Final Comments

Probably the most disappointing result of my attempt for retrospective continuing care funding was the attitude that comes across from my dealings with the Health Service Ombudsman (the Ombudsman) that they really 'couldn't have cared less'. It appeared that they were quite content to prop up a flaky system of questionable legality and basically chose to ignore all the points I put to them. Their 'professional adviser' was wrong on so many items and procedural aspects and the fact that previous Ombudsman decisions were ignored resulted in a farcical disregard of justice. Rather than pursuing my mother's case with an open mind, it feels like the Ombudsman decided the result before starting the investigation and fitted the case together in order to reject.

In the general scheme of things, obtaining CHC funding is a postcode lottery. The Suffolk, Norfolk and Cambridgeshire strategic Health Authority places the bar very high indeed (1), and even then, in some cases different PCT's came up with different results so the whole system is somewhat flaky. Each primary care trust has its own complex "eligibility criteria" which it uses to assess whether individuals qualify for this funding package. Eligibility criteria will vary between health authorities. Evidence suggests some health professionals do not even understand these guidelines and even within the same authority, two people with very similar health needs can be assessed very differently when it comes to fully funded NHS care. A report by the charity Carers UK suggests that many trusts are tightening up these criteria and only the pensioners with the most severe health needs now get full care.

The past involvement of the Ombudsman, who investigated numerous complaints which led to a significant number of 'benchmark' cases produced a number of reports, although not legally binding, provided clarification of many issues and steered the path for funding reform. These have been based around the 'reasonableness of the process followed' or incorrect clinical decision making so one would presume that there is a reasonable expectation in appealing to the Ombudsman, they would stick to their previous decisions. Not so it would seem

In February 2003 the Health Service Ombudsman published a report (2) entitled 'NHS Funding for long term care' drawing attention to a significant number of complaints investigated regarding eligibility criteria used by health authorities during the period from 1996 to 2001.The report concluded that the health authorities were using over-restrictive eligibility criteria that were not in line with the Department of Health guidance or with the Coughlan Judgment. The report highlighted, amongst others, the following: -

- Allowing health authorities to develop their own local criteria lead to variations in eligibility across the country leading to a postcode lottery.
- There was a need to develop a clear, well-defined national framework
- There was a need to ensure staff had detailed guidance and procedures on the assessment of patients and the application of eligibility criteria.
- The report also published the findings of four investigations into complaints about the way health authorities set and applied their eligibility criteria.

In June 2001, Continuing Care: NHS and Local Councils responsibilities (3) was issued which required all 95 Health Authorities (as they were at the time) to agree a joint continuing health and social care eligibility criteria with local authorities. The guidance indicated the key issues to consider when establishing criteria, some of which are relevant as follows:-

- Whether the nature or complexity or intensity or unpredictability of the individual's healthcare needs (and any combination of these) 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.
- Whether the individual has a rapidly deteriorating or unstable medical, physical or mental health condition and requires regular supervision by a member of the NHS multi-disciplinary team.
- Whether the individual is in the final stages of a terminal illness and is likely to die in the near future
- The location of care should is not the sole or main determinant of eligibility. Continuing NHS healthcare may be provided in a hospital, residential home, nursing home, hospice or the individual's own home.
- Eligibility criteria, application or rigorous time limits for the availability of services by a health authority should not require a council to provide services beyond those they can provide under section 21 of the National Assistance Act 1948.

Additionally, in the National Framework, assessments of eligibility should be organised so that the person being assessed and their representative understand the process, and receive advice and information that will maximise their ability to participate in informed decision making about their future care. Procedurally, these also apply retrospectively. An assessment for eligibility should be considered: -

- On discharge from hospital and the client is not being offered rehabilitation or other NHS funded services that may lead to an improvement in the condition.
- If physical or mental health deteriorates significantly and the current level of care seems inadequate whether at home or in care.
- When, as a resident of a nursing care home, the nursing care needs are being reviewed (which should be done at least annually).
- If there is a rapidly deteriorating condition with an increasing level of dependency and the person may be approaching the end of their life. This End of Life' Care (Fast Track Pathway Tool) is to ensure that people with a rapidly deteriorating condition, and may be entering a terminal phase, with increasing level of dependency, are supported to be in their preferred place of care as quickly as possible. The NHS has responsibility to provide care fees for people in the final stages of a terminal illness. This can be provided in a hospital, hospice, care home or in the person's own home. People who require palliative care, as they are in the final stages of a terminal illness, must be 'fast-tracked' for immediate provision of NHS continuing healthcare

So the above references summarise in general terms the principles that you might think would be adopted by the Ombudsman. Elsewhere on this site are details of my complaint to the Ombudsman, their report and my comments disagreeing with their report. In relation to the above, I will summarise the issues I have with the Ombudsman decision and the inescapable conclusion of feeling very let down by total lack of support and understanding from this authority.

