

Please note

The telephone numbers of the Parliamentary and Health Service Ombudsman changed on 15 March 2009.

The new contact details are:

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Complaint against: The former Cambridgeshire Health Authority and South Cambridgeshire Primary Care Trust

The Pointon case

We are departing from our usual practice and publishing the full text of this investigation earlier than planned in order to amplify the edited version published by the Alzheimer's Society on their website, which may have led to some confusion about the Ombudsman's findings.

As always, the findings relate to the unique set of circumstances surrounding the case and do not set a precedent for a class of cases. The Ombudsman looks at each case on its merits.

Complaint as put by Mrs Pointon

1. The account of the complaint provided by Mrs Pointon was that when he was 52 years old, her husband Mr Pointon, was diagnosed with early onset dementia. Mr Pointon's physical and mental state deteriorated steadily and in 1998 he was admitted to a nursing home. Initially, he settled in well but by early 2000 he had become less mobile and was suffering from regular falls. Mrs Pointon decided to bring her husband home and care for him herself with the aid of two full-time carers working alternate weeks. This care was financed by Direct Payments from Social Services (monies paid directly to Mr Pointon) and contributions from Mr and Mrs Pointon.
2. Between April 2000 and June 2001 Mr Pointon received NHS funded respite care in a psychiatric unit for up to five days every five weeks. However, this had to be discontinued when he began to suffer from car sickness and panic attacks during the journey to and from the ward. In August 2001 Mrs Pointon asked the former Cambridgeshire Health Authority (the Health Authority) to fund either Mr Pointon's continuing health care costs, or the cost of two full-time carers every fifth week, in order to provide her with a break similar to that formerly provided when Mr Pointon was in the hospital ward. After a care assessment and a multi-disciplinary meeting a suggestion was made for possible funding of one extra carer for three and a half hours a day, for six days, every five weeks.

3. Mrs Pointon complained to the Chief Executive of the Health Authority in January 2002. She was dissatisfied with the amount of funding that had been suggested and challenged the Health Authority's interpretation of their eligibility criteria for funding continuing care. On 1 April 2002 the Health Authority ceased to exist. The budget for funding such care passed to South Cambridgeshire Primary Care Trust (the PCT). On 20 May, after a nursing assessment of Mr Pointon's needs and further meetings between the PCT and Social Services it was decided that all Mr Pointon's health care needs were already being met by the NHS, that the respite care required was social care and therefore he was not eligible for any extra NHS funding. Mrs Pointon remained dissatisfied.

4. The matters investigated were that:

- (a) the Health Authority misapplied their local eligibility criteria and relevant Department of Health guidance; and
- (b) the PCT also misapplied the local eligibility criteria and relevant Department of Health guidance, and in particular they relied on inaccurate or inadequate information, failed to take account of relevant facts in their assessment and took account of irrelevant factors;

and that this resulted in Mr Pointon wrongly being refused NHS funding for respite care at home.

Investigation

5. The statement of complaint for the investigation was issued on 22 October 2002. Comments were received from the PCT and relevant papers were examined. A Professional Assessor - a Mental Health Nurse - was appointed to advise on the clinical aspects of the case; her report is reproduced in paragraph 37 of this report. One of the Ombudsman's Investigators took evidence from Mrs Pointon and PCT staff involved. I have not put into this report every detail investigated; but I am satisfied that nothing of significance has been overlooked.

Background

6. The statutory framework for the provision of health services is outlined in paragraph 7 below; paragraphs 8-12 summarise relevant national guidance; relevant Health Authority policy and criteria are summarised in paragraph 13.

Statutory framework

7. The provision of health services in England and Wales is governed by the National Health Service Act 1977, which states in section 3(1) that it is the Secretary of State's duty to provide services 'to such extent as he considers necessary to meet all reasonable requirements ... including such facilities for ... the after-care of persons who have suffered from illness as he considers are appropriate as part of the health service ...'. The National Health Service and Community Care Act 1990 (the 1990 Act), the relevant parts of which were implemented in April 1993, significantly increased the responsibilities of local authorities so as to include provision of accommodation for people who need it by reason of illness. Section 47 of the 1990 Act required local authorities to carry out an assessment of a patient's needs before deciding whether or to what extent they were required to provide services to meet those needs.

National guidance

8. In 1995 the Department of Health issued guidance (HSG(95)8) on NHS responsibilities for meeting continuing health care needs. The guidance detailed a national framework of conditions for all health authorities to meet, by April 1996, in drawing up local policies and eligibility criteria for continuing health care and in deciding the appropriate balance of services to meet local needs. The guidance stated that '[health authorities] ... will need to set priorities for continuing health care within the total resources available to them. While the balance, type, and precise level of services may vary between different parts of the country in the light of local circumstances and needs, there are a number of key conditions which all health authorities ... must be able to cover in their local arrangements. These are set out in Annex A ...'. Annex A includes the following passages:

'F Respite health care

'For many people local authorities will have the lead responsibility for arranging and funding respite care. The NHS however also has important responsibilities in this area and all health authorities ... must arrange and fund an adequate level of care. In particular however they should address the needs of:

'...

‘- people who are receiving a package of palliative care in their own homes but where they or their carer need a period of respite care.

‘In making arrangements for respite care health authorities ... should pay careful attention to the wishes of patients and their carers.

‘Local policies should include details of arrangements and eligibility criteria for people who require respite care from the NHS.

‘H Community health and primary care services for people at home or in residential care homes

‘Community health services are a crucial part of the provision of continuing care for people at home ... Health authorities should work closely with local authorities ... to agree the likely demand for continuing community health services support, taking account of the impact of:

‘- changes in the number of people who need care in their own home as a result of the new community care arrangements;

‘- changes in acute sector practice and provider plans to reduce hospital lengths of stay;

‘...’

‘This should be reflected in health authorities’ policies on continuing health care ...’

9. In August 1999 the Department of Health issued further guidance on continuing health care in a circular HSC 1999/180. This was in response to a Court of Appeal judgment in the case *R v North and East Devon Health Authority ex parte Coughlan* (the Coughlan case). Miss Coughlan was described in the judgment as tetraplegic, doubly incontinent, requiring regular catheterisation, and with difficulty in breathing. The judgment summarised its conclusions as follows:

‘(a) The NHS does not have sole responsibility for nursing care. Nursing care for a chronically sick person may in appropriate cases be provided by a local authority as a social service and the patient may be liable to meet

the cost of that care according to the patient's means ... Whether it was unlawful [to transfer responsibility for the patient's general nursing care to the local authority] depends, generally, on whether the nursing services are (i) merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide and (ii) of a nature which it can be expected to provide. Miss Coughlan needed services of a wholly different category. ...'

