Who pays for care, and who should pay?

Who pays for care, and who should pay? In this article Hilary Caldicott, a member of Oxford Diocese's Health and Social Care Group, explains how to navigate the complex world of NHS 'Continuing Care'. She explains how she challenged the authorities on the issue of who should pay for her mother's care when she developed Alzheimer's, and explains the new national framework for Continuing Care, launched in October 2007.

NHS Continuing Care refers to the system that pays for the care required by people whose long-term health needs are such that they are considered to be entirely the responsibility of the NHS. The majority of this group of people are older people suffering from dementia, but there are also many younger people who require long-term NHS care, for example because of incurable degenerative illness or brain damage following an accident. The system is also described as 'fully funded' NHS care.

Up until the mid-nineties, the NHS cared for people with this level of need in its own institutions, most of which were old-style longstay hospitals. If people could manage in a residential home without nursing input, they were assessed financially and if appropriate charged for their care, but NHS care was and is free at the point of delivery. If your illness or disability leaves you with healthcare needs, you are entitled to receive all your care free.

In 1996 the Government published eligibility criteria which appeared to change these rules, tightening them so that very few people with needs arising from chronic illness or disability would ever qualify for free NHS care. The guidance given to NHS managers by the Department of Health at this time regarding eligibility was based on the test that the nature, intensity, complexity or unpredictability of an individual’s needs required regular supervision by a member of the NHS multidisciplinary team. This criterion was used to exclude virtually all applicants for NHS care, and hundreds of thousands of gravely ill or severely disabled people were compelled to sell their properties and pay for their own care until their assets were exhausted.

It is important to note that the establishment of eligibility criteria did not alter the law, and in the end it was the courts that upheld the principle of a free NHS, in allowing the appeal of a younger disabled woman called Pamela Coughlan against a decision by the North and East Devon Health Authority to transfer responsibility for her care to Social Services. The landmark 1999 Court of Appeal judgement that bears Ms Coughlan's name is available on the Internet (at www.sochealth.co.uk, under the Health Law/Cases heading) and repays careful reading. The critical issue in the appeal was described by Lord Justice Woolf as 'whether nursing care for a chronically ill patient may lawfully be provided by a local authority as a social service (in which case the patient pays according to means) or whether it is required by law to be provided free of charge as part of the National Health Service.'
Lord Woolf found that the particular eligibility criteria used by NE Devon HA were unlawful. He agreed that it was possible for a local authority to provide care with an element of nursing, but proposed a test that the nursing should be incidental or ancillary to the provision of accommodation and of a nature that it was reasonable to expect a local authority to provide. He was emphatic that the needs of Pamela Coughlan went far beyond this test. She is tetraplegic following a road traffic accident but has unimpaired intelligence and is able to tell her carers what she requires, so in a number of respects she is more able than thousands of people who have been turned down for NHS care, but Lord Woolf ruled that she has disabilities and needs that are in law beyond the scope of local authority services.

The Coughlan judgment is the legal benchmark for decisions about continuing care, but its implications are frequently ignored by decision-makers in the health service. After 1999, the Department of Health largely left it to health authorities to make up their own minds and there have been widespread variations nationally. The Health Ombudsman has been highly critical of the system, as was the House of Commons Health Select Committee which reported in 2005. The Department of Health has at long last responded to these concerns by publishing a new National Framework setting out in what circumstances the NHS will pay for care, and this will be implemented from October 1st 2007. The document can be viewed on the Department of Health website, www.dh.gov.uk

For many, the Framework does not go far enough. It does emphasise the central importance of the Coughlan judgment, and it offers a decision-making tool (the Decision Support Tool) designed to ensure that the full range of factors which have a bearing on an individual's eligibility for NHS continuing care are taken into account; these factors include consideration of health care needs which are particularly significant in dementia, such as behaviour and communication. There are eleven care domains to be considered in each individual assessment, namely behaviour, cognition, communication, psychological/emotional needs, mobility, nutrition (food and drink), continence, skin (tissue viability), breathing, drug therapies and medication (symptom control) and altered states of consciousness. The result of completing the tool should be an overall picture of the individual's needs, capturing their nature, complexity, intensity and/or unpredictability and thus the quality and quantity of care required. It should be noted that there is no longer a specific requirement for supervision by a member of the NHS multi-disciplinary team.

The Framework needs to be tested, but on first reading it looks as if it provides stronger ground for arguing that most people with severe dementia, for example, should qualify to have the costs of their care met in full. As well as new cases, people who have been denied NHS continuing care in the past should ask for re-assessment according to the National Framework, or their advocates should ask on their behalf. However, the Framework still falls short of upholding the rights of people with chronic illness who do not need a high level of specialist care. None of the care domains which score the highest on the Decision Making Tool (behaviour, breathing, drug therapies and altered states of consciousness) and are therefore most likely to indicate that full funding is required, apply to Pamela Coughlan.

It is fair to say that there is a case for looking again at the mechanisms for funding the care of people with longterm health needs in an affluent society where life expectancy
has increased significantly. Many people would be willing to consider contributing to the board and lodging element of the care, particularly if they no longer require an independent home of their own. This was the solution suggested in the report of the 1999 Royal Commission on longterm care, but it was rejected by the Government as too expensive. Instead, a new system of funding part of the nursing costs of people in nursing homes was created as part of the Health and Social Care Act in 2001. Everyone who has nursing needs and is being cared for in a nursing home setting is entitled to payments from the NHS, in the form of a Registered Nursing Care Contribution (RNCC). This is not to be confused with full funding and is not an alternative to it. It is a contribution to care provided by a registered nurse, with three bands – high, medium and low. As of April 2007, these are respectively £139, £87 and £40 per week, but the National Framework will replace the bands with one single payment of £103 per week.

