

## **Inquiry by the House of Commons Health Committee into NHS Continuing Care,**

***Session 2004-5, Sixth Report:  
NHS Continuing Care, Evidence: Volume II***

### ***Evidence by Marion Shoard***

This evidence is submitted by Marion Shoard. I have experience of the Continuing Care system through my mother, who lived in a Continuing Care establishment in east Kent for four-and-three-quarters years until her death in January 2005. My knowledge of the Continuing Care system also arises from the research I carried out for my 640-page book published in 2004 *A Survival Guide to Later Life* (Constable and Robinson).

I welcome the statement by the Minister announcing that a national framework setting out criteria for assessing eligibility for Continuing Care will be drawn up. I am particularly concerned about the eligibility criteria as far as people with dementia are concerned, and firmly believe that they should be consistent across England but also reflect the prime purpose of Continuing Care provision - to support people with very great health care needs.

### ***Eligibility Criteria***

In 2004 my mother's health trust, Canterbury and Coastal Primary Care Trust, announced that it was going to reassess her for her Continuing Care. I assumed that the criteria that it would use would reflect the Department of Health's guidance on the purpose of Continuing Care, in other words, Annex C of circular HSC 2001/015: LAC (2001) 17, *Continuing Care: NHS and Local Councils' Responsibilities*, which sets out the "key issues to consider when establishing continuing NHS health care eligibility criteria". However, I found that the PCT and its overseeing Strategic Health Authority had developed sets of Continuing Care criteria which differ markedly from the purpose of Continuing Care as set out in HSC 2001/015: LAC (2001) 17, Annex C.

Apart from people who are in the final stages of a terminal illness or likely to die in the near future, Annex C says that Continuing Care should be provided because "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 the NHS multidisciplinary team, such as the consultant, palliative care, therapy or other NHS member of the team". However, both my late mother's Strategic Health Authority (Kent and Medway) and her primary care trust (Canterbury and Coastal) put a great deal of emphasis on those whose symptoms happen to involve disruptive, aggressive or non-compliant behaviour. Thus in its "Mental Health Criteria", the Kent and Medway Strategic Health Authority states that a person must meet at least one criterion in each of three categories, A, B and C. Three of the five criteria in A relate to disruptive, aggressive or non-compliant behaviour, as do two of the three under B and two of the four in C. For example, category B says that the person must either pose "A serious risk to themselves or others, or serious self-neglect, as a consequence of severe and enduring mental illness or personality disorder", or exhibit "challenging behaviour, defined as behaviour of such intensity, frequency or duration that the physical safety of the person is likely to be placed in jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary facilities", or to have "serious physical frailty".

Yet patients who lash out, or are disruptive, unpleasant, aggressive or utter profanities will not necessarily be those with the greatest health care needs. They may well be those whom health and social services authorities find most difficult to place in private care homes, but that is a very different matter from the objectives for Continuing Care as set out in Annex C of circular HSC 2001/015: LAC (2001) 17.

This emphasis on people who are difficult to handle rather than simply seriously ill is carried through in the eligibility framework drawn up by the Canterbury and Coastal Primary Care Trust. In a diagram headed "Areas of Need/Degree of Severity/Intensity/Stability", the officials assessing people for eligibility for Continuing Care are invited to tick a box in one of a number of categories. Several of these categories are restricted to aggressive, disruptive, unpleasant or challenging behaviour - "challenging behaviour/activity" and "evidenced aggression" and "risk to self or others" - so that those who do not exhibit such symptoms would score nil in these areas. But the emphasis on disruptive people also bears fruit in the sub-divisions within several of the other categories. Thus in the category "personal care", the spectrum of choices offered, in five divisions, does not span the intensity or extent of a person's personal care needs arising from illness or disability: rather it spans the extent to which the patient when receiving help, whether it is a little or a great deal, is resistant or compliant. The same obtains for another category, "feeding": what is measured is not the degree of assistance needed but whether the patient accepts help or objects to receiving help. My mother was not at all disruptive, aggressive or non-compliant, but had massive health care needs arising from Alzheimer's disease. Had she lived, she may well have lost her bed in favour of a person who was less poorly but disruptive.

Had my mother managed to hang on to her bed, she would have faced another hurdle which also finds no place in HSC 2001/015: LAC (2001) 17 – reassessment every three months.

Three-monthly reassessment may perhaps be appropriate for patients who are recovering from some physical illness or trauma. Dementia does not fall into this category. A person with dementia is assessed as needing Continuing Care on account of the nature, complexity, intensity or unpredictability of their mental health needs is likely to be very poorly indeed. They are not going to recover. The differences in suffering from dementia arise from differences between patients, not substantial changes over time in the impact of the condition on the individual. My own mother, for example, was in a state of more or less continuous anxiety and distress for six years; I did not witness any diminution in her health care needs at all. But the Continuing Care facility where she lived for the last four-and-three-quarters years of her life became her “home”: even if she could not name the institution or the people who looked after her, in some sense she became familiar with that physical space and the particular human voices, routines of care and method of caring she experienced there. Had her Continuing Care been withdrawn after reassessment, she would have lost her “home”. Or, perhaps she might have been granted Continuing Care for three months, then been refused it and moved out of her facility, then at some later stage moved back in again. It is hard to think of any state of affairs more likely to increase the suffering of the people involved and of their families than the uncertainty afforded by 3-monthly reassessments. It is widely accepted that moving any person with dementia often makes their condition worse. There is also substantial research evidence to show that relocating any institutionalized elderly people to a new residence can have a dramatic effect on their mental health and life expectancy. The policy thus seems to me cruel in the extreme but also unrealistic because it is bound to become swamped in lengthy and expensive appeals. I do not disagree that people receiving Continuing Care should undergo reassessment, but the period between reassessments needs to be carefully thought out in relation to the type of patient involved.

