

SECTION 3: Your complaint

We need to know what happened and why you are unhappy with the response to your complaint. Please attach additional sheets of paper if you need more room to set out your complaint. Please do not just say 'see attached' and provide copies of previous correspondence. If the organisation has not addressed all of the issues raised in your complaint, then we may decide that there is further work for the organisation to do before we look at your

6. Please briefly explain what your complaint is about:

My Mother had Alzheimer's Dementia. She was admitted to hospital on the
24th. April 1998 for observation wher her condition deteriorated
significantly. She became frail, immobile, agitated, doubly incontinent and quite dissociated
from her surroundings and in quite a poor state
In September she was moved to a Care Home. The NHS discharged her
without any CHC assessment or clinical review of her needs, becoming the responsibility of
Social Services. Consequently she was forced
to pay for her care until her death in 2002. The local authority
struggled to meet her needs. Because all her needs arose from a cranial illness, the NHS should
have been responsible for her care package.

7. Why are you still unhappy following the response(s) from the organisation(s)?

Suffolk PCT rejected my retrospective appeal for funding, a decision upheld by NHS England.
Midlands and East IRP. However, their assessment process was based on 'eligibility criteria'
that are not 'Coughlan compliant'. I have enclosed a covering letter and a few documents in
support of my case which outline the historical basis for this
application.

8. Has the organisation responded to all the issues raised in your complaint?

If the answer to this question is NO, then please set out below the issues that have not been addressed.

The problem here is that Suffolk PCT criteria for continuing health care funding are based on complicated eligibility criteria such as 'nature intensity, complexity and unpredictability' of an illness in conjunction with a yes/no qualification of extreme behaviour or disturbance of _____ elderly people with dementia. None of this has any relevance to the Coughlan judgement. I attempted to raise the issue of Coughlan _____ compliance with the IRP but the Chairman refused to allow this as _____ it was not part of their remit.

9. How have you, or the person you represent, been affected by what happened?

Very frustrated at all the road blocks presented during the process of this claim.

Agnes [REDACTED] – Retrospective Request for Continuing Care Funding

My mother was first diagnosed with dementia problems in January 1996 and received a support service from Age Concern (ACCESS) an organisation working for Ipswich Social services at that time. As part of the service for elderly mentally confused people she attended an NHS Day Care centre twice a week at Minsmere House in Ipswich. There she was assessed by a Dr.T.Nejo who prescribed Stelazine (Phenothiazine) early 1996 until at least May 1998. Stelazine is an anti psychotic drug which produced Parkinsonian side effects, shakes, mobility difficulties and eating difficulties. Despite the fact that I registered concerns on several occasions, the lack of concern from Dr.Nejo bordered on the irresponsible. I should have complained formally about his treatment of my Mother, in retrospect I should have done so at the time. In August 1997 she was seen at Minsmere House by another psychiatrist Dr.Stevens, who prescribed Aricept which seemed to keep her condition stable. About this time she confirmed that she might like to go into a Care Home as I think she recognised it was getting risky for her at home on her own. She was offered a 10 day short term trial visit to a Local Authority Care home at [REDACTED], Ipswich on the 22nd.June 1998.

However, on the 24th.May 1998, my mother decided, totally out of character, to go on a long walk, became totally disorientated and confused, and was taken into Heath Road Hospital, Ipswich for observation. Apart from her **confusion, she was otherwise healthy and mobile**. Subsequently it was found that she had bowel cancer and was operated on in July under general anaesthetic. This was likely to have contributed to her general decline. In hospital, the Aricept and Stelazine were stopped. On the 10th.August 1998 she was moved to Hartismere Hospital, Eye, Suffolk. In September 1998, she was discharged from hospital. In a provider assessment report dated 30/10/98 it clearly states that after discharge from hospital. my Mother was'**in quite a poor state, frail, immobile, somewhat agitated, confused and rather disassociated from what is going on around her....**' When eventually discharged she was in a "**very poor state**". Because my Mother was now **disabled and also incontinent**, a continuing care assessment should have been done prior to hospital discharge but was not. The NHS was therefore clearly negligent in this regard. Leaving aside the colonic cancer, my mother went into hospital mobile, anxious and confused with her dementia illness. She came out of hospital disabled, immobile, arthritic, incontinent having difficulty in feeding herself and no less anxious and confused with Alzheimer's.

