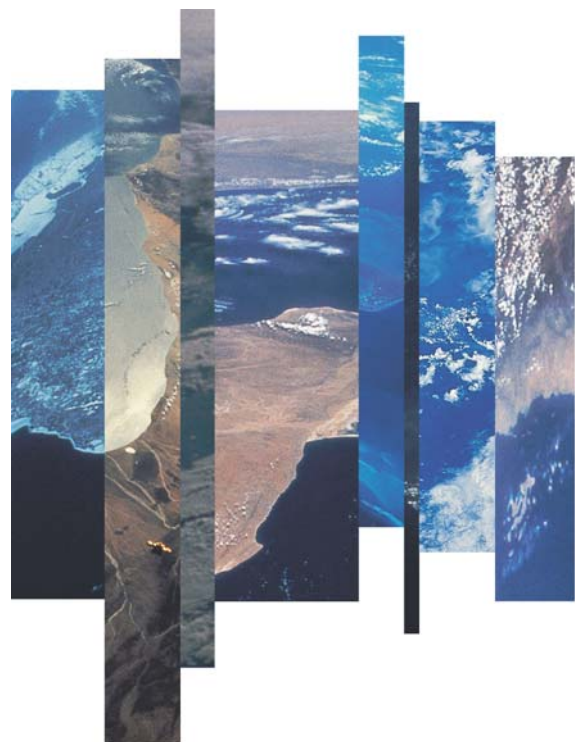




Melanie Henwood Associates
Health & Social Care Consultancy

Background Paper for BBC Panorama
**Self-funding of long-term care and
potential for injustice**

March 2006

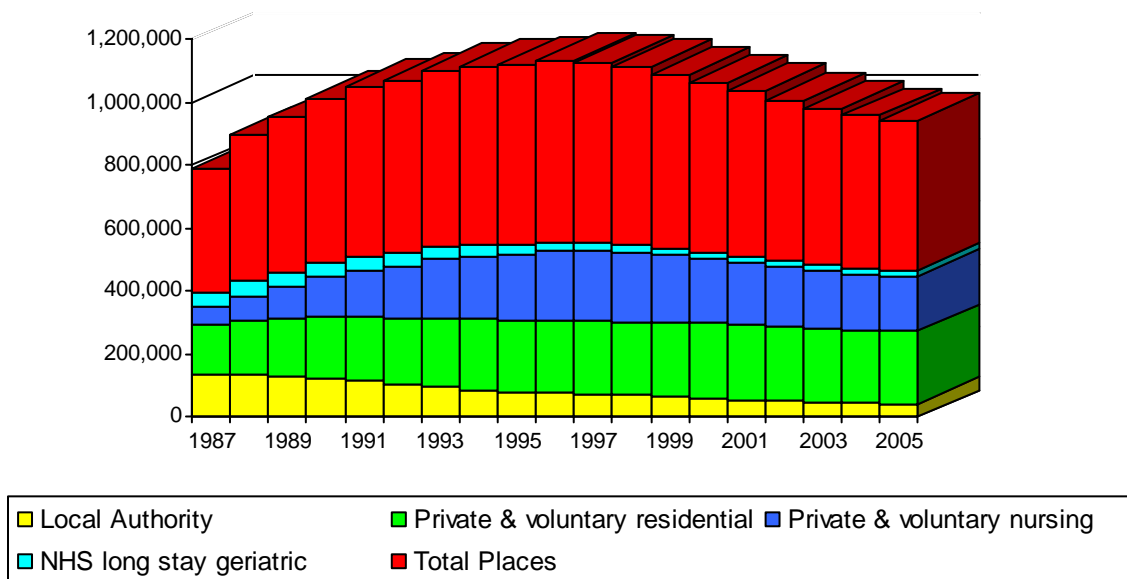


**Self-funders and long term care:
A note on numbers, houses sold to pay for care & associated legal issues**

1 Introduction

- 1.1 One of the key issues that arises in discussions of long term care concerns the numbers of people who are obliged to sell their homes to pay for care, and how many of these that might have been ‘wrongly’ sold because the people should in fact have qualified for NHS funded continuing health care (ie care free of charge).
- 1.2 This is a complex territory and it is likely that only the most basic ‘guesstimates’ can be indicated. However, this note explores some of the facts and figures that need to be taken into account and offers some tentative conclusions.
- 1.3 Before examining some of these issues it is important to outline the context to the debate on long term care. Over time there has been a significant shift in the nature and location of long term care provision for elderly people and others needing permanent residential care. While many long stay hospital wards have closed there has been an expansion of residential and nursing home provision, particularly in the independent (private and voluntary) sector. The graph below charts these trends over the last 20 years.