1. There is no getting away from the fact that the criteria used to assess my mother by Suffolk SHA were totally non-compliant with the Coughlan ruling and hence illegal. The Ombudsman had complained enough about over-restrictive criteria used by some health authorities and indeed the DoH had provided guidance on this. So we have the ludicrous situation where, in my mother's case, the Ombudsman was in effect upholding the illegal assessment criteria used by Suffolk SHA. It is impossible to see that the Authority's criteria, which were not changed in the light of the Coughlan judgment, are compatible with it.
2. The unnamed adviser used by the Ombudsman mixed up the health needs of Couglan with a 'home for life promise' which is fundamentally not the case as far as CHC funding is concerned. The so called "health needs test" is nothing to do with a "housing needs test". The advisor's view of the Coughlan case, the "health needs test" or "primary needs test" was not that adopted by the court of Appeal in Coughlan, it did not lay down the "primary health needs test". I question the competence of this advisor. Also the advisor said that (Coughlan) case law compliance has been embedded in the National Framework. This presumption has not been tested in law but retrospective case studies have shown that the bar in the National Framework is too high to claim Coughlan equivalence.
3. On discharge from hospital, my mother was not assessed as was her entitlement. That the NHS had an obligation to fund my mother's care because, were it not for the falls she sustained in hospital, the unnecessary psychotic medication and mobility restrictions she may not have needed to go to the care home.
4. One aspect of my mother's Alzheimer's was that, by definition, the condition was unpredictable and likely to deteriorate in time in-line with her continuing care needs. However, no allowance for this was made in any of the SHA/IRP or Ombudsman reviews which on the face of it seems strange seeing as how Suffolk Social Services were insisting that she needed extensive nursing care and were threatening to section her under the Mental Health Act because of her healthcare needs. You would think therefore that this implied a continuing healthcare need and funding eligibility.
5. One of my complaints to the Ombudsman was that the Chair of the IRP refused to let me make a full statement. The Ombudsman said that there was no evidence of this....but in fact there was. I sent in a full statement to the IRP before the review, a copy of this was sent to the Ombudsman. A comparison of this statement with the IRP minutes would clearly reveal missing items.
6. To follow on from 4), at the end of her life my mother was receiving palliative care. The NHS has responsibility to provide care fees for people in the final stages of a terminal illness. This can be provided in a hospital,

hospice, care home or in the person's own home. People who require palliative care, as they are in the final stages of a terminal illness, must be 'fast-tracked' for immediate provision of NHS continuing healthcare. The question is why did the Ombudsman not even consider this aspect of my complaint?