At Heath Road Hospital, Ipswich, her condition got worse. Before admission she was reasonably mobile and could support her own weight. Her dementia was also stabilised with the use of Aricept. However when in hospital:-

- She was taken off Aricept although it had provided a stabilising effect on her condition in the preceding 10 months.
- She developed further mobility problems and kept falling over as she was not carefully monitored by nursing staff. Nurse assistance was poor.
- She was given a special chair for sitting in which by virtue of its design prevented her from standing up.
- She was no longer able to feed herself.
- See Document #1; Letter to Jackie [REDACTED] 24-6-98.
- She was found to be anaemic.
- A catheter was inserted
- A Dr Head gave my mother a cocktail of 3 drugs for schizophrenia, insomnia and psychosis, Risperidone, Temazepam and Melleril.
- The drug cocktail did nothing to help her mobility and muscle condition.
- See Document #2; Letter to Dr.Sheehan, 11-8-98.

In not providing a continuing care assessment before discharge, the NHS was negligent in not identifying my Mother's nursing care needs. Prior to hospital discharge the NHS should have been required to complete a 'Multi-disciplinary assessment' (MDA) to determine what on-going care is required and where and by whom it can best be provided. It would appear that the NHS by default chose to transfer responsibility onto Social Services without the due process of assessment that my Mother was entitled to. There was clearly no agreement to discharge my Mother from hospital. It seems to have been assumed that since my Mother had a trial place agreed before her stay in hospital that she could be discharged to the same local authority care home on a permanent basis. Further to this the NHS did not make it clear to Social Services the proper tests they should apply before deciding whether my Mother should remain the responsibility of the NHS or be means tested by Social Services.

At this point it is worth pointing out that neither my wife nor I had ever come across anyone with Alzheimers in our lives. Consequently we knew very little about the condition, its effects and the responsibilities of the NHS with such an illness. Also as we lived 150 miles from Ipswich, it was difficult enough with a full time job to see my mother as often as I would have liked but I would have made a better effort had I realised she was in a far worse medical condition than I had been told. I was very dependent on those in charge of my mother's care keeping me informed but realistically this just didn't happen. In retrospect, I often made decisions based on inadequate or simply incorrect facts.

I was informed by Social Services that my mother's transfer to [REDACTED] Residential Home for Older People, Ipswich, Suffolk on the 4th.September 1998 was simply the take-up of the previously agreed care place. However, I was not totally aware of her true medical condition but in #7, I made it clear that hospital discharge in the condition reported to me, was against my wishes. The care home Manager, [REDACTED] [REDACTED] apparently agreed to take her into the Home Special Needs Unit as long as she was weight bearing. But in fact my Mother was 'disabled' and could no longer support her own weight. It is questionable whether Social Services should have accepted my Mother when they went against their own admission criterion of the patient being able to support her own weight. It seems that Social services did not look at the totality of my Mother's needs before taking responsibility for her. I was not involved in any of this decision making and we were not informed of how the Care Home provided for people with dementia.

From the 4th.September 1998 to her death on the 6th.November 2002, my Mother was resident at [REDACTED]. On the 20th.October 2004 I lodged a retrospective claim with Norfolk, Suffolk and Cambridgeshire SHA. My claim was heard by the Retrospective CHC Panel, Suffolk Primary Care Trust on the 30th.May 2012. The reason for the long delay in the timescale was simply that documents were lost and not followed up in a timely manner. My claim was refused. An Independent Review was held on Wednesday 28th.August 2013 by NHS England, Midlands & East, Cambridge. The IRP upheld the original SHA decision.

The following items are relevant to the case:-

- i. Document #3: Suffolk NHS PCT 30th.May 2012 meeting minutes, Eligibility Criteria documentation and 2012 Primary Health Needs Test summary. (Please note: any highlighting in this document has no relevance to the current complaint.)
- ii. Document #4: Statement dated 16th.August 2013 for IRP 28th.August 2013
- iii. Document #5: IRP review minutes 28th.August 2013-10-11 and IRP Comparison of Assessment Domains and National Framework summary.
- iv. Complete documentation package prepared by the SHA. This is an extensive package, 625 pages in total which covers the complete history of my Mother's illness from the initial dementia diagnosis, her pre-hospital care, her stay in hospital, discharge to [REDACTED]e Care Home, various assessments, the decline in her condition, medication regimes etc and her final days. This package is not enclosed. If necessary I could send a copy or preferably contact NHS England, Midlands and East at Fulbourne, Cambridge.