Nursing, residential and long stay hospital care, UK 1987 - 2005



- 1.4 An inquiry by the House of Commons Health Committee in 2005 observed that in many respects these trends are positive and offer a better quality of life, but “*it has also meant that increasing numbers of people who would previously have received free NHS care, are now cared for in private, fee-paying residential or nursing homes*” when previously they would have been cared for in community hospitals and “entirely funded by the NHS.”¹
- 1.5 Whether a person receives long term care from the NHS or instead enters the means-tested social care system depends on whether they satisfy eligibility criteria for NHS continuing health care. These criteria were introduced in April 1996 following guidance issued the previous year by the Department of Health. Health authorities were required to develop their own eligibility criteria for continuing health care having regard to the complexity, intensity or unpredictability of a patient’s health care needs, and their need for regular supervision by a consultant, specialist nurse or other member of the NHS multi-disciplinary team.
- 1.6 Concerns about the apparent unfairness of the system which saw people having to fund all or part of the costs of their care which they believed they would receive from the NHS, were an important part of the background to the establishment of the Royal Commission on Long Term Care in 1997. The Commission reported in 1999² and recommended that all nursing care and personal care should be provided free of charge (and funded through taxation), while people should be means-tested for the living and housing cost components of their residential accommodation.
- 1.7 The Government did not accept the central recommendation on removing personal care costs from means-testing, but did address anomalies that had been identified which meant that people accommodated in nursing homes were effectively paying for nursing care which they would receive free of charge in any other setting. In order to resolve this the Registered Nursing Care Contribution (RNCC) determination was introduced from October 2001 and established three bands of need for nursing care (low, medium and high) that would be paid for by the NHS (currently at the rates of £40, £80 and £129 per week respectively).
- 1.8 Since 1996 there has been repeated challenge to eligibility for NHS continuing care. Problems have been identified around the way in which criteria have been interpreted

¹ House of Commons Health Committee (2005), *NHS Continuing Care*, Sixth Report of Session 2004-05, Volume 1, HC 399-1, London: The Stationery Office.

² Sir Stewart Sutherland (1999), *With Respect to Old Age: A report by the Royal Commission on Long Term Care*. Cm 4192-1, London: The Stationery Office.

and applied in ways that are too restrictive. The NHS Ombudsman has become increasingly involved in responding to individual cases where patients and their families have disputed decisions that they do not qualify for continuing care, and there have been a number of high profile cases taken to judicial review.

- 1.9 It is against this background that the question of selling homes to fund long term care, and the legality of the system that leads to this requirement, is considered.

2 How many homes are sold to pay for care?

2.1 Around 20,000 people in England have their long term care costs met entirely by the NHS because their primary need is for health care (i.e. they meet the criteria for NHS continuing health care). In addition to these there are more than 350,000 people resident in care homes. Some of these will be supported by the local authority and their care costs will be met because they have insufficient capital and income to meet the costs themselves. There is a national framework for determining what contribution people should make towards the costs of residential care. Anyone with capital greater than £20,500 has to pay the full costs of their care and accommodation; below this level a contribution is calculated based on capital and income; capital is disregarded below £12,500. With certain exceptions, the value of a person's home is counted within their capital assets. A deferred payment agreement may be allowed if a person does not wish their home to be sold; this leads to a legal charge being placed on the value of the property which the council will claim back at a future date when the property is sold (usually following the death of the person).

2.2 A figure of 40,000 homes being sold every year to pay for care is frequently quoted. The source of this figure is *not* the number of self-funders in nursing homes (estimated at 42,000 in 2001 when the RNCC (Registered Nursing Care Contribution) arrangements were introduced. Rather, the figure has various – and somewhat confused – origins in different pieces of research.

2.3 The major source for the 40,000 figure estimate is likely to be derived from work more than a decade ago by Professor Chris Hamnett on housing equity and inheritance.^{3 4} This figure was estimated on the basis of some very broad assumptions about home

³ Hamnett C (1995), 'Housing equity release and inheritance' in Allen I and Perkins E (Eds), *The Future of Family Care for Older People*, London: HMSO.

⁴ Hamnett C (1997), 'Housing wealth, inheritance and residential care in Britain', *Housing Finance* No 34 pp35-38.

ownership and entry to residential care, and about the apparent discrepancy between forecasts of the rising number of properties passing into inheritance (because of the growth of owner occupation) and the numbers actually doing so.