10. The Department's guidance included in its description on the judgment:

'(b) The NHS may have regard to its resources in deciding on service provision.

'(c) ... HSG(95)8 ... is lawful, although could be clearer.

'(d) Local authorities may purchase nursing services under section 21 of the National Assistance Act 1948 only where services are:

- (i) merely incidental to the provision of the accommodation which a local authority is under a duty to provide to persons to whom section 21 refers; and
- (ii) of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.

'(e) Where a person's primary need is a health need, then this is an NHS responsibility.

'(f) Eligibility criteria drawn up by Health Authorities need to identify at least two categories of persons who, although receiving nursing care while in a nursing home, are still entitled to receive the care at the expense of the NHS. First, there are those who, because of the scale of their health needs, should be regarded as wholly the responsibility of a Health Authority. Secondly, there are those whose nursing services in general can be regarded as the responsibility of the local authority, but whose additional requirements are the responsibility of the NHS.'

11. Authorities were advised by the Department to satisfy themselves that their continuing care policies and eligibility criteria were in line with the judgment

and existing guidance, taking further legal advice where necessary. If they revised their criteria they should consider what action they needed to take to re-assess service users against the revised criteria.

12. In June 2001, the Department of Health issued guidance in circular HSC 2001/015, on the new arrangements for continuing health care embodied in the Health and Social Care Act 2001. This required health authorities to comply with the guidance by October 2001 and, working in conjunction with primary care trusts, to agree joint eligibility criteria and set out their respective responsibilities for meeting continuing health and social care needs by 1 March 2002. The guidance specified clearly that one of the key issues to consider when establishing continuing care eligibility criteria was that ‘the location of care should not be the sole or main determinant of eligibility. Continuing NHS health care may be provided in an NHS hospital, a nursing home, hospice or the individual’s own home’. A further circular - HSC 2002/001, was issued in January 2002 which provided guidance on the implementation of the single assessment process for older people, as part of the National Service Framework for Older People.

Local guidance

13. The Health Authority’s policy and criteria for eligibility for meeting continuing health care needs, dated April 2000, which superseded the criteria of North West Anglia, and Cambridge and Huntingdon, Health Authorities, was written with regard to the principles of the Coughlan finding and reviewed in line with the requirements of HSC 2000/015 (paragraph 12) in March 2002. It included the following references to NHS funded health care in an individual’s home:

‘9.0 WHERE IS CAMBRIDGESHIRE HEALTH AUTHORITY’S CONTINUING HEALTH CARE PROVIDED?’

‘...’

‘9.2 Where clinically appropriate and possible, people may receive their continuing health care at home. At other times, because of the complexity and intensity of a person’s illness ... or in order to ensure the most effective use of resources, it will be necessary to receive this care as an in-patient ...’

‘9.3 Initial assessment for continuing health care can take place in hospital, the patient’s own home or in a residential or nursing home setting ...

‘10.0 HOW DOES THE SOCIAL SERVICE DEPARTMENT FIT IN?’

‘Many patients with less than 100% continuing health care needs may also require support from the Local Authority Social Services Department. Both agencies are committed to working in partnership to provide comprehensive and co-ordinated services to people needing services and support ...

‘11.0 CAN NHS CARE BE FUNDED IN A PERSON’S OWN HOME?’

‘Yes, community and specialist nursing and therapy services are either available to people through direct access or on referral from their general practice. Specific nursing services may include, for example, continence advice, palliative care, Parkinson’s disease, diabetic care or stoma care.

‘ ...

‘14.0 WHAT ABOUT PEOPLE WHO DO NOT FALL WITHIN THE ELIGIBILITY CRITERIA ...

‘ ...

‘The difference between “social” and “health” care is not an easy distinction to make. The picture is confused by the willingness of the NHS in earlier years to care for people who were frail and dependent, without assessing whether their needs really were for health, rather than social care. ...

‘There is still a public perception that people who need help with activities of daily living should, on account of their dependency, remain the responsibility of the NHS (and this is particularly so in the case of dependency arising from an illness such as dementia). This is not something that this Health Authority subscribes to but that, dependent on

assessed need, the necessary services should be provided by the most appropriate agency or agencies.

‘PEOPLE WITH PHYSICAL AND/OR SENSORY DISABILITY

‘ ...

‘People in a Community Setting

‘Those living at home ... need a multi-agency reassessment to ascertain whether additional resources can be provided or whether they are eligible for full NHS care.

‘Eligibility Criteria

‘... Below are some of the clinical characteristics for guidance but there should not be an over-reliance on having a certain number of these. Eligibility may come from one condition alone ... or from several lesser factors. ...

‘PEOPLE WITH DEMENTIA (OF ANY AGE)

‘ ...

‘Those living at home ... may also have specific health needs that can no longer be met within usual community health, community mental health and social care resources. Such people need a multi-agency reassessment to ascertain whether it is appropriate to provide additional resources in the community to meet their health needs and/or whether they need “in patient” care.

‘Eligibility Criteria

‘ ...

‘Below are some behavioural and physical characteristics for guidance, ... Eligibility may come from one condition alone (such as persistent risk of harm to self ...) ...

‘Patients with advanced dementia that also have a severe degree of behavioural disturbance ... [such as] a risk to self or others if not receiving observation and intervention.

‘...’

‘... who also have physical problems which require specific care management by appropriately skilled staff in order to reduce the risk of significant deterioration of physical health and safety. Consideration will be given to the level of risk of further deterioration if the patient should be relocated ...’

‘...’

‘SHORT TERM ADMISSION/RESPITE’

‘... It provides relief and health gain for individuals or their regular carers ...’

‘Eligibility Criteria’

‘The need for NHS funded health respite care is guided by the following eligibility criteria:

‘The patient meets the criteria for continuing in-patient care but their care plan specifies care outside hospital.

‘The main informal carer has been delivering a high level of skilled nursing care but is temporarily unable to continue and the patient therefore needs hospital admission. ...’