The Department of Health agrees that the RNCC contribution does not replace the Coughlan test, but in practice there are serious concerns that people are routinely assessed as being entitled only to this contribution when in fact they meet the Coughlan test and should receive all their care free. Maureen Grogan's successful High Court challenge in January 2006 turned on this point. Her counsel argued that assessor were only granting fully funded NHS care to people whose needs were above the highest RNCC band. As that band included people with extremely serious conditions, it was virtually impossible to obtain fully funded care. In this judgement Lord Justice Charles directed the Health Authority to the Coughlan test, describing it as the 'primary health need test' and characterising the existing eligibility criteria as 'fatally flawed' because they did not specify such a test. Once again, the Courts upheld the rights of chronically ill people to NHS care when NHS staff had failed to do so.

A personal account

I encountered this system in 2004, as my mother's representative. Joan Caldicott was born in Edinburgh in 1919 and was a trained nurse, winning the gold medal awarded to best nurse of the year in both her Registered Sick Children's Nurse training and her State Registration. She believed in and defended the NHS and never worked for any other employer after it was created in 1948. She was also a devoted wife and a loving mother and I don't remember her ever asking for anything, but in the last 19 months of her life she was denied the NHS care that was her right. She developed vascular dementia and eventually, after a fall at home in which she broke her elbow, she required 24-hour nursing care because she was immobile, unable to communicate effectively and doubly incontinent. My 86 year old father could no longer care for her at home because she required two people even to move her to a different position in a chair, so she was admitted to a nursing home where she died with characteristic grace and calm in May 2006.

It seemed to me self-evident that my mother met the Coughlan test. She had a home, so there was no question of her needing an alternative one, and a husband who wanted to care for her and was very distressed that he could no longer do so. If her nursing needs were incidental and ancillary to her need for accommodation, why could she not have been supported at home by visits from the Community Nursing Service? She was turned down for continuing care while in hospital for surgery following her fall and I appealed immediately, but it took over two years before the Strategic Health
Authority convened a Panel to hear the full appeal, having been directed to do so by the Healthcare Commission; by this time, my mother had died. The appeal was successful, and the Primary Care Trust refunded all the costs of care plus interest to my mother's estate, which means that it has been repaid to my father.

In retrospect, we should perhaps have refused to pay from the beginning, but my father was not happy with the quality of the care provided by the hospital where my mother had been taken for emergency surgery, and wanted her moved to a nursing home where he could visit her regularly. We could not, in all conscience, have left her in the ward, and that meant agreeing a contract with a nursing home and paying. However, it is worth noting that many other families have refused to pay from the outset and have said that they are willing to defend their position in court. For further advice, look at the website www.nhscare.info

As a Christian, I have had to examine my thinking in all this very carefully, and I know that we are not all comfortable in a campaigning role. There are people who argue that to charge for longterm healthcare is just, and Tony Blair himself has changed his position from early on in his premiership, when he said that older people should not lose their homes to pay for care; ten years on, his line was that the country cannot afford to pick up the tab. However, the country has already made the decision that healthcare will be funded through central taxation, so people charged for their care in this way are paying twice. My parents' generation paid a very high level of income tax to help establish the welfare state, with a promise from the government of the time that it would meet all their needs from the cradle to the grave. The law has not been altered in any substantive way since 1946. The more I have thought about this, the more it seems an unprincipled attack on people who are vulnerable and an easy target because many of them have lost the capacity to argue their own cases.

There is also very little debate about the unintended consequences of this shift in responsibility for funding. To be profligate is now a sensible strategy, since you will receive care if you need it whether you can pay for it or not. Also, the sense that older and disabled people have of being a burden is intensified; a very distressed woman with a diagnosis of multiple sclerosis told me she would definitely take her own life at the age of 75 rather than see her daughter, who lived with her and cared for her, made homeless because the house would need to fund nursing care as she became progressively more disabled.

If you want to challenge a decision

If you find yourself grappling with this bewildering system, whether as a disabled person or as a carer, remember there is help available and don't try to go it alone. The 'Guide to fully funded NHS Care' a joint publication by Age Concern, the Alzheimer's Society, Help the Aged, and the Royal College of Nursing, is a good place to start, and includes sample letters to be sent to Primary Care Trusts. Nicola Mackintosh, Pamela Coughlan's solicitor, acted as advisor to the authors of the Guide. It is available on the websites of all the funding organisations.

From my own experience, I think it is important not to give up in the early stages, and to keep notes throughout and research your case carefully. You don't need to pay a solicitor to challenge these decisions, at least initially, and you can find a great deal of
information on the Internet. It is important to remember that health and social service staff don't necessarily understand the law themselves, or even implement their own criteria correctly. The handling of my mother's case by the Primary Care Trust was littered with errors, including giving me written reasons for rejecting her appeal that were invalid according to their own eligibility criteria document! I was also told time and again by professionals that there was no chance that I would win the case. I hope that my indomitable mother is having a good chuckle in her everlasting life!

Hilary Caldicott

Hilary Caldicott is happy to respond to e-mail enquiries on continuing care. Please contact Alison Webster in first instance.