



NHS funding for long term care: follow up report



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Foreword

NHS funding for long term care: follow up report

In February 2003, I published a report on the NHS funding of long term, or continuing, care. It highlighted problems with the application of local eligibility criteria and with the national guidance framework. This had resulted in actual or potential injustice to some disabled and elderly people, who were paying for their own care when the NHS should have paid for it. I recommended that strategic health authorities and primary care trusts should take steps to remedy retrospectively any injustice and that the Department of Health should clarify its guidance and provide support to the NHS bodies concerned in carrying out that work.

Following our report, more people claimed retrospective funding than were initially expected. We recognise that considerable efforts and resources have been expended in dealing with these cases, which have raised the profile of an important area of health care. In a written statement to the House of Commons on 16 September 2004, Dr Stephen Ladyman, the Parliamentary Secretary of State for Community, said that around 20% of those cases reviewed by the end of July 2004 were found to be eligible for full funding and the NHS expected to pay around £180 million in restitution. However, we have received, and continue to receive, numerous complaints about continuing care - almost 4,000 in all since February 2003. Many of the complainants are themselves frail, elderly people who have been trying unsuccessfully to obtain and understand the criteria for funding continuing care in their area and find out whether or not their spouse or relative will qualify. Complaints have arisen partly because of a lack of available information about how to go about getting an assessment for continuing care funding and partly because of the significant delays in carrying out the retrospective reviews; it looks unlikely to me that all 28 strategic health authorities will completely clear the backlog by the end of 2004. I have also received many complaints about the process for carrying out reviews, the reasonableness of the decisions reached and delays in providing agreed restitution.

Evidence from these complaints suggests to me that it is in the public interest to lay this further report before Parliament in accordance with Section 14(4)(b) of the Health Service Commissioners Act 1993. These complaints reveal some persistent problems at the heart of the continuing care framework. First, it has become clear that the absence of clear and consistent national criteria for continuing care funding has resulted in much confusion and potential inequity in the way strategic health authorities made decisions on patients' continuing health care needs. Secondly, NHS bodies need further support and guidance from the Department of Health to ensure all new requests for continuing care are decided promptly and properly and according to a national framework.

My main concern (once we are reasonably satisfied that no-one has been wrongly denied funding) is to look to the future. I welcome the outline commitment to commission the development of a national consistent approach to assessment for fully funded NHS continuing care given by Dr Ladyman in a written statement to the House of Commons on 9 December and hope that it addresses all the shortcomings identified in this report. The independent review commissioned by the Department endorses the recommendations in this report and their findings closely match what we have found in the complaints to my Office. We both identify the need for national criteria; accredited assessment tools; training for NHS staff; better record keeping and documentation; and assurance that people who should have had their case reviewed have not been overlooked. In the short term, the process of retrospective reviews needs to be promptly and thoroughly completed. Some people have already had to wait far too long. Longer term,

much learning has come out of the reviews and this should inform future work on continuing care both nationally and locally. The ultimate goal must be to secure the foundations for fair and equitable treatment of those who are entitled to NHS funding of their long-term care.

Ann Abraham

Health Service Commissioner for England

December 2004

Summary

We reported in February 2003 on problems with the process for assessing eligibility for NHS funding for long term, known as continuing, care. Our investigations found that local criteria for determining eligibility for funding might have been over-restrictively or poorly applied by NHS bodies. Some disabled, frail or elderly people, who were in fact eligible, had therefore been denied funding of their health care and accommodation by the NHS and had paid for means-tested services arranged by their local authority. We recommended that primary care trusts and strategic health authorities, which had taken over from the former health authorities, should trace those people who might be affected, review their circumstances and where justified make restitution, and that the Department of Health should guide and support them in that work.

Responding to demand for retrospective reviews

Following our report, the demand for re-assessment was greater than anticipated. The Department of Health assured us that the reviews would be completed by 31 December 2003, but it was clear well before that date that there would be a backlog and the Department eventually extended the deadline to 31 March 2004. They later reported that by that date only 57% of the retrospective reviews (6,644 out of 11,655) had been completed and we understand that some NHS bodies might not have completely cleared the backlog by the end of 2004. Since February 2003, we have received nearly 4,000 complaints about continuing care, most of which were initially passed back to the strategic health authorities to review and resolve locally.

Local capacity to deal with the demand for retrospective reviews was severely restricted in places, contributing to considerable delays in starting on them. The Department of Health has stated that the NHS expects to pay a total of £180 million in restitution. However, it expects the strategic health authorities to find the administrative resources needed for the reviews out of their own budgets. Adequate explanations of the purpose of the reviews, and training for assessors and panel members, was either patchy or non-existent.

Despite the large numbers of claimants, we would like reassurance from the Department that sufficient efforts have been made to trace all those who might have been affected.

Reviewing and developing eligibility criteria

We recommended that strategic health authorities should review the criteria used in their areas since 1996 (when written criteria were first required) for compliance with the law as it stands and with national guidance. We also recommended that the Department of Health should review its guidance, making it much clearer who is eligible for funding.

They did not do this but asked strategic health authorities to complete the task of integrating the former health authorities' criteria which applied across their areas. This was a difficult task carried out in parallel with the retrospective reviews and required considerable effort to integrate several often-diverging sets of criteria from the former health authorities.

The processes of criteria revision and retrospective review have led to a greater understanding of continuing care and of the factors that determine eligibility. However, in the absence of revised national guidance there remain difficulties of interpretation and confusion about the distinction between continuing care funding and 'free' nursing care. This may mean that there is still scope for some people to be disadvantaged. We believe there is a compelling case for establishing clear, national, minimum criteria for determining who is eligible for continuing care funding.