Ombudsman’s report on NHS funding for long-term care

14. In February 2003 the Ombudsman published a report (HC 399) incorporating the texts of four completed investigations following complaints made to her about the arrangements for funding long-term NHS continuing care. In the report, she expressed concern that patients receiving such care may have suffered injustice because of failings in these arrangements, and she called for redress from the authorities involved. She also recommended that health bodies should review the criteria used by their predecessor bodies, and the way that those criteria had been applied, and that efforts should be made to remedy any injustice to patients who had been wrongly assessed. The Ombudsman’s report also highlighted her concerns about lack of information given to patients and

carers, and the continuity of assessments. The introduction to the report included the following:

‘... Looking at most sets of criteria we have seen, it is fairly easy to identify a group of people who would definitely not be eligible for funding, and a very small group of people who definitely would be eligible (many of whom would not be well enough to leave hospital). But there are a large number of people in the group in between. Now and in the past, a line has to be drawn through that group, and this is done using generally quite subjective and broadly drafted criteria. Yet which side of the line a patient’s needs are judged to fall can make an enormous financial difference to the patient and their family.

‘Some authorities have attempted to address this problem by producing detailed guidance and procedures on the assessment of patients and the application of criteria. Some use specific assessment “tools”. Where the guidance and procedures are well-drafted and properly promulgated and understood by those doing assessments, they can at least assure some degree of consistency in the application of the criteria within the authority’s area. But unless they are published alongside the criteria themselves, patients and carers can be left inadequately informed as to how decisions about eligibility are actually being made.

‘Other health authorities have little or no practical guidance about the application of criteria, and it is left to clinical staff in the community or hospitals to interpret them as best they can when assessing patients. This will almost inevitably lead to inconsistency ...’

Key events

15. I set out below a summary of key events drawn from records and supporting evidence:

1998 - Mr Pointon was admitted to a nursing home as his wife could no longer manage him at home. An NHS fully funded bed was offered as the Health Authority had purchased a block of beds that had to be paid for, whether they were used or not, but Mrs Pointon decided to use the nursing home of her choice. Cambridgeshire Social Services Department funded this placement under the Community Care Act.

January 2000 - Mrs Pointon was distressed at her husband's deterioration and decided to employ carers, through the Social Services Direct Payments scheme, to assist her in caring for her husband at home. She requested a health assessment in January 2000.

March - Mr Pointon returned home and was eventually cared for by Mrs Pointon and two 24-hour carers. This was part funded through Direct Payments (in line with the Carers and Disabled Children's Act 2000) by Social Services.

April - Mr Pointon received respite care in a specialist unit for one week in every five, this was NHS funded.

June - Social Services requested an assessment to determine whether trained nurse input was required or whether a carer could provide care. This assessment was carried out by a member of the District Nursing Team. She concluded that there was a requirement for 'carers with experience of looking after people with challenging behaviour', but qualified nursing input was not required.

July - an occupational therapy assessment identified that for effective and appropriate care to be provided to deal with Mr Pointon's challenging behaviour, more help was required from staff experienced in the management of dementia.

February 2001 - an assessment on behalf of the Health Authority was undertaken by the Manager (a nurse), the Social Worker, and the Occupational Therapist. The assessment report stated that Mr Pointon's health needs were being met and that no additional health funding was required; Social Service Direct Payments continued.

July - Mr Pointon's consultant psychiatrist (the Consultant Psychiatrist) and the community psychiatric nurse (the CPN) visited Mr Pointon. He was no longer able to cope with travelling to the specialist unit for respite care. The CPN advised that, as the dementia was now advanced, the in-patient team who had a greater level of expertise should assess Mr Pointon's needs.

August - Mrs Pointon requested NHS funded continuing health care to pay for two additional full-time carers every fifth week, a letter from their General Practitioner and the Consultant Psychiatrist supported additional ongoing care in the community.

22 August - a member of the District Nursing Team and the CPN carried out a further assessment.

November - after taking advice from the Consultant Psychiatrist that extra care was needed in the home the Manager, a member of the District Nursing Team and their manager offered one extra carer for three and a half hours a day, every fifth week.

January 2002 - Mrs Pointon asked for a review of this decision and made a formal complaint regarding the application of the Health Authority's eligibility criteria for NHS funded continuing care. Meanwhile a complaint was lodged with the Health Service Ombudsman.

March - a record of the assessment of 22 August 2001 was received from the CPN, who supported the request for extra respite care to be provided by someone with some knowledge of dementia and good communication skills.

April - the newly formed PCT requested a further assessment, which was performed on 15 April by a member of the District Nursing Team. The purpose of the assessment was to determine whether Mr Pointon needed frequent intervention by a trained nurse during a 24-hour period. The member of the District Nursing Team concluded that a regular visit every three weeks was sufficient.

April - the PCT decided that Mr Pointon's health care needs were being met through the involvement of a multi-disciplinary NHS team who would continue to provide the same level of care on an ongoing basis, including during periods of respite.

May - members of the PCT took a letter confirming this decision to Mrs Pointon at her home.

July - Mrs Pointon disputed the PCT's decision and sought an independent medical opinion.

September - the independent medical report was reviewed by the PCT at a multidisciplinary meeting; the report concluded that Mr Pointon could not be in a more severe condition and that he met the criteria for 100% continuing care as his needs were entirely health related. The Consultant Psychiatrist agreed with this view although the Manager and the Director dealing with this case (a

Nurse) did not. The view of a community consultant geriatrician (the Consultant Geriatrician) was sought.

October - the Consultant Geriatrician decided that Mr Pointon did meet the eligibility criteria for NHS funded continuing care.

November - December - the PCT and Social Services discussed various options available to support Mr Pointon and the implications involved. If Mrs Pointon decided to apply for 100% NHS funding she would have lost the Direct Payments from Social Services and the carers would be supplied and employed by the NHS. The PCT accepted the Consultant Geriatrician's opinion that Mr Pointon met the criteria for continuing care but chose to defer application of the eligibility criteria to enable continuity of care in the home setting through Direct Payments. Mrs Pointon decided to accept a joint package which combined her Direct Payments and NHS funded respite care.

Complaint (a) - the Health Authority misapplied their local eligibility criteria and relevant Department of Health guidance

Mrs Pointon's evidence

16. **Mrs Pointon** said that from 1998 until 2000 Mr Pointon was cared for in a nursing home. The Health Authority had offered him a fully funded place in a nursing home where they had purchased a block of beds but Mrs Pointon did not feel that that home suited Mr Pointon's need for a balance of peace and seclusion with adequate supervision. She asked the Health Authority if they would agree to pay for his care in a different nursing home of her choice, but was told that they were not able to do this. Nevertheless Mrs Pointon proceeded with the home of her choice.

