

Guide to fully funded NHS care

AGE
Concern



Alzheimer's Society
Dementia care and research

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Royal College
of Nursing

This guide has been produced to help people in need of services, their carers, and professionals working in health and social care to know when the NHS is responsible for paying for the full cost of packages of care. It is called by various names – most commonly continuing NHS health care, continuing care or fully funded NHS care. In this leaflet we use the term fully funded NHS care. It means that your health needs are such that it is the responsibility of the NHS to provide all the care you need. In your own home, this means that the NHS funds all the health care and social care you are assessed as needing. In care homes, it means that the NHS makes the contract with the care home and pays the full fees for the person's accommodation as well as their care.

Recently there has been a great deal of discussion about who is entitled to this full funding. There have been two leading court cases, one in 1999 (the Coughlan case) and more recently the Grogan case (January 2006). The confusion caused by the criteria for

who gets fully funded care, and who only gets help with their nursing costs has been the subject of much criticism by the Health Service Ombudsman, the Health Select Committee, voluntary organisations and the media. This criticism has caused many people to question whether their care packages should have been fully funded by the NHS.

Below we set out:

- ◆ why this leaflet is important to you
- ◆ a summary of the legal position for you to use when thinking about whether you should challenge the decision
- ◆ what action you can take if you think your care should be fully funded by the NHS, or you want your case looked at again
- ◆ suggestions for professionals who are involved in decisions about who is entitled to fully funded NHS care.

Although we set out the main legal issues relevant to continuing care, the position on each case will depend on the individual facts. The law in this guidance applies to England and Wales.

Why this leaflet is important to you

Anyone in a nursing home might want to query whether they have been correctly assessed as not needing fully funded NHS care. Even those in residential care, especially people who are in a home specialising in a particular condition such as dementia or Alzheimer's, might be able to qualify for fully funded NHS care if the nature or type of their care is such that it counts as health care.

People at home often miss out. They may receive free help from the local nursing services but the NHS should also pay for the social care part of their package. More and more people are being helped to remain at home even when they have very high health care needs or are receiving palliative care towards the end of their lives. They should have all their care paid for by the NHS not just the district nursing element. It does not matter who provides the care.

Professionals working in health or social care want to make sure their decisions are correct and follow the correct legal tests and so may find this leaflet helpful.

What is the issue?

The question of whether a person is entitled to fully funded NHS care will determine whether they have to pay for their care services or whether the NHS should pay.

The important issues about health and social care are:

- ◆ services provided by the NHS are free at the point of delivery because the NHS pays for them, and usually charges cannot be made
- ◆ services which are provided or arranged through social services departments of local authorities are means tested
- ◆ if care is provided via social services all or some of the cost can be passed on to the person receiving the services depending on their financial position. They are therefore charged for their care, in some cases even if they receive welfare benefits
- ◆ if care is provided via the NHS then there should be no means test or charging.

It is therefore important to know whether the law requires the services to be provided by the NHS, social

services or by a mixture. This is called the 'health and social care divide'.

The myths

For many years, there has been a widespread **misconception** that:

- ◆ once a person is not a hospital inpatient, then they have to pay for their care
- ◆ care outside hospital is not health care, but has become social (or personal) care
- ◆ people in care homes, whether 'residential care homes' or 'nursing homes', always have to pay for their care.

This is not legally correct!

Eligibility criteria

Since 1996, all health authorities (and now Strategic Health Authorities and Primary Care Trusts) have had to have in place eligibility criteria which specify who is entitled to fully funded NHS care, and who is not (i.e. who must pay via the social services means test). There is concern that these criteria have varied around the country (health care by post code), and more importantly that the criteria which are being applied might be unlawful.

Contributing to care home costs

Many people who have been placed in care homes by social services think that the state is funding their care because social services are paying for their care costs. In fact these people are contributing towards their care costs because they are charged out of their income (including benefits and occupational pensions) by social services. The charges leave them with only a small amount of money for essentials such as toiletries, clothes etc. It is therefore important to recognise when a person is being charged for their care, even when it seems that their services are being provided or arranged by social services.

Mental health needs

People with mental health needs are as entitled to fully funded NHS care as people who have physical health needs. However, our experience shows that people with mental health needs are treated differently to those with physical health needs. This may be due to the fact that nursing for people who have mental health needs (such as dementia) or learning disabilities is often considered to be merely

supervisory in nature, and called ‘personal care’. Physical health interventions are more easily labelled as health care. In practice, eligibility criteria can often discriminate against people with mental health conditions and we consider that this needs to be addressed urgently.

Sectioning under the Mental Health Act

Some people have been ‘sectioned’ under the Mental Health Act 1983 and are then provided with a package of ‘aftercare’. Special rules may apply in these cases. More information can be obtained from the organisations listed at the end of the leaflet.

