusion, hallucinations, poor communication or level of understanding, and so on. These, as well as all the physical problems, arise directly from an organic disease of the brain and are, therefore, health needs and should form part of the assessment.
- The NHS has a mindset that continuing NHS health care can only be provided in a nursing home or in hospital. This report blows that wide open too and recommends that strategic health authorities ensure that the criteria for funding care at home are clearly defined and make it clear

that NHS funded care at home is an option. It also gives people more choice.

- The report also insists that respite care funded by the NHS (and therefore subject to the same criteria) can be provided at home, with someone coming in to replace you. For a long time, I thought that respite meant Malcolm having to be shipped off somewhere. I hated him going away (he always came back traumatised by being parted from familiar people and things and sometimes in a poor physical state) whereas respite at home for him has really worked. And I get time to myself and a quiet mind.

Appendix 3 'Free' nursing care and continuing NHS health care

In 1997 the government set up an advisory group, called the Royal Commission on Long Term Care, to advise the government on how to fund the care of older people in the future.

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 involved 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, but unfortunately the English government did not. The Alzheimer's Society and the other organisations listed in this booklet continue to campaign for the full implementation of the recommendations of the Royal Commission on Long Term Care, which would ensure the same benefits for people with dementia in England, Wales and Northern Ireland.

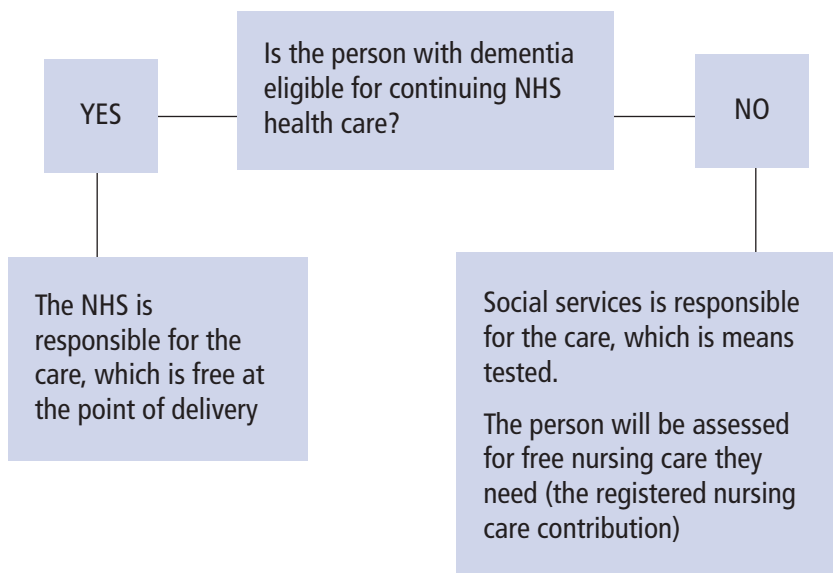
Instead of adopting the recommendations of the Royal Commission, the government introduced what it calls 'free nursing care'. This is a contribution by the NHS to meet only the registered nursing costs of a care package for people in

nursing homes only. The care home place will be the responsibility of social services and not health and so it will be means tested.

How do continuing NHS health care and 'free nursing care' fit together?

Ask yourself 'Is the person with dementia (or other condition) eligible for continuing NHS health care?' If the answer is 'yes', the care will be funded by the NHS and will be free.

It is only if the answer to that question is no that the second question arises. That is, 'Is the person with dementia (or other



condition) entitled to any financial assistance with the cost of their nursing care (free nursing care)?'

A registered nurse will decide the registered nursing care contribution towards the overall costs of care. In England, this is divided into three bands, as defined by the Department of Health:

High – £125 a week:

People with high needs for registered nursing care will have complex needs that require frequent mechanical, technical and therapeutic interventions. They will need frequent intervention and re-assessment by a registered nurse throughout a 24-hour period, and their physical/mental health state will be unstable and/or unpredictable. Primary care trusts can pay more if they think it is needed.

Medium – £77.50 a week:

People whose needs for registered nursing care are judged to be in the medium band may have multiple care needs. They will require the intervention of a registered nurse on at least a daily basis and may need access to a nurse at any time. However, their condition (including physical, behavioural and psychosocial needs) is stable and predictable and likely to remain so if treatment and care regimes continue.

Low – flexible, from £40 to £77.49 a week:

People whose care needs can be met with minimal registered nurse input. Since April 2004, primary care trusts can pay in between the two lower bands.

In Wales, there is only one band and people in nursing homes who are assessed as needing nursing care get £105 a week to cover the cost of care.

In Northern Ireland, people are awarded up to £100 a week towards the cost of nursing care.

The criteria for the highest band is very similar to the criteria for continuing NHS health care. This is why it is difficult to understand why some people only get £125 when others get fully funded in a care home.

Appendix 4 Getting access to a patient's notes

Rules about patient confidentiality mean that it is sometimes difficult to get access to someone's medical or social services notes. Generally, the person whose records you want to see must give consent. This is very difficult in circumstances where people with dementia are incapable of giving consent. If the person does have capacity to decide that they wish you to have access to their files they should always write a clear instruction to this effect.