17. Mr Pointon remained in the nursing home for two years. By 2000 however, his health had begun to deteriorate and Mrs Pointon decided to care for him at home. The severe behavioural problems, which had characterised his illness during its earlier stage, had now diminished. Photographs of Mr Pointon when he returned home and one month after his return, showed a very noticeable improvement in his physical well being. At this time Mr Pointon's care expenses were supported by Direct Payment contributions from Social Services. As agency live-in carers had proved unsatisfactory in the past, Mrs Pointon recruited and trained a team of carers.

18. Mrs Pointon described the Health Authority's assessment of Mr Pointon's needs, which was undertaken in February 2001 by the Manager. She was not

convinced that the assessment tool that had been used, with its bias towards physical conditions, was an appropriate one for assessing the needs of people with dementia and, in her opinion, it did not address her husband's needs. It did not reflect the constant vigilance necessary in order to respond to the unpredictable elements of her husband's condition.

19. Until June 2001 Mr Pointon had attended a psychiatric unit for respite care for one week in every five. However, as his illness progressed, the staff at the centre advised that Mr Pointon's condition was too advanced for the scope of their facilities. The centre's resources were not able to respond to Mr Pointon's need for constant supervision and he also became unable to cope with car journeys to and from the centre. Therefore, it was necessary for alternative respite care arrangements to be established.

20. Because of that need Mrs Pointon requested a reassessment of her husband's condition in August 2001, with a view to the Health Authority contributing to the cost of a respite care package. This further assessment involved input from both a member of the District Nursing Team and the CPN who had met Mr Pointon between January and May 1998 when he had been in hospital. Mrs Pointon thought that this had been a helpful assessment. (Note: Unfortunately, there is no written record of the assessment, only a brief letter from the CPN to the Manager dated 25 March 2002, four months after a suggestion from the PCT for three and a half hours respite care had already been made, in November 2001.)

21. Mrs Pointon explained that from March 2000, Mr Pointon's care at home had been supported by Direct Payments from Social Services; however, there was a sizeable shortfall between those payments and the actual cost of the care. The largest of these occurred when the NHS funded respite care had to stop in June 2001. From then on, Mrs Pointon paid personally for a respite carer to take her place at home for one week in five, (initially at a cost of £405 per week, rising to £455 in 2002).

Complaint (b) - the PCT also misapplied the local eligibility criteria and relevant Department of Health guidance, and in particular they relied on inaccurate or inadequate information, failed to take account of relevant facts in their assessment and took account of irrelevant factors

Mrs Pointon's evidence

22. A member of the District Nursing Team undertook a further assessment on behalf of the PCT in April 2002. **Mrs Pointon** said that this assessment was

based on a very informal discussion with the member of the District Nursing Team during a 20 minute visit, early in the morning. During this time Mrs Pointon had been attending to her husband's needs. Previous assessments had taken between one and three hours. Mrs Pointon said that it had not been made clear to her that the purpose of the member of the District Nursing Team's visit had been to complete a formal assessment of Mr Pointon's needs. Mrs Pointon said that she had learned subsequently that the member of the District Nursing Team had been asked to complete the assessment at very short notice, following her return from a period of leave. Mrs Pointon said the assessment had contained a number of errors of fact and gave only a partial view of Mr Pointon's needs. It had not indicated the unpredictability of his needs.

23. It had not been made clear to her at any of the assessments, whether her husband was being assessed against eligibility criteria for NHS continuing care or those for Social Service funded care with a limited, incidental, element of nursing care. She believed that this confusion had characterised the whole case and created the situation where her husband apparently met the criteria for social/nursing care but not for NHS funded continuing care. Mrs Pointon felt that the two processes should be meshed together more closely. She thought that neither the nursing care criteria nor the PCT's eligibility criteria for continuing care took sufficient account of patients' psychological needs.

24. Mrs Pointon thought that there was a very narrow definition of nursing care in the eligibility criteria which was biased towards acute care and discriminated against people with dementia and other long-term degenerative conditions, all demanding nursing skills of a different kind. She believed that the PCT had unfairly applied to a domestic setting the criteria for funding care in a nursing home, thus imposing conditions that were impossible to meet at home, such as the frequent intervention of a trained nurse in a period of 24 hours. When Mr Pointon was later deemed to meet the continuing care criteria for 100% NHS funding in November 2002, the PCT offered no realistic provision for funding Mr Pointon's care at home, only in a nursing home or hospital.

25. Mrs Pointon felt that the Manager, in assessing her husband's needs, had been concerned to ensure that the conclusions of all subsequent assessments had corresponded to those that she had reached in February 2001. Mrs Pointon said that she had greatly valued the support that the CPN had been able to give her and she had been very distressed when this help had been withdrawn. She had been advised that the CPN would no longer be able to offer her support, as their responsibility was restricted to work with people suffering mild to moderate

levels of dementia. She believed that the family carer had an even greater need to have strong psychological support in the end stages of caring for someone with dementia, especially when difficult decisions have to be made on behalf of a patient who is unable to communicate his wishes.

26. Mr Pointon was now totally reliant on others for his needs to be met. He was also subject to epileptic seizures, muscular spasms, panic attacks and episodes of choking, and he required constant supervision. The arrangement for funding Mr Pointon's care utilised Direct Payments from Social Services, which met the majority of the costs, and a contribution from the PCT, to cover the respite element of his care. However, as part of the care is funded by Social Services Mr Pointon had been assessed to make a contribution to the cost. Mrs Pointon had been advised by her solicitor that there were legal means by which the PCT would be able to contribute to Mr Pointon's care costs by the transfer of funds to the Social Services Department, in order to maintain the Direct Payment arrangement.

PCT's response to the statement of complaint

27. In her formal response of 5 December 2002 to the statement of complaint the Chief Executive of the PCT wrote:

‘... Since taking on the responsibility for this case in April 2002, the PCT has sought the views of the various professionals involved in Mr Pointon's care ... The case has been complicated because of the differing professional opinions expressed ... in particular, differences ... [about whether the] aspects of care he now needs are health or social in nature.