The Coughlan case

In 1999, the Court of Appeal heard the case of Pamela Coughlan, a disabled woman who argued that the NHS was responsible for her care. This was due to her condition and the type and level of nursing care that she needed. The health authority in her case said that she did not meet the eligibility criteria for fully funded NHS care because she only needed general nursing and not specialist nursing.

Ms Coughlan argued that the NHS had wrongly tried to transfer responsibility for health services, including general nursing, onto social services and that this meant that people were being unlawfully charged for health care which should be paid for by the NHS.

The Court of Appeal agreed with Ms Coughlan and quashed the health authority’s eligibility criteria as they were unlawful. It laid down a test for deciding when the NHS was responsible for funding a care package (in a nursing home):

- (a) where the person’s reason for the placement in the home was primarily a health need, then the NHS was responsible for funding the whole package of care
- (b) the local authority social services department can only be legally responsible for nursing care which is:
 - ‘merely incidental or ancillary to the provision of the accommodation’ – this involves consideration of
 - the quality of the nursing care (i.e. the type) and
 - the quantity of the nursing care (i.e. the level).

The Court added that social services can only be responsible for services which are of a **nature** which a social services agency can provide.

The judgment also said that Ms Coughlan's condition and need for nursing care meant that she was entitled to fully funded NHS continuing care as her nursing needs were beyond the legal scope of social services to provide.

This has become known as the 'Coughlan test'.

The government's response to Coughlan

Following the judgment, the government asked all health authorities to check that their eligibility criteria complied with the Coughlan judgment. However, the Department of Health left it to health authorities to make their own minds up, so that there was still widespread confusion as to who was entitled to fully funded NHS care. The geographical variations continued, and people were still being charged for health services which should have been funded by the NHS.

The Health Service Ombudsman has

since criticised the lack of direction from the Department of Health. She comments that eligibility criteria used by health authorities still transfer responsibility for health care onto social services when the NHS should be responsible.

NHS payments for nursing care – the 'RNCC' banding system

In 2001 the government decided to introduce a new system for residents of nursing homes, called 'free nursing care for all'. However, this is not the same as fully funded NHS care.

This system, known as the Registered Nurse Care Contribution (RNCC) involves the NHS making a small financial contribution towards the overall cost of the care package. It is for care which is provided by registered nurses employed at a nursing home. It does not pay for care provided by nursing assistants. There are three bands of registered nursing input (high, medium and low) which result in a different level of financial contribution by the NHS (the contributions from April 2006 are £133, £83 and £40 per week for each of the bands). In Wales there is a single

RNCC band. The Department of Health said that the new system did not replace the Coughlan test which was still the test for eligibility for fully funded NHS care. However, there are serious concerns that, in practice, people are assessed as being entitled only to this contribution to their care costs under the RNCC system when, if the Coughlan test was properly applied, they would be eligible for fully funded NHS care, that is, the cost of the whole care package.

The Grogan case

In January 2006, the High Court heard a challenge on behalf of a resident of a nursing home, Mrs Grogan, to the eligibility criteria used by Bexley Care Trust. Mrs Grogan argued that:

- ◆ assessors were only granting fully funded NHS care when needs were seen to exceed the criteria for the highest RNCC band
- ◆ as the highest RNCC band included people in extremely serious conditions needing constant nursing care, getting fully funded NHS care was almost impossible
- ◆ a far higher test than that set out by the Court of Appeal in Coughlan

for fully funded NHS care was being used. It caused confusion and made no sense to those who were applying the tests.

The High Court Judge agreed with Mrs Grogan and found that:

- ◆ 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 care eligibility to the RNCC bands.

He criticised the Department of Health for failing to produce clear guidance and direction to the NHS. He added his voice to the Health Select Committee and Health Service Ombudsman in urging the Department of Health to remedy the situation to make sure that the ongoing distress, confusion and injustice did not continue.

The judge 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, health care 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 meet 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

How this affects you

After reading the information in this leaflet, you may think that you or someone you know may be eligible for fully funded NHS care, or that you may have been wrongly assessed under the RNCC scheme when you should be fully funded.

What you can do

If you think you have been wrongly assessed you should:

- ◆ write to the chief executive of your PCT asking what action he or she is taking following the Grogan judgment
- ◆ ask the chief executive of the PCT to arrange for a reassessment of your needs according to the Coughlan and Grogan judgment
- ◆ if social services fund your care: write to the director of social services/adult services of your local authority and ask why social services considers that your package of care is its responsibility, as opposed to the NHS
- ◆ if a means test by social services results in you having to pay for your own care, because your resources are above the threshold:

write to the director of social services/adult services of your local authority and ask why social services considers that your package of care is your responsibility, as opposed to the NHS

- ◆ if necessary, seek help from an advice agency or legal advice.