People often think that an enduring power of attorney (EPA) gives someone a right to access medical or care notes. This is not true. An EPA only gives people a legal right to look after someone's financial and legal affairs.

Details about who is entitled to have access to records are set out in the Data Protection Act 1998, which gives rights of access to everyone with regard to their own records. However, under the act there is no provision for access on behalf of someone who lacks sufficient mental capacity to authorise access by another. This means that an individual who lacks the capacity to make decisions has, in effect, no legal right of access to their records and cannot give someone else consent to see them either.

Some health bodies and social services departments do not seem concerned about this and will happily release a personal file to the main carer, particularly if that carer is a close relative. However, these bodies may suddenly become concerned about duties of confidentiality when a dispute arises.

The reasons for refusal of access usually consist of either or both of the following:

- There is no statutory right of access.
- The local authority is bound by a duty of confidentiality owed to the incapacitated person and so cannot release the information.

This is not the full picture.

The law requires the public and private interests in maintaining confidentiality to be weighed against the public and private interests in disclosure. The exact nature of those

interests and where the balance lies in any particular case depends on the circumstances of the case.

It can be 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. It is probably best to make a simple request for access initially because the authority may be prepared to grant access without question. However, if access is refused, a full case can be made using the above principles.

These principles were established in the Stephens case, described below.

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. She was initially told by the local authority 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 private 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 disclosure would harm S's son or any other person or that S's son was in any sense objecting to that disclosure. The balance was firmly in favour of disclosure to S and was ordered by the court.

Appendix 5 Some commonly asked questions

Q What if I think that the person being cared for should be eligible under the Coughlan judgment and current guidance, but they do not seem to be according to local eligibility criteria?

A The local criteria and any assessment tools should not impose a stricter test than the Coughlan judgment and the national guidance. If they do, they may be unlawful.

If the local criteria are unlawful, you can challenge them through a judicial review or through the NHS complaints procedure followed by, if necessary, the health service ombudsman.

The first stage of the NHS complaints procedure is the local resolution stage in which the strategic health authority will try to resolve your complaint informally. If that fails, you can request an independent review. You can get advice and support in lodging a complaint from the independent complaints advisory service (ICAS) in your area.

If your request for a review is refused or if your review is unsuccessful, you can complain to the health service ombudsman.

The alternative route for challenging the legality of the local criteria is through a high court procedure known as judicial review. The court will decide whether the criteria are lawful and, if it decides they are not, will overturn the existing criteria and require the strategic health authority to draft new ones that do comply with the law.

Judicial review can be an effective legal remedy, but it is expensive and risky. As well as your own legal costs, you would have to pay the strategic health authority's legal costs if your judicial review was unsuccessful. If the person with dementia is financially eligible for public funding by the Legal Services Commission, and there are good legal grounds for a judicial review, then it is worth considering. In most cases you will need a solicitor, who will instruct a barrister on your behalf.

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

A The strategic health authority is responsible for making the arrangement for reviews and must appoint an independent chair.

Before getting to the formal review stage, there will be an attempt to resolve your request informally; usually this is at primary care trust level. It is only if that fails that you move on to the procedure set out in the Directions described below.

You must submit a written request to the strategic health authority for a review. If you already made your case in writing at the first stage, you can simply send a letter requesting a review and attaching your 'case' for continuing NHS health care.

The strategic health authority has to notify the independent chair when a request for a review is received. The Directions say that the strategic health authority 'may' refer the request to a review panel, so it does not have to do this. However, the guidance states that the request should go to the panel unless the person's condition falls 'well outside the eligibility criteria or where the case is very clearly not appropriate for the panel to consider'.

The rules and procedures are set out in the Continuing Care (NHS Responsibilities) Directions 2004 and in Annex E of the current guidance. See the Department of Health website www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/TertiaryCare/ContinuingCarePolicy/fs/en

Or contact:
 Department of Health
 PO Box 777
 London SE1 6XH
 Telephone 08701 555455

Q Do I need a solicitor?

A This leaflet is intended to help you conduct your own case. People have found solicitors helpful, but there is nothing to stop you taking all these steps yourself and/or using ICAS to help you.

If you are considering judicial review, you should contact a solicitor with expertise in judicial review cases unless you have access to legal advice yourself.

Q Are there different types of independent review panels?

A There are different types of review panel and it can be confusing.

An independent review panel that is part of the complaints process is different from a continuing NHS health care review panel.

A complaints panel deals with all sorts of complaints about the NHS and can look at complaints about the criteria.

This is different to a continuing NHS health care review panel, which will only look at whether the process of making decisions has been handled properly and in accordance with the local criteria.

If the review panel is a continuing NHS health care review panel, but not part of the complaints process, you do not usually have an automatic right to go to the health service ombudsman if they say the person does not meet the continuing NHS health care criteria. However, the ombudsman has indicated that for the purpose of continuing NHS health care reviews she will consider whether to investigate cases after an independent review has taken place, without having to go to the complaints procedure. This is on a case by case basis.

This booklet explains what to do if you or the person you care for have been charged for care that you think should have been paid for by the NHS. It explains what continuing NHS health care is, how you might be able to get it, and how to complain if your request for continuing NHS health care is turned down.

Although this information focuses on people with dementia, much of it will also be relevant to people with other conditions.