‘... We met with Mrs Pointon and her solicitor ... to discuss the outcomes available ... [Mrs Pointon's] preference would be for ... continuation of the existing package of care through Direct Payments ... but with supplementary NHS funded respite care provided in the family home.

‘... The PCT opinion [was] informed by:

‘[the Consultant Geriatrician's] *professional opinion* that **Mr Pointon does meet the eligibility criteria for NHS Continuing Care**. Given the range of differing professional opinion received ... we had sought [the Consultant Geriatrician's] independent assessment ... to reach a conclusion about the nature of his clinical needs;

‘what we believe ... to be *the most appropriate way of meeting these needs*;

‘confirmation from [the Consultant Geriatrician and the Consultant Psychiatrist], that they are confident that the care package ... will be *clinically appropriate* ...

‘... The NHS cannot make these Direct Payments to a patient ... [so] the PCT has worked with Social Services to construct a joint package of care that can be provided through Direct Payments. ... Social Services ... have therefore, supported the PCT in agreeing to jointly fund the package, and hence enable us to continue direct payments. ...

‘I have given Mrs Pointon my sincere apologies ... As part of investigating this complaint we have ... agreed a range of actions across our agencies to help ensure this type of delay does not occur in future ...

‘Response to paragraph 4 [of the statement of complaint]

‘...

‘The PCT would respond that:

‘The PCT became responsible for provision of Mr Pointon’s health care provision on 1 April 2002. ... we have sought the opinion of a wide range of health and social care professionals in assessing Mr Pointon’s health care needs. These assessments have informed the PCT’s decision in relation to whether:

‘Mr Pointon’s health care needs are being met by the provision of continuing health care in the community

‘Mr Pointon’s needs are so complex, unpredictable and unstable that he meets the eligibility criteria for NHS funded continuing care and thus whether he should be in receipt of health care services over and above those [provided by the community]

‘The PCT should be funding additional respite care

‘...

‘Summary of health professional views sought

‘...

‘... [the] Consultant Psychiatrist believes that Mr Pointon does meet eligibility criteria. ...

‘[The member of the District Nursing Team] concluded that Mr Pointon’s physical and mental condition had NOT deteriorated to a point where they were unpredictable and unstable requiring frequent intervention by a trained nurse ...

‘...’

‘Given that Mrs Pointon remained unhappy ... the PCT sought one final independent view from [the Consultant Geriatrician] ... specifically to consider Mr Pointon’s needs in relation to the eligibility criteria for NHS funded continuing care ...’

‘[The Consultant Geriatrician] undertook an assessment of Mr Pointon’s needs on 29 October 2002 ... and concluded that in his opinion Mr Pointon DID meet the eligibility criteria for NHS continuing care for people with physical and/or sensory disabilities. ...’

‘**Conclusion**

‘... What has delayed resolution of this case is the differences in professional opinion ... which have ranged from one end of the spectrum of continuing care needs to the other ...’

‘*Summary of proposal being recommended:*

‘... that the PCT accepts ... that Mr Pointon meets the PCT’s eligibility criteria for NHS Continuing Care’

‘... as none of the options currently available to the PCT offers the most appropriate means of meeting Mr Pointon’s care needs, ... with Social Services we have agreed to fund a joint package of care:

‘Social Services will continue to make Direct Payments ...’

‘the NHS will continue to provide ongoing health care in the family home ...’

‘the NHS will provide additional respite care in the family home one week in every five ...’

Evidence of PCT staff

28. The **Manager** explained that she was a qualified nurse and had taken up this current role in October 2001. Following the establishment of the PCT in April 2002 her role had been as a co-ordinator rather than an assessor.

29. She had previously met Mr Pointon when she had been involved with the inspection of a nursing home in which he had been living. Although she had not had the responsibility for continuing care assessments, because of her role and her experience in evaluating nursing care needs, she had been asked in February 2001, to convene a meeting with appropriate professionals to evaluate Mr Pointon's requirements. Her responsibility had been to ensure that the group looked at Mr Pointon's needs at that point in time, but had also taken account of the past and looked to the future. She stated that, at that stage, the question of continuing health care provision for Mr Pointon had not been raised.

30. She said that she had undertaken a joint health and social care assessment of Mr Pointon's needs. Financial considerations had not played a part in the assessment. She emphasised that her decisions were always based on the needs of the individual patient and that other people with a high level of need were being supported in the community by the PCT, including people with tracheostomies (a surgical opening through the neck to relieve obstructions to breathing). She was aware that Mrs Pointon had access to support from the Consultant Psychiatrist when she required it.

31. For the assessment she had sought the opinion of the Nurse who dealt with dementia, a member of the District Nursing Team and the CPN, who had jointly agreed that Mr Pointon's needs could be met by the community healthcare and nursing services supporting the care provided by Mrs Pointon and paid for by Social Services Direct Payments. At that time Mr Pointon also received respite care in a NHS psychiatric unit where his needs were monitored.

32. In June 2001 Mr Pointon's needs changed and it was no longer possible for him to receive respite care in the psychiatric unit. The Manager was asked to convene a further assessment of Mr Pointon's needs, in order to advise on the way in which his respite care at home should be provided. She sought opinions from the professionals involved in Mr Pointon's care, a member of the District Nursing Team, the Nurse who dealt with dementia, the CPN and the Consultant Psychiatrist. The Manager said that she had referred to the Consultant Psychiatrist for advice, and not because she thought that this was a continuing care issue. She said that she had been very concerned to ensure that Mrs Pointon did not lose the Direct Payments as these enabled her personally to manage her husband's care. The information from this assessment was used to formulate the proposal, which was put to Mrs Pointon in November 2001. This was, that Mr Pointon's respite needs could be met by the addition of one extra carer visiting for three and a half hours a day, for six days, every five weeks.

The Manager accepted that the arrangements had not taken into account the full time carer's requirement for time off during the day, and that the visit time would have been increased to cover this. It was expected that this would have provided respite for Mrs Pointon.

33. Until June 2001 Mr Pointon had been in receipt of NHS funded respite care which was, in the Manager's view, based on the clinical opinion provided by the Consultant Psychiatrist, inappropriate at that time. The respite care provision he received was for people with behavioural problems due to their dementia, as opposed to the physical needs that Mr Pointon presented. His needs could have been met in a nursing home with a joint Health and Social Care package.