- 2.4 Further estimates have been offered by Liberal Democrat MP Paul Burstow who has sent various questionnaires to social services departments in England to establish “how many people were forced to sell their homes in order to pay for residential and nursing care.” This led to an estimate of 70,000 people a year selling their homes. Responses were received by 66 out of 104 councils (64%); only 38 could provide information which indicated that 2,267 people out of 14,041 residents “were known by the local authority to have sold their home” to pay for care. This represented 16% of residents, and the 70,000 figure was generated purely by extrapolating from this estimate nationally. Whether such a crude approach has any validity is debateable since this methodology takes no account of variations in levels of owner occupation.
- 2.5 The latest data on the total numbers of adults resident in care homes comes from the report on the state of social care published in December 2005 by the Commission for Social Care Inspection (CSCI).⁵ In 2003-04 (latest figures) 277,000 adults (all ages) were supported to live in residential homes or nursing care. An estimate of 115,000 places occupied by self-funders was offered by CSCI on the basis of calculated occupancy rates and the number of registered places available. CSCI however, pointed out, that the figure of 115,000 “is likely to underestimate the true level of self-funding” since around 10,000 people are believed to be fully self-funding but have their care managed by the council “*and so appeared in the statistics as council-supported residents.*” CSCI concluded that at least 30% of residential places are occupied by people paying for their own care. How many of these people enter homes each year can be estimated on the basis of average length of stay data which suggest annual resident turnover of around 35-40%.
- 2.6 A further indication of the numbers who might have to sell their homes to pay for care comes from the Government’s response to the Health Committee report on continuing care. The 12 week disregard of property from the means-test for residential care is said to benefit “around 30,000 people a year.”⁶ In addition, there is the deferred payments scheme whereby people can delay selling their homes in

⁵ CSCI (2005), *The state of social care in England 2004-05*, London: Commission for Social Care Inspection.

⁶ *Response to Health Select Committee Report on Continuing Care*, Presented to Parliament by the Secretary of State for Health, July 2005, Cm 6650, P.7.

order to meet care costs; it is not known how many people use this scheme nationally.

- 2.7 These various estimates suggest a range of figures on the likely numbers of properties that have to be sold each year to pay for residential care. Precise figures are unavailable because information (for example on deferred payments) is not collected centrally. However, it would seem reasonable to conclude that the number of homes sold each year to pay for care probably *is* somewhere in the region of 40,000.

3 How many homes are ‘wrongly’ sold?

- 3.1 A second question which arises is how many, or what proportion, of these cases may have illegally required people to sell their homes. Essentially this is the issue about the numbers of people who may have been wrongly denied fully funded NHS continuing care either because the criteria used by their Strategic Health Authority were wrong, or they were wrongly applied by a Primary Care Trust which did not follow the test of a ‘primary health need approach’ (whereby if a person’s primary care need is a health one, the NHS will be responsible for meeting it). The primary health need criterion was established by the Coughlan judgment of 1999 (R Vs North and East Devon Health Authority ex parte Coughlan). The most recent judicial review which has challenged the legality of decisions on the basis of the Coughlan case is the Grogan judgment published in January 2006.⁷
- 3.2 The Grogan case featured a Claimant who had been judged not to qualify for NHS continuing health care; she challenged this decision on the basis that the assessment was flawed because it was based on criteria that were flawed. The Grogan judgment examined the confusion that arises between the RNCC definitions (particularly for the high band) and the definition of eligibility for NHS fully funded care. The judge acknowledged the “understandable confusion and dissatisfaction” of others (including the Health Select Committee and the Health Service Ombudsman) that the definitions of the bandings (particularly high band) appear to set a *higher* threshold of needs than would qualify a person for NHS continuing care.
- 3.3 The judgment, however, stated that the argument made by the Claimant “*does not lead inevitably to the conclusion that on a lawful consideration, overview and*

⁷ Case No CO/2008/2005, *Maureen Grogan V Bexley NHS Care Trust*.

assessment of all her needs (even if they establish a need for high band RNCC nursing) the Claimant qualifies for Continuing NHS Health Care.”⁸ The conclusion was not that the Claimant automatically qualified for Continuing NHS Health Care, but that the decision that she did not “should be set aside and this question should be remitted to the Care Trust for fresh and further consideration.”