30th May 2012 Suffolk PCT Review

Prior to this meeting I was not sent a complete documentation package, although I was able to ask for certain pages identified by the initial summary document. I attended the meeting and was asked a lot of questions about my Mother's condition but in retrospect this was not very satisfactory from my point of view since I was not very close to my Mother's care and I did not have the benefit of the complete documentation package. The meeting Chair stated that the Panel would be applying the 2002 Norfolk, Suffolk and Cambridgeshire local SHA eligibility criteria for NHS funded CHC in line with the 2007 Decision Support Tool. However, the meeting minutes did not record any remark regarding the 2007 Decision Support Tool.

The panel decision seems to have been based on a yes/no tick sheet for behavioural disturbance/violent behaviour/disinhibited sexual behaviour/inappropriate defecation/frequent medical interventions etc., which seems to place health care needs at an absurdly high and inappropriate level.

The PCT have also provided a subjective document related to the concept of 'nature, intensity, complexity and unpredictability' of a health need. However, in studying the full documentation package which was subsequently sent to me, the PCT panel managed to get a few facts wrong:-

- a) It states that Ms. [REDACTED] was able to weight bear. This is fundamentally incorrect and there is multiple evidence in the documentation package to the fact that she **could not weight bear**.
- b) It states that transfer was with the support of 2 carers and a handling belt. Normally 2 or 3 carers were present and a hoist was used
- c) It states that there is no evidence to suggest Ms. [REDACTED] was at a risk of choking. **This is not the case**. 18 instances were recorded of my Mother putting too much food into her mouth and trying to swallow between 27-10-98 and 15-9-01. In addition there are 4 records of my Mother vomiting in bed in 1999 and 4 records in 2000.
- d) It states that Ms. [REDACTED] skin remained intact during the period being assessed. **This is not correct**. There are instances of skin blistering.
- e) It states that Ms. [REDACTED] needs were not particularly intense, lengthy or frequent. From the daily care record provided in the documentation package, the daily routine for my mother's care required **7.3 carer hours (min)** to 8.5 carer hours (max) over a daily 24 hour period.
- f) It states that 'there was a need to monitor for signs of constipation and to administer laxatives on a required basis'. In 1999 my Mother had 15 District Nurse visits and 12 enemas administered. From December 2001 to October 2002, my Mother had 670 doses of Lactulose given, 340 doses of Sphagula and 300 doses of Senna. Note! Although I have quoted from the 'daily care record', in reality there are not comments or records on every day. For example, in 2002, there are 69% of possible day records and about 40% in other years. The nighttime records are much lower, around 15%. Hence, incidences could have been somewhat higher.

IRP Review Statement; 16th August 2013

The IRP panel review was scheduled for the 28th.August 2013 although I applied for the review on the 6th.August 2012. In order that my comments regarding the initial PCT findings could be circulated to the IRP Panel members, I submitted the above document on the 16th.August. Prior to the meeting I was informed that the IRP could only look at PCT procedural issues and the application of the National Framework and/or SHS eligibility criteria. These aspects are covered in detail in the letter. With the full documentation package relating to my Mother's care now at hand, I took the opportunity to study this in detail and complete an assessment of her care needs based on the National Framework using the DOH Decision Support Tool, Appendix A. I used the Care Domain sheets to define my Mothers level of needs based on the various assessments and daily care records at [REDACTED] from 98 to 1-1-2002. The result is that my Mother **was** eligible for CHC funding since there were 2 incidences identified as severe across all the care domains.