34. The Manager said that, part of her role was to deal with complex cases where health needs could not be met within local NHS services whether they were 100% health funded or joint packages with Social Services. She said that continuing care was a NHS provision and would be provided within the local NHS services. In the PCT there was a specific unit for continuing in-patient care and a NHS community service for people who wished to be cared for in their own homes.

35. The Manager said that because of the complexity of the case she had involved other professionals. She agreed that family carers could perform more tasks than social carers due to their one to one knowledge and, as they are not employed by Social Services, they can perform tasks that a social carer would not be able to, because of Health and Social care regulations. The test she applied to determine whether a task was a nursing or non-nursing was whether she would need to replace a carer with a qualified nurse. When considering replacing a family member, who that person is, is one of the factors involved but not the only one. The assessment and judgment of those who are closely involved ie. a member of the District Nursing Team and the General Practitioner are also taken into account. Mr Pointon's needs as well as those of the carers were considered.

36. The Manager said that Mrs Pointon had not been able to accept that, although her husband had previously been offered an NHS continuing care bed, this was because a number of block purchased continuing care beds were not being utilised and were being paid for by the Health Authority whether they were occupied or not. It did not mean that he met the eligibility criteria or that his needs were such that the funding of a community package would be the sole responsibility of the NHS. She said that the third assessment in April 2002 had

taken place at a time when the PCT was being formed. It had subsequently been suggested that an assessment of Mr Pointon's needs should be undertaken by appointing an independent nurse who would assess Mr Pointon's needs over a three-day period whilst he was being cared for at home. However, this action was not initiated as Mrs Pointon's solicitor sought an opinion from the independent Consultant. The Manager said that the independent Consultant had not spoken to the professionals involved with Mr Pointon's care. The Chief Executive of the PCT had subsequently sought the Consultant Psychiatrist's opinion and she had confirmed that Mr Pointon met the criteria for continuing NHS care. However, the PCT was unable to obtain a written assessment of Mr Pointon's needs from the Consultant Psychiatrist. Both the Consultant Psychiatrist and the Consultant Geriatrician had been in agreement with the independent Consultant's assessment.

37. I produce next, the report prepared by the Ombudsman's Assessor for this case.

Report by the Professional Assessor to the Health Service Ombudsman for England of the clinical judgments of staff involved in the complaint made by Mrs Pointon:

Professional Assessor: Ms Y, RGN, RMN, SCM, MSc in Nursing

i. Basis of report

This report has been compiled after referring to relevant documents, including correspondence from the solicitors (acting on behalf of the complainant) and from South Cambridgeshire Primary Care Trust including 'Policy and Eligibility Criteria for NHS funded continuing health care'. I accompanied one of the Ombudsman's Investigators at interviews with Mrs Pointon and the Manager.

ii. Background

Please see chronology at paragraph 15.

iii. Application of the continuing care criteria

There are key issues that need to be considered surrounding the case, these are:

iii(a) That the Health Authority's policy and eligibility criteria used to assess Mr Pointon's needs did not comply with the relevant Department of Health guidance

The Department of Health's guidance (HSC 1999/180:LAC (99) 30 and HSC 2001/015:LAC (2001) 1) makes a clear distinction between specialist nursing and general nursing services. It clearly outlines that a local authority could provide nursing care if it is incidental or ancillary to the provision of accommodation and of a nature which can be expected to be provided by an authority whose primary responsibility is to provide social services.

Comment

From the documentation provided (the Health Authority's April 2000 policy and eligibility criteria) and from the interview with the Manager, the following issues arose. Mr Pointon had been assessed using different criteria, which seemed dependent specifically on what was being requested at the time, and not based on his continuing health care needs.

The assessment that took place on 15 April 2002 used the eligibility criteria for people with dementia. This assessment focused on whether the patient could no longer be nursed at home or in a residential setting and required in-patient care. Therefore, if the carer preferred a patient to be nursed at home, even if they were eligible for an in-patient bed, NHS continuing health care funding was precluded in the home setting. One of the criteria in the assessment considered the risk to self if not receiving observation and intervention. As had been previously identified, Mr Pointon needed 24-hour care and always had someone with him as he was likely to choke, and was subject to both minor and major epileptic fits. The PCT stated that because the myoclonic jerks (sudden spasms) and fits were being controlled by medication and observation Mr Pointon was not 'at risk'. The Consultant Psychiatrist thought that Mr Pointon's needs were mainly physical (although Mr Pointon had advanced dementia). Another assessment was carried out by the Consultant Geriatrician in October 2002. The eligibility criteria used on that occasion related to people with physical and/or sensory disabilities. In assessing those criteria it is my opinion that Mr Pointon met four of them, but his needs also encompassed those criteria for people with dementia. It appears that Mr Pointon's eligibility for continuing health care funding may have been compromised since 1998 when Mrs Pointon identified a more conducive environment for her husband to be cared for in than the one offered by the Health Authority and funded the extra cost herself.

The Health Authority policy relates to the appropriate guidance HSG(95)8 and HSC 1999/180:LAC (99) 30 that required each health authority to have a plan for the delivery of appropriate services to meet the continuing health needs; in

the case of Mr Pointon this was in relation to people with dementia. The policy states clearly that where the primary need for care is a health need, the service responsibility rests within the NHS and is provided free at the point of delivery, whereas the local authority would be eligible to fund a placement if the need for care was a social need. Joint funded packages would also be available where applicable.

The policy reflects the requirements of the Department of Health guidance but it is the interpretation of the guidance by individuals involved in the process that appears to be where the difficulty arose. This is because the eligibility criteria are somewhat ambiguous in nature. The criteria offer a list of possible characteristics to judge patients against, instead of a more comprehensive and holistic, domains of care approach. The ambiguity of both the eligibility criteria and the Department of Health guidance led to confusion.

iii(b) The Health Authority's eligibility criteria and assessment tools are focused towards acute care

The Health Authority's eligibility criteria for people with dementia and also for people with physical and/or sensory disabilities appear to have an over emphasis on the physical aspects of care rather than the requirements for psychological support for individuals.

The assessment criteria for dementia focus on the difficulties of behaviour, particularly violence and risk, but do not include the mood changes, delusions and hallucinatory experiences, and visual spatial difficulties which are common problems associated with advancing dementia. They also include the advice that, if patients with advanced dementia also have specific care management needs relating to mood etc, requiring care by skilled staff, that these criteria are covered by the assessment for people with sensory and/or physical disabilities. However, the criteria for individuals with sensory and/or physical disabilities appear to be based solely on physical needs and the requirements of individuals with illnesses which require palliative care, ventilation and medical intervention. There is no part of the criteria which relates to the psychological needs of the patient.