- 3.4 It is not possible to generalise on the basis of Coughlan, or Grogan (or indeed any other case) to estimate how many other people may be in a similar position. However, it is apparent that such cases are not unique. The NHS Ombudsman has been increasingly involved in investigating complaints about refusal of NHS funding for long term care. The Department of Health responded to the Ombudsman’s concerns in 2003 by requiring all SHAs to review whether continuing care criteria in use in their area since 1996 were consistent with the Coughlan judgment, *and* to investigate cases where people may have been wrongly denied continuing care and make appropriate restitution.
- 3.5 The review process was to have been completed by the end of December 2003; this deadline was subsequently extended to 31 March 2004 in recognition of the complexity and time consuming nature of the process. By this date 12,000 cases had been reviewed and full or partial restitution was awarded in 20% of cases at an estimated cost of £180 million. In the wake of the retrospective review, and in response to a request from the Health Service Ombudsman, the Department of Health issued a further letter in November 2005 to ensure *“that the correct process is being used to differentiate between people who receive fully funded NHS continuing care and the high band of NHS funded nursing care.”⁹*
- 3.6 There are a number of arguments about whether the cases reviewed represent all of those that should have been investigated and whether additional cases have been overlooked (hence the letter issued by the Department of Health). That is an unanswerable question. However, the notional figure of 20% of cases being judged to have been unfairly treated in being previously refused NHS continuing care *might* provide some basis for estimating the numbers that have been unfairly required to sell their homes. However, it could also be argued that 20% *over-states the* position since the retrospective review process included cases back to 1996 which pre-dated the introduction of the RNCC process which provided for a more systematic

⁸ Ibid, para 104.

⁹ Department of Health (2005), *Ensuring that all recipients of high band NHS-funded nursing care have been correctly considered against eligibility criteria for fully funded NHS continuing care*, 28 November.

consideration of care needs. If we are concerned here with the present situation (rather than the broader historical trend) it is probable that the proportion 'wrongly' deemed ineligible for continuing care is closer to 5 - 10%.

3.7 Clearly, by no means all of the 40,000 people potentially selling their homes would be entering care homes providing nursing (and it is these with which we are primarily concerned since they will have a higher level of care needs). The people who are most likely to fall into the 'unfairly treated' category are those with high level care needs that have been deemed not to meet the test of primary health need and have instead been assessed under the RNCC banding system. Nationally it is believed that there are between 15 -20,000 people in the high band of RNCC. Let us assume that around 40% of the 40,000 people who sell their homes to pay for care are entering nursing homes; this would suggest 16,000 each year. Some 15% - 20% of these (2,400-3,200) would be likely to fall into the top band of RNCC.

3.8 It is this top band which has attracted most attention and concern that it can potentially overlap with eligibility for fully funded NHS continuing care. Evidence submitted by the Ombudsman to the Health Committee inquiry stated:

*"It seems to us, and is supported by our legal advice, that if a person's needs for registered nursing care are deemed to be at high band RNCC level, it is difficult not to say that that person should also be eligible for NHS continuing care funding, given the similarity of wording...it is difficult to see how a person with health care needs that properly place him or her at high band RNCC would even have reached the stage of an RNCC assessment, had he or she been properly assessed for NHS continuing care. This is because the level of health care needs that warrant high band RNCC would seem to be, at the least, equivalent to those that should qualify a person for continuing care funding, if not higher."*¹⁰

3.9 The confusion which has arisen over the definition of this band does *not* mean that all those people who have been judged to be high band (and some of those in the medium band) would automatically qualify for NHS continuing care on the basis of the Primary Health Need Approach. Indeed, the Grogan judgment states that determining whether the Claimant qualifies on an application of the Primary Health Need Approach requires an assessment of *all* relevant needs which should not be determined by reference to 'generalisations or classes'. Looking at a range of

¹⁰ House of Commons Health Committee (2005), Op Cit, para 93.

scenarios for the proportions of people who might have been wrongly categorised and should have been awarded NHS continuing care could suggest the following:

	5% of top band RNCC	10% of top band RNCC	15% of top band RNCC	20% of top band RNCC
a) assuming 15% in RNCC top band	120	240	360	480
b) assuming 20% in RNCC top band	160	320	480	640

4 **Legality of Criteria**

- 4.1 The estimates above are derived by assuming that a proportion of those in the top band of RNCC might have been wrongly denied fully funded NHS continuing care (estimated on the basis of the proportion of cases successfully awarded restitution in the national retrospective review). This makes a number of assumptions about the legality of the criteria for continuing care and of their relationship with the criteria defining the three bands of RNCC. However, the legitimacy of the criteria has been challenged both by Coughlan, and more recently by Grogan. *If the criteria are not legal (i.e. they do not meet the Coughlan test), then the relationship with the RNCC bands becomes de-coupled. If the criteria are flawed, we cannot estimate the numbers who may have been unfairly treated simply by reference to earlier tests which were predicated on the assumption that the criteria were Coughlan-compliant.*
- 4.2 The Grogan case effectively challenged the Department of Health guidance on fully funded care and that on the RNCC nursing care bandings. As noted above, the Coughlan judgment of 1999 established that where the patient's primary need is for health care, this is the responsibility of the NHS (i.e. fully funded continuing care). The RNCC bands therefore describe nursing care that *is* incidental or ancillary to the provision of accommodation and are of a nature which an authority whose primary responsibility is to provide social services can be expected to provide (and that all the nursing needs including the RNCC could have been lawfully provided by the local authority prior to Section 49 of the Health and Social Care Act 2001).¹¹

¹¹ Grogan V Bexley NHS Care Trust & Others, Op Cit, para 55.