7. In the Ombudsman's report, it confirms on a number of occasions that the IRP reached 'a reasonable decision' regarding my mother's case but it was the SHA that was using illegal criteria and should have been the subject of the complaint. Not the IRP, who were only investigating whether procedural rules were applied correctly.
8. The chances of eligibility success vary according to one's postcode. Different PCTs interpret the rules differently. By way of example a survey by Community Care Magazine found that 40% of completed challenges were successful. The number of appeals rose by 9% from 2009-10 to 2010-11 while the proportion of successful completed challenges rose from 33% to 40%, a freedom of information survey of 49 primary care trusts or PCT found that within these figures there were significantly different rates of successful appeals. Suffolk has a poor record (4). Some cases will score lower than some in the full CHC assessment and this shows that even if a person doesn't show obvious signs that they are difficult to look after, they can still be found eligible if their needs are taken as a whole.
9. One thing that is very difficult to understand and to a large extent explains the difficulties I have with the Ombudsman is that on the one hand whilst the Ombudsman is prepared to uphold complaints and criticise assessment tools in favour of complainants with seemingly similar or worse medical conditions than my mother, in my mother's case the Ombudsman seems to be upholding the very system originally complained about? **This is grossly unfair**. The healthcare guidance prior to Coughlan was shown to be wholly inadequate by that case and the replacement 2001 guidance was rejected as wholly unfit for purpose by the Health Service Ombudsman, the High Court, the Health Select Committee and many other commentators. So how come the Ombudsman continues to uphold it?
10. Using decided cases as comparators, they illustrate Ombudsman bias toward my mother's case:-
    - Leeds Ombudsman Case Report E62/93-94; .....this criticises continuing care statements placing an over-reliance on the needs of a patient for specialist medical supervision in determining eligibility for continuing in-patient care. This was exactly the case with Suffolk SHA eligibility criteria but made no difference.
    - Dorset Health care NHS Trust case E208/99-00.....this person had Alzheimer's and was admitted to a nursing home receiving services similar to Pamela Coughlan's.....the Health Service Commissioner found that funding for continuing care had been wrongly refused since this person had a degenerative condition likely to qualify for eligibility as time went by. The Ombudsman made no such allowance for my mother in the same circumstances.
    - Berkshire Health Authority case E814/00-01108.....if appropriate criteria gad been applied in the first place this person would have qualified for fully funded care.
    - Birmingham Health Authority case E1626/01-02.....if assessment criteria which were in line with the then guidance and the Coughlan judgement this person may well have been deemed eligible for NHS funding.
    - Shropshire Health Authority case E5/02-03110...in this case the Ombudsman had the benefit of an independent clinical assessor to state that this person needed full assistance with all her personal tasks, not properly regarded as merely incidental or ancillary to accommodation. The Ombudsman made no such allowance for my mother.
    - South Cambridgeshire NHS Trust case E22/02-03....assessment tools were skewed in favour of physical and acute care, a criticism upheld by the Ombudsman.
    - Torbay Care Trust 2007**...**A Mr Pearce argued that his mother's case met with a second exception to the rule: that her condition was so poor that her 'primary' need was to be nursed. As the Alzheimer's Society put it, 'being incapable of doing anything but chewing and swallowing'. Mr Pearce battled through various appeals hearings and finally convinced the Health Service Ombudsman.
    - NHS Worcestershire 2009..... Judith Roe was extremely ill. She couldn't make a cup of tea and forgot she had put food on the stove. It was clear she needed full-time care. Her son wanted to know just how ill his mother had to be before her condition was deemed a health issue. After a five-year battle, the Health Service Ombudsman ordered NHS Worcestershire to reimburse care fees.

- And there's more....

THE RULING THEY IGNORED

THOUSANDS of people a year have to sell up their homes to fund nursing care because a legal ruling ten years ago is being widely disregarded, it is claimed.

Many families are paying for care they should have got free of charge although they do meet the criteria for NHS 'continuing care'.

The row centres on the interpretation of the term 'continuing care' by primary care trusts, which have to foot the bill. If a trust decides the individual does not qualify for free NHS care, the costs have to be met by the family after means testing.

A Court of Appeal ruling in 1999 made it clear that when elderly people needed long-term care because they were ill, health authorities had to pay for both their nursing care and 'personal care', which covers help such as dressing and washing.

The landmark case which led to national guidelines was named after Pamela Coughlan, pictured, a former art teacher who was paralysed as the result of a car accident.

Means test rules in England state that anybody who has been assessed as being ineligible for nursing care must pay for residential care, as long as they have assets worth more than £23,000. Those who fall below the threshold, or who pay their own bills until they do, are eligible for NHS help. A home is disregarded if a spouse is living in it.

In Scotland, the NHS foots the bill for all care but families must pay for the 'accommodation' element.

References

(1) Vindlacheruvu. M., et.al., NHS Continuing Care: Reliable decisions? J.Age Ageing (May 2006) 35 (3): 313-316 Research letter

(2) Health Service Ombudsman., Session 2002/3., NHS funding for long term care., HC399.

(3) DoH., Continuing Care: NHS and Local Councils responsibilities (HSC 2001/015) LAC(2001)18

(4) Wigens L., Health Overview Scrutiny Committee., NHS Suffolk., January 2012