IRP Review, 28th.August 2013

Please see the IRP review minutes. The **review was thorough and provides a good summary of the case**. Now whilst the IRP could only review the application of the local SHA criteria (which were assumed to be Coughlan compliant) they upheld the decision of the Retrospective CHC Panel, Suffolk Primary Care Trust. However, the Panel noted that the PCT's completion of the primary health needs test was confusing in parts and whilst the case was assessed against the Norfolk, Suffolk and Cambridgeshire SHA criteria, it might have been appropriate for the PCT to also consider the needs against the Decision Support Tool of the national Framework to ensure that all my Mother's needs and the level of those needs were fully considered. As part of the IRP minutes, the application of the Decision Support Tool Domains were considered in line with my assessment in the 16th.August statement. There is a high degree of correlation between the 2 assessments.

My Complaint to the Ombudsman

In approaching the Ombudsman, I wish to challenge the decisions of the Retrospective CHC Panel and the IRP in their decision that my Mother's needs were only 'incidental and ancillary' to the provision of accommodation.

- Under the '1946 National Health Service Act' which became law on 5th July 1948, every resident British citizen having an illness, disability or injury became entitled to receive NHS care 'free at the point of need'. The NHS say they "hold a continuing commitment to the founding principles of the NHS which can be summed up as: **The provision of quality care that meets the needs of everyone, is free at the point of need.** However Suffolk NHS seem to have adopted a policy of subjecting patients to 'Eligibility Criteria' by which means they seek to avoid paying for the continuing health care which many frail sick and vulnerable elderly people require. This is discriminatory and totally unlawful because nowhere does the National Health Service Act provide for the application of 'criteria' to determine who is or is not entitled to receive care 'free at the point of need' In fact the Act specifically states: 'The services so provided shall be free of charge'.
- One event which is highly relevant to my Mother's case is the Coughlan judgement in 1999. I have a copy of Pamela Coughlan's daily nursing regime, signed by her, which I should like to compare to my mother's daily needs. They are remarkably similar yet on the one hand her needs are defined as health care needs yet the SHA Panel defined my mother's needs as 'personal care'. As follows:-
 - Coughlan required washing and a sling hoist for bathing. Same for my Mother
 - Coughlan required continence pads to be changed as required several times a day. Same for my Mother
 - Coughlan required to be lifted into her wheelchair. Same for my Mother
 - Coughlan required assistance with eating food. Same for my Mother
 - Coughlan required turning every 2-4 hours throughout the night. Same for my Mother
 - Coughlan did not require regular medication other than enemas. In her last year my Mother required significant and regular medication.
 - Coughlan suffered with headaches and required positional intervention. My mother was often in pain and cried out.
 - Coughlan had a very active mind and did not require any stimulation. My Mother had advanced dementia and a very poor quality of life
 - Coughlan did not require psychiatric care. Nor did my Mother
 - Coughlan had tetraplegia but retained use of her arms. My mother was immobile.
 - Coughlan could read books, write letters and use the 'phone. My Mother couldn't do any of this.
 - Coughlan could select her own clothing. My Mother couldn't.

- In many respects Coughlan lived an autonomous life, being intellectually active and, with the help of care assistance, a redoubtable campaigner. Her condition was stable, she had little need for NHS ‘specialists’ and could live in many semi-independent settings. If, as the Court held, her care needs put her well outside that which could be funded by a social services authority, then the bar to accessing NHS Suffolk PCT CHC would appear to be set at far too high a level. There is little doubt that these criteria were illegal and more restrictive than national guidance allowed.
- In summary therefore, in relation to the Coughlan judgement:-
 - Coughlan did not require psychiatric intervention
 - Coughlan did not show violent behaviour
 - Coughlan did not show any behavioural disturbance
 - Coughlan did not require regular medication
 - Coughlan did not require extensive healthcare support
 - Coughlan was not at risk of harm to herself or others
- The obvious conclusion to the above sections is that clearly my Mother’s health care needs were equal to those of Pamela Coughlan, if not more so, then clearly under the Law, my Mother should have qualified for continuing care costs
- Where there is a ‘health need’ (an illness or disability) this is the sole responsibility of the NHS. To deny NHS care to patients whose care needs are fundamentally comparable with those of Pamela Coughlan, is both a failure to heed and apply the National Health Service Act, the National Assistance Act, the ‘Coughlan Judgment’ and even the (albeit unlawful) National Framework and to substitute a policy of discrimination. It is also completely contrary to Human Rights legislation. **ALL so-called ‘social and personal care needs’ which arise as a direct consequence of a medical condition are inseparable from it. Thus if an underlying illness or disability - a ‘health need’ - were to suddenly disappear so too would all related care needs, thereby confirming unequivocally that the ‘primary need is a health need’ (an illness or disability) “for which the NHS is as a matter of law responsible” (Lord Woolf in ‘Coughlan’)**
- The application of ‘eligibility criteria’ which determine the right to NHS care based on the ‘quality’ and ‘quantity’ or the ‘intensity’, ‘complexity’ and ‘unpredictability’ of the care required is again unlawful. No such concepts are mentioned anywhere in the Health Act or were decreed in ‘Coughlan’ because nothing like it applied to Pamela Coughlan.
- The DOH issued a guidance note (EL(96)8), in February 1996. That referred to the danger of eligibility criteria being over-restrictive and mentioned the risk of an over-reliance on the needs of a patient for specialist medical opinion when determining eligibility for continuing care. It said that there would be a number of cases where the complexity or intensity of nursing or other clinical needs might mean that a patient was eligible for continuing care even though they no longer required medical supervision
- People with mental health needs are as entitled to fully funded NHS care needs as are people who have physical health needs. The criteria adopted by the Norfolk, Suffolk and Cambridgeshire Strategic Health Authority discriminate against people who have a mental health illness (dementia) which seems to be considered as ‘supervisory’ in nature and called ‘personal care’. It would appear that physical health interventions are more easily labelled as ‘health care’.
- My Mother had Alzheimer’s dementia, a cranial illness and disability for which she required round the clock care and it matters not whether she was in a care home or a nursing home, I consider her care