- 4.3 The Grogan judgment examined the logic of the guidance in which a need for nursing care in the high (and medium) bands does not qualify a person for NHS continuing care because the nature and extent of such care does not indicate a primary health need. Furthermore, the guidance holds that not only are these nursing services incidental or ancillary to the provision of accommodation which a local authority is under a duty to provide, but these services are not on a par with the nursing needs of Pamela Coughlan. However, the eligibility criteria used by Bexley NHS Care Trust made no reference to the Primary Health Need Approach, nor to the Coughlan test as to what a local authority can lawfully provide, *or* to the test to be applied by the decision maker (by reference to the Guidance or the Coughlan case).¹² The Grogan judgment concluded that the criteria in use in Bexley were “fatally flawed” in failing to identify the test or approach to be applied in reaching the judgments required. Moreover, it was concluded that the approach of the Care Trust was not lawful since it failed to follow the Primary Health Need Approach.
- 4.4 In remitting the Grogan case to the Care Trust for fresh and further consideration, and setting aside the decision that the claimant does not qualify for continuing NHS health care, the judgment raises fundamental issues about the legality of criteria operating in other Strategic Health Authorities. The then Minister of Health (Dr Stephen Ladyman) stated to the Health Select Committee inquiry that all 28 sets of SHA eligibility criteria for fully funded NHS continuing care were legal and in line with current guidance¹³. The Health Committee challenged this assertion and pointed to submissions which indicated to the contrary that many criteria in use are not Coughlan-compliant. The Grogan judgment adds weight to this conclusion by finding that the criteria in use in Bexley NHS Care Trust (drawn up by the South East London Strategic Health Authority) were not lawful.
- 4.5 The need to reconsider whether criteria for NHS continuing health care across the 28 Strategic Health Authorities *are* legal, and the possibility that they may not be, raises questions about the basis for estimating the numbers or proportions of people who may have been wrongly denied NHS continuing care. The estimate that several hundred people each year might have wrongly been required to sell their home in order to pay for care is based on a central assumption that the criteria being applied are Coughlan-compliant. If this is *not* the case, then logically it must follow that the numbers affected could be significantly higher.

¹² Ibid para 90.

¹³ House of Commons Health Committee (2005), *NHS Continuing Care*, Sixth Report of Session 2004-05, HC 399-1, para 103.

5 Conclusions

- 5.1 The illustrative figures that have been proposed above are riddled with health warnings and cautions. They have been assembled on a 'best guess' basis. It seems likely that somewhere in the region of 40,000 homes are sold each year in order to pay for long term care. A small proportion of people who have sold their homes are likely to be paying for care which they should in fact have received free of charge because they meet the criteria for NHS continuing care. How many people fall into this category cannot be predicted with any real confidence. A range of scenarios suggests somewhere between 120-640 people *could* be involved each year (representing in the region of 1 per cent of those who have sold their homes to pay for care). However, the figures could be significantly greater (perhaps thousands rather than hundreds of people) if the criteria being applied are not actually Coughlan-compliant and do not use a test of Primary Health Need. Whatever the precise numbers, it can be concluded that a significant minority of people entering long term care each year experience a major injustice in being wrongly denied fully funded care and present a challenge that must be addressed by further guidance and the forthcoming national framework for continuing care criteria.

Melanie Henwood



Melanie Henwood is an independent health and social care consultant. She is a lay member of the General Social Care Council; a specialist adviser to the House of Commons Health Select Committee and an adviser to the Older People's Steering Group of the Joseph Rowntree Foundation.

She has held visiting fellowships at the London School of Economics, the University of Leeds, and the University of New South Wales, Sydney. She has more than 20 years' experience in research and analysis, focusing particularly on community care and services for older people and their carers, and is a frequent commentator on health and social care issues in the professional press and on broadcast media.

Before establishing her own consultancy in 1991, Melanie held research posts at the King's Fund (1989-91), the Family Policy Studies Centre (1983-89), and the University of Bath (1981-83).