I urge the committee to recommend that the government’s new national framework on Continuing Care should make it absolutely clear that the purposes of Continuing Care are those set out in circular HSC 2001/015: LAC (2001) 17. I do not believe that Kent and Medway is an isolated case. Thus the eligibility criteria of Bedfordshire and Hertfordshire Strategic Health Authority, for example, include provision for three-monthly reassessments and devote one of their three categories of candidates for Continuing Care to people exhibiting “Highly Challenging Behavior”.

I also urge the committee to consider aspects of Continuing Care other than eligibility in putting forward their recommendations to government. These are as follows:

## **Choice**

I believe that if a person is granted Continuing Care and that care is to be received in an institution - a Continuing Care facility run by a health trust or a care home with which the trust has a contract - then the person to receive care, or their representative if they lack mental capacity, should be consulted about where the person is to be placed. When my mother was first awarded Continuing Care in 2000, I was simply informed of the name and address of the facility where that care would be delivered: I was not given any information about the range of possible venues, still less any choice over which of these would be my mother's future home. This denial of choice flies in the face of the government's current focus on the provision of choice in health care. I cannot see why a person granted Continuing Care cannot be offered choice of location in the same way that, if a person is to go into a care home and social services is to pay the fees because the person's own financial resources fall below the £20,000 threshold, then it must allow the person involved a choice of home, as set out in the Direction of Choice circular (Department of Health (1992), The National Assistance Act (Choice of Accommodation) Directions, Local Authority Circular (2) 27).

This denial of choice in the location where Continuing Care will be taken also reflects a failure to acknowledge that the places where people receive Continuing Care become their homes. Many elderly people receiving Continuing Care have dementia and, if such people receive sufficient food and liquid and an equable temperature, they can live for many years, as did many of the residents of my mother's Continuing Care facility. However, NHS Continuing Care units (unless they fall within a nursing care home) are treated as "health" rather than "social" care and as a result often lack the attention paid in good care homes to the provision of activities such as gardening, crafts, dance, games and short outings which can make the lives of residents more interesting and rewarding: in their absence, every day is an almost exact replica of the day before. Attention to such matters would also make Continuing Care establishments more interesting and attractive for visitors. Encouraging visiting by family and friends is particularly important in the field of dementia. People with dementia benefit greatly from one-to-one reassurance. Even in Continuing Care establishments, staff are unlikely to have sufficient time to engage in this contact for as long as is desirable; relatives and friends may have much more time at their disposal. Furthermore, they can provide a vital link with the past for a person with dementia and in this way help to reduce or at least mitigate the disorientation caused by progressive loss of memory, language and cognitive powers.

NHS Continuing Care units have been told in a letter from the Department of Health that they should take note of the national minimum standards for care homes and themselves review their services to ensure that they meet them. In a letter concerning the Care Standards Act 2000: National Minimum Standards – Care Homes for Older People, CI (2001) 4, March 2001, the Chief Inspector, Social Services Inspectorate of the Department of Health stated: “Local authorities and independent providers of care homes and any NHS trusts which provide residential care homes should take note of these standards and review their services so that they are prepared to meet these standards when they are implemented”.

The committee may care to consider whether this instruction should be included in new national guidance on Continuing Care, whether it forms part of a new national framework or comes in some other form. They may care to bear in mind that NHS Continuing Care units do not receive inspections or even visits from the Commission for Social Care and Inspection in the way that care homes do. Such visits to Continuing Care facilities as may be made by the Commission for Health Improvement as part of its rolling programme of inspecting health trusts involve a different approach from the inspection of care homes. CHI officials are unlikely to pay much attention to the extent to which such facilities provide acceptable “home” environments, unlike the announced and unannounced CSCI inspections of care homes in which inspectors examine not only the physical care of residents, but also their emotional care and whether they are given the opportunity to lead interesting lives. Furthermore, the CSCI can require instant change if it is concerned about what it discovers. The CHI has no similar powers of enforcement.

Some people receive Continuing Care in their own or a relative’s home. They are also denied choice in a different area. While people receiving community care services through social services have the option of managing their services themselves under the Direct Payments System, (and indeed social services departments are now legally required to offer the Direct Payments option), people receiving Continuing Care at home are told by health authorities that it is not possible to receive that care through Direct Payments. The Direct Payments system allows the user choice over who provides a service, the nature of that service and how and when it is provided; I believe that people with Continuing Care (or their representatives if they lack mental capacity) should have this choice just like those whose needs are less intense.

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This state of affairs has significant repercussions. People who receive Continuing Care at home often have a fitter person, such as a partner, living with them who acts as their de facto carer as they are on hand for 24 hours a day, including the many, often extended periods, such as night-time, when care workers and district nurses are absent. Yet in one case I know well this de facto carer is not classed as a "carer" as he would be if the cared-for person (his wife) received community care services administered by social services. As a result, he is not entitled to carers' financial benefits like Carer's Allowance and the Carer Premium. De facto carers like this elderly man may well not receive a carer's assessment as they would were community care services involved. Finally, and perhaps most importantly, the pretence that visiting care workers and nurses can provide all the care that is needed to deliver Continuing Care at home means that these de facto carers are likely to receive little, if any, training. They deserve proper training, both in the care of the cared-for person and in the steps they can take to ensure that caring does not jeopardise their own health. A fortnight's training would seem to me to be a minimum.

I should be delighted to elaborate on any of these points to the committee.

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