Comment

Mr Pointon was assessed using the criteria identified above. He suffered from mood changes and some behavioural disturbance. These have now reduced due to the advanced stage of dementia. He also experienced visual spatial difficulties (and still does) and hallucinatory experiences. None of these

problems are reflected in the eligibility criteria or the assessment tools. However, assessments in September and October 2002 by the Consultant Psychiatrist and the Consultant Geriatrician clearly stated that Mr Pointon had continuing health care needs. The assessment carried out by the independent Consultant stated that Mr Pointon was in the terminal stages of dementia that could hardly be more severe. The independent Consultant disagreed with the PCT's assessment of the severity of Mr Pointon's condition and said that he had health care needs well beyond anything that the average care worker was competent to deal with. The Consultant Psychiatrist also agreed with this assessment. However, the Manager and the Director dealing with this case, who is also a nurse, disagreed. It seems that the PCT's decisions were based on the nurses' assessments.

iii(c) The definition of nursing care used by the PCT

The eligibility criteria and the assessments reflect the amount of nursing input required and the level of provision to be supplied. This relates specifically to the requirement for qualified nurse input for any particular interventions that have been identified. The interventions relate to criteria that have a bias towards acute physical care.

In the multi-disciplinary meeting in September 2002, when the report by the independent Consultant was discussed, there was debate around the definition of nursing care. The Consultant Psychiatrist agreed with the independent Consultant that the care that Mrs Pointon was providing was 'equal to if not superior to that provided by many qualified nurses who specialise in the area of dementia care'. Both the Manager and the Director felt strongly that Mrs Pointon 'was not providing nursing care, that it took many years to gain nursing qualifications and skills and that these could not be self taught'. They agreed that Mrs Pointon was giving highly personalised care; with a high level of skill, which she had acquired due to the vast knowledge she had about her husband's needs. The Manager stated that the care given could not be highly professional, as it was not provided by a qualified nurse.

Comment

Mr Pointon has required nursing care for the past nine years, during which time it has been delivered by the District Nursing team and his wife, assisted by carers. Some periods of time have been spent in a nursing home and in an NHS continuing care mental health facility where he was monitored during periods of respite care.

When I visited Mr Pointon, it was clear that the care he received was of a particularly high standard and addressed all his physical needs, but in addition catered for his psychological needs. The care was delivered in a professional manner with consideration to the dignity and privacy required for such care. The atmosphere was not one that could be replicated in a continuing care ward. Mrs Pointon has trained the carers, who cover the 24-hour period, how to care for her husband.

In the last assessment the Consultant Psychiatrist felt that again, Mr Pointon did meet the continuing care eligibility criteria but that if he required an in-patient bed he could be nursed in a general continuing care ward.

iii(d) That proper consideration was not given by the PCT to Mr Pointon's eligibility for NHS funded continuing care in his own home

The Health Authority's, and subsequently the PCT's policy, seems to be focused on hospital care and restrictive in the criteria used to assess caring for people in their own homes. In this case NHS funding has not been forthcoming because Mrs Pointon chose to provide individualised care at home. On each assessment this preferred provision of care has precluded Mr Pointon from receiving NHS funding unless given in a location chosen by the Health Authority/PCT.

Comment

Mr Pointon has received excellent care from his wife and carers in his own home. The Department of Health guidance outlines the importance of patient/carer choice, as does the Carers Act 2002. The Department of Health guidance HSC 2001/015 (paragraph 12) refers to the location of continuing care. The Health Authority/PCT policy briefly mentions in points 9.2 and 9.3 that continuing health care can be delivered at home. Then the content of the policy quickly returns to the view that in-patient or nursing home care would be most appropriate to ensure the most effective use of resources. The reference to NHS care being funded in a person's own home in point 11.0 refers only to palliative care, continence advice, Parkinson's disease, diabetic and stoma care as examples. The policy outlines criteria for people who do not fall into the eligibility criteria for NHS continuing health in-patient care; it states that 'there is still a public perception that people who need help with activities of daily living should, on account of their dependency, remain the responsibility of the NHS (and this is particularly so in the case of dependency arising from an illness such as dementia)'. They comment that this is not something they subscribe to, but that it is dependent on assessed need.

Within the policy there are brief statements about 'people in a community setting'. All that is actually said relates to a multi-agency assessment to determine whether additional resources are required to meet health needs or whether in-patient care is required. Little is said about 100% NHS funding, especially in patients' own homes. A chart on page 6 demonstrates that if 100% funding for NHS care is required this will be provided in a nursing home for more advanced stages of illness, not in the individual's own home.

Comment

It is not clear how the Health Authority and the PCT would provide full NHS funded care in a person's own home. In Mr Pointon's case the NHS could only provide 100% funding if he was cared for in hospital or a nursing home. Because of this, Direct Payments continue, but do not meet the full cost of having two carers; the additional cost continues to be met by Mrs Pointon even though her husband would be eligible for an in-patient continuing care bed. Mrs Pointon is also unable to claim for Invalid Care Allowance due to her age.

iv. Conclusions

- *The policy and eligibility criteria, which were used to assess Mr Pointon's needs, did not fully comply with the relevant Department of Health guidance, in that, the assessment tools are focused towards acute care and make no provision for the psychological needs of the individual with a mental health problem.*

- *The continuing care criteria for 100% NHS funding appeared to offer little provision for caring for individuals in their own homes and mainly focused on acute care. That practice may not be compliant with the Department of Health guidance HSC 2001/015:LAC (2001) 18. Proper consideration was not given to Mr Pointon's eligibility for NHS funded continuing care and Mrs Pointon's preference to nurse him at home caused them to be penalised.*

- *The PCT may need to take into consideration the needs of carers, in accordance with the Carers Act 2000.*

Findings (a)

38. Mrs Pointon complained that the two assessments of her husband's eligibility for NHS funded respite care, which were commissioned by Cambridgeshire Health Authority in February and August 2001, did not address Mr Pointon's psychological needs and were biased towards physical symptoms. They did not take into account the vigilance that was needed to deal with the

increasing possibility of Mr Pointon having an unpredictable physical episode such as choking or fitting, as a result of his reactions to any visual or spatial changes.