Useful contact addresses and information sources are listed at the end of this leaflet.

We have also suggested a form of letter which you may wish to use, or adapt, if you wish. The letter is at the end of this leaflet.

If you are a professional working in health or social care you should:

- ◆ ask your employer what action is being taken to implement Coughlan and Grogan compliant criteria
- ◆ ask your employer whether the existing criteria being used in your area will be checked so that they are lawful
- ◆ ask your employer when they will be able to assure you that these actions have taken place

- ◆ request that further training and development be provided for all staff involved in the assessment and determination of entitlement to fully funded NHS care
- ◆ keep a record of when you raised these questions with your employer
- ◆ continue to assess and determine your patient's/client's need for care
- ◆ inform your employer in writing if you have workload/capacity concerns
- ◆ act within your code of professional practice/accepted best practice
- ◆ seek support/guidance from your professional body/trade union.

If you live or work in Lewisham, Bexley, Greenwich, Bromley, Lambeth and Southwark then:

- ◆ the effect of the Grogan case is that the eligibility criteria that have been applied across your area are unlawful
- ◆ you may wish to follow the suggested action above.

Finally, although both the Coughlan

and the Grogan cases were about people in hospitals and nursing homes, do not forget that if you have a primary health need you may be entitled to have all of your care package funded by the NHS even if you live in a residential home or in your own home.

The draft letter on page 10 can be used to ask for a review of the decision about whether care should be fully funded by the NHS or not. People who have been assessed by social services and told that they would have to pay the whole fee or part of the fee, based on the person's resources, can also write to social services. The words in square brackets can be used so that letters can be sent to both the Primary Care Trust and social services.

Date

Your address etc

Dear (*name of chief executive of Primary Care Trust*)

[Dear *name of Director of Social/Adult Services*]

I wish to request a review of (*my mother's*) continuing NHS health care.

I believe that (*my mother, Helen Smith*), has been (*and is being*) wrongly charged for care that should have been paid for by the NHS.

I am requesting a review/reassessment in light of the recent Grogan judgment. As you may be aware, the judge confirmed that the criteria used by SE London Strategic Health Authority were fatally flawed because they did not set out the Coughlan 'primary need' test in full and also linked eligibility to the registered nursing care contribution bands. They also did not make clear to social services the proper tests that they should apply before deciding whether the person should remain the responsibility of the NHS or be means tested by social services.

I would like to have details of the action your trust [department] has taken to ensure that guidance being used in your area by both the primary care trust and social services is not similarly flawed and that decisions are being properly made so that they are legal. If you consider that it is not flawed please send me copies of the relevant sections of guidance that is being used with details of why you think it is line with the judgments.

I am concerned that the tests in the Coughlan and Grogan cases were not applied to (*my mother's*) case. Please arrange for a full reassessment to be undertaken.

(Insert here details of your case/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 and if in a nursing home the band of RNCC she is in.)

I therefore believe that (*my mother*) should meet the Coughlan test for fully funded NHS care, and that the package is beyond the remit of social services, so she should not have been means-tested.

[I have sent this letter to you as CE of PCT and also to director of social services]

Please progress this review and update me as soon as possible as to the action you intend to take.

Yours sincerely

Name

This leaflet has been commissioned by Age Concern, the Alzheimer's Society, Help the Aged and the Royal College of Nursing. It is produced in conjunction with Nicola Mackintosh of Mackintosh Duncan solicitors who was the lawyer for Ms Coughlan.

Alzheimer's Society:

Website: www.alzheimers.org.uk

Alzheimer's Helpline 0845 300 0336 (open Monday to Friday, 8.30am to 6.30pm)

Email helpline@alzheimers.org.uk

Information leaflets *When does the NHS pay for care? And Assessments for NHS-funded nursing care* can be obtained by calling the helpline or downloaded from the website.

Age Concern

Website: www.ageconcern.org.uk

Information Line 0800 00 99 66 (open everyday, 8.00 am to 7.00pm)

Factsheet 20 *Continuing NHS health care, NHS funded registered nursing care and intermediate care*, can be obtained by calling the Information Line on or downloaded from the website.

Help the Aged

Website: www.helptheaged.org.uk

SeniorLine (open Monday to Friday, 9am to 4pm) on 0808 800 6565

Email seniorline@helptheaged.org.uk

Information Resources Team on 020 7278 1114

Information leaflets *Care Homes, Paying for your Care Home, Paying for your Care Home: Problems with Local Authority funding and Community Care: Legislation, guidance and case law* can be downloaded from the website or can be ordered over the phone.

Royal College of Nursing

Website: www.rcn.org.uk

RCN Direct: (open 24 hours 7 days a week) 0845 772 6100

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