needs should have been assessed by the Health Authority as “medical” rather than “social”. As you know, in 2003 the Ombudsman stated that the application criteria used by all SHA’s and Social Service bodies since 1996 was somewhat in error in applying very tight eligibility criteria and should be reviewed with a view to appropriate compensation. With some help from my wife and I, my Mother was in effect **funding her own illness** which surely can’t be right when the NHS should be free at the point of need.

- In the NICE-SCIE Dementia guidelines published by The Psychological Society in 2007, Alzheimer’s dementia is classified as a progressive and irreversible clinical syndrome characterised by a widespread impairment of mental function, with some or all of the features, memory loss, language impairment, disorientation, change of personality, difficulties with activities of daily living, self-neglect and behaviour that is out of character. It is associated with complex needs and in the later stages, high levels of dependency and morbidity. These needs are often beyond the skills and capacity of carers and services. As the disease progresses, and in the later stages, people with dementia will present carers and social staff with complex and challenging support problems including aggressive behaviour, restlessness, wandering, eating problems, incontinence, delusions and hallucinations and mobility problems that can lead to falls and fractures. These professional descriptions of Alzheimer’s disease reflect clearly my Mother’s condition, contrary to the purely ‘social’ needs classified by the panel using Suffolk Continuing Health Care Eligibility Criteria.
- In a Health Ombudsman’s follow-up report, “NHS funding for long term care” it states that it is the healthcare needs, not the diagnosis, that determine whether the criteria for funding are met. His examination of the complaint raised two key issues. First, that assessment of non-entitlement to NHS funding was based on inadequate clinical evidence; secondly, that funding was denied due to an emphasis on the requirement for 'specialist' intervention, a word which appears in the strategic health authority's eligibility criteria. They had concerns about the strategic health authority's insistence on the need for specialist intervention (which DoH's guidance did not require) in order for a patient to be considered eligible for funding. The NHS Ombudsman decisions and the Court judgments have, in general, placed the bar for qualifying for NHS CC support at a modest level, whereas the guidance issued by the Department of Health has put it much higher, suggesting in effect, that eligibility for NHS funding is limited to a very few patients with unusual conditions.
- Accordingly, as it has become acceptable and feasible to care for all but the most acutely ill, in non-hospital settings, the NHS has admitted responsibility for fewer and fewer patients, even though the ‘disenfranchised’ are objectively in need of ‘health care’. The NHS has therefore redefined its role: its *raison d’etre* is not to care for ill people but rather, to care for certain limited categories of ill people: most particularly, acutely ill people. Such a re-branding has had the effect of ‘shunting costs’ to social services: ie the funding responsibility for patients who in former times would have unquestionably been its responsibility

P. [REDACTED]; October 2013