39. The assessments were made against the Health Authority's 'Policy and Eligibility Criteria for NHS Funded Continuing Health Care'. This policy which had been produced by the Health Authority in April 2000 was reviewed in March 2002 in light of HSC 2001/015, which consolidated the guidance on continuing care, particularly in light of the Coughlan judgment. In making my findings I have taken account of the advice of the Assessor, who in paragraph iii(a) of her report stated that although the local policy reflected the relevant Department of Health guidance, it had been misinterpreted by staff, was focussed towards acute care and made no provision for the assessment of psychological needs of patients with illnesses such as dementia.

40. The Manager undertook the first assessment in February 2001. At that time Mrs Pointon was caring for her husband at home, helped by carers partly funded by Social Services Direct Payments. The NHS were funding respite care in a psychiatric unit for one week in five. The Manager has stated that this assessment was not intended to test Mr Pointon's requirement for continuing care. The Health Authority's policy stated that such assessments should be performed by a multi-agency team, and I accept that a record of the assessment was sent to the Consultant Psychiatrist who felt that the input of an Occupational Therapist was more appropriate, given Mr Pointon's physical and mobility needs. The decision was that no further funded care was needed at that time. However, given Mr Pointon's condition I believe that it should have been performed against the Health Authority's criteria for continuing health care, in that medical input should have been included and it should have taken note of the Coughlan requirement to judge both the amount and the type of nursing care required.

41. Furthermore, in a situation such as this, with a patient whose mental and physical condition was inevitably going to deteriorate, it would seem short-sighted not to explore both the physical and psychological problems, with a view to the kind of support that would be needed in the near future.

42. The second assessment on 22 August 2001, on behalf of the Health Authority, was undertaken by a member of the District Nursing Team and the CPN. This was in response to Mrs Pointon's request for NHS funded respite care at home when Mr Pointon was no longer able to travel to the psychiatric

unit. Mr Pointon's General Practitioner supported the request for additional ongoing funding. After taking advice from the Consultant Psychiatrist, who advised that extra help should be provided within Mr Pointon's home, the Health Authority suggested that a carer for a few hours a day, for six days, every five weeks would be sufficient. The decision appeared to have been taken without any regard to the Health Authority's policy on short-term admission or respite (end of paragraph 13). I would question whether, even if Mr Pointon had become less mobile, the need for funded respite care should drop so dramatically when he was permanently placed in his own home. It appeared that full NHS funding for respite care would only have been available if he had been an in-patient. Surprisingly, a letter from the CPN who assisted at that assessment, but was not received by the Health Authority until March 2002, supported Mrs Pointon's request.

43. I understand that the Health Authority ceased to exist on 1 April 2002. However, I agree with the Assessor that the local eligibility criteria reflected the guidance from the Department of Health, but that the ambiguities within the criteria, particularly those referring to dementia and sensory and/or physical disabilities, caused staff to produce inappropriate assessments that concentrated solely on Mr Pointon's physical needs. I uphold this complaint.

Findings (b)

44. I turn now to the actions of the PCT who took over the responsibility for continuing care cases in April 2002. They also took over the Health Authority's eligibility criteria. Mrs Pointon had complained in January 2002 to the Health Authority about their decision not to fund an extra carer every five weeks to maintain the pattern of respite care. She had also complained to this Office. The incoming PCT agreed with Mrs Pointon that a further assessment of her husband's condition should be carried out on 15 April. It was completed by a member of the District Nursing Team and was headed 'Health Needs Assessment'. Once again this assessment followed the pattern of assessing purely physical and nursing needs against very specific criteria (paragraphs 17 and 18) that it would be very difficult to provide in the home setting. The Consultant Psychiatrist was consulted by the Manager, but once again was asked very specific questions about the type and frequency of professional input that Mr Pointon needed at that time and gave no recognition, either to Mr Pointon's psychological needs, or to the unusually high standard of care that Mrs Pointon and her team were providing.

45. The Assessor criticised the range of this assessment and confirmed that the questioning rendered funding for respite care at home practically impossible. The PCT and Social Services decided that Mr Pointon's health needs were being met, that the respite care was purely social and refused funding in May.

46. In subsequent discussions the clinicians and the nurses agreed that Mrs Pointon was giving highly personalised care with a high level of skill. This was later described by the independent Consultant as nursing care equal if not superior to that that Mr Pointon would receive in a dementia ward.

47. In September 2002 the independent Consultant commissioned by Mrs Pointon, produced a report which confirmed that Mr Pointon's symptoms stemmed solely from a health condition that was severe, complex and unpredictable, needing 24-hour care and frequent interventions to prevent him harming himself. After the Consultant Psychiatrist and the Consultant Geriatrician had confirmed the independent Consultant's opinion that Mr Pointon did meet the eligibility criteria for NHS continuing care, a package of care was agreed with Social Services whereby the NHS would fund the cost of an additional carer every fifth week. The PCT have explained that they can only make Direct Payments within a package of payments with Social Services. However, they have also agreed that should Mr Pointon require in-patient care at a future date, then he would be admitted to an in-patient facility agreed by Mrs Pointon. It is sad to reflect that this solution is the one that Mrs Pointon suggested in January 2002. Whilst I am pleased that agreement was reached eventually, I agree with the Assessor's opinion that the PCT assessed Mr Pointon against the wrong criteria, once again focusing on physical needs and also failing to recognise that the standard of care provided by Mrs Pointon was equal to that that a nurse could provide. I uphold the complaint.

48. In May 2003 in the light of the Ombudsman's report (paragraph 14), the Department of Health issued guidance to Strategic Health Authorities and PCTs on the procedure to use when reviewing continuing care cases dating back to April 1996. It is my opinion that they should also review the eligibility criteria to ensure that the criteria for funding care at home, and the recognition of patients' psychological as well as physical needs, are clearly defined. While I am aware that the continuity of her husband's care is one of Mrs Pointon's main concerns, I **recommend** that the PCT discuss with Mrs Pointon, in the light of the Department of Health guidance, the provision of Mr Pointon's current funding, and determine whether any retrospective payments are indicated.

Conclusions

49. I have set out my findings in paragraphs 38 to 48. The PCT has agreed to my recommendation in paragraph 48 and has asked me to convey through my report - as I do - its apologies to Mrs Pointon for the shortcomings I have identified.

Reissued November 2003