The process of retrospective assessment and review

In April 2003 the Department of Health issued a suggested procedure for carrying out the retrospective reviews. Some primary care trusts were unaware of it, local expertise in continuing care was sometimes limited and support from the Department was often lacking. Many NHS bodies made considerable efforts to carry out the reviews robustly and fairly. But the complaints to us show that there was significant variation in the way NHS bodies approached reviews and that in some cases they were poorly carried out. Particular problems include:

- Assessment methods: in the cases we have seen the quality of clinical assessments and of decision-making has been very variable. We recommend that there should be nationally accredited assessment tools and good practice guidance to assist healthcare professionals in applying eligibility criteria;
- Panel procedures and documentation: membership of panels has varied considerably, decisions have been taken without the necessary clinical input and the quality and availability of relevant documentation has been limited;
- Variable communication with, and involvement of, patients and relatives: some NHS bodies have made considerable efforts to communicate effectively throughout the process. Others have done less than the bare minimum, for example sending one-paragraph rejection letters with little reasoned explanation of decisions; and
- Restitution: some recent complaints have revealed delays in making agreed payments.

- Clarifying standards for record keeping and documentation both by health care providers and those involved in the review process;
- Seeking assurance that the retrospective reviews have covered all those who might be affected; and
- Monitoring the progress of retrospective reviews and using the lessons learned to inform the handling of continuing care assessments in the future.

Conclusions and recommendations

Most NHS bodies have made considerable efforts under difficult circumstances to make restitution to patients and their families for previous failures to pay continuing care funding. Department of Health figures show that up to 20% of those reviewed by the end of July 2004 have received restitution. And some improvements have been made to procedures for assessing eligibility in new (non-retrospective) cases. **However, we do not believe these go far enough and recommend that the Department of Health needs to lead further work in six key areas to improve the national framework for continuing care and its application by:**

- **Establishing clear, national, minimum eligibility criteria which are understandable to health professionals and patients and carers alike;**
- **Developing a set of accredited assessment tools and good practice guidance to support the criteria;**
- **Supporting training and development to expand local capacity and ensure that new continuing care cases are assessed and decided properly and promptly;**

Background

1. In February 2003, we published a report on arrangements for NHS funding of the long term care, known as continuing care, of older and disabled people (NHS funding for long term care - HC 399). NHS funded continuing care is a package of care arranged and funded solely by the NHS for people who need it because of disability, accident or illness. It can cover physical and mental health needs and can be provided in a range of settings - care homes, patients' homes or hospitals.

2. A pattern was emerging from the complaints we had received about NHS funding for such care. Our investigations found that some NHS organisations had made decisions about eligibility for NHS funding based on local criteria that appeared to us to be over-restrictive or not in accordance with the law as it stood. The indications were that this might be a widespread problem. We also concluded that national guidance did not provide a clear, well-defined framework for making fair, logical and transparent decisions about individual entitlement. The effect was to cause injustice and hardship to some vulnerable and elderly people and their relatives.

3. We therefore recommended that strategic health authorities and primary care trusts, which have taken over the work of the former health authorities, should review the criteria used by their predecessor bodies, and the way those criteria were applied, since 1996 (when it first became mandatory to have written criteria). They also needed to identify those patients who might have been disadvantaged by wrongly interpreted or unfair criteria and remedy any consequent financial or other injustice. We recommended that the Department of Health should consider how to monitor those bodies in that work, review and clarify national guidance on eligibility, check that criteria used in the future followed that guidance and consider how to clarify the framework for assessment of eligibility. Annex A lists the conclusions and full recommendations from our report.

Responding to demand for retrospective reviews

Delays in carrying out reviews

4. A week after the publication of our report, the Department of Health asked strategic health authorities to review whether continuing care criteria in use since 1996 were compliant with the law and to determine how many people might have been wrongly assessed under non-compliant criteria. It had already asked, in August 2002, each strategic health authority to bring together into a single set the former health authorities' criteria for determining eligibility for NHS funding for continuing care. In May 2003, the Department asked authorities to carry out by 31 December 2003 retrospective reviews of eligibility for funding in cases where it might have been wrongly refused. In addition, later in 2003, the Department commissioned an independent review of progress with continuing care in nine strategic health authorities (Continuing health care: review, revision and restitution - published by DoH on 9 December 2004).

5. Although we had indicated in our report in February 2003 that 'significant numbers of people and sums of money are likely to be involved', the large scale of applications for retrospective review and restitution was unexpected. In view of this, the Department of Health extended the deadline for dealing with them to 31 March 2004. We passed on to the Department of Health early concerns that we had heard from NHS bodies about difficulties in meeting both the December and March deadlines. However, on both occasions the Department assured us that their information showed the targets would be met and we passed on these assurances to complainants, their representatives and Members of Parliament. It became evident that the Department's information was unreliable. It was very disappointing that in September 2004 the Parliamentary Under Secretary of State for Community reported that only 57% of the retrospective reviews (6,644 out of 11,655) had been completed by the extended deadline of the end of March 2004. This prompted a flood of complaints to us - mainly from frail, elderly people who were themselves carers or from their relatives - about delays in receiving a decision. Furthermore, it now seems unlikely to us that all strategic health authorities will have completed their

reviews by the end of December 2004, a full year after the original deadline. In all, since February 2003 we have received nearly 4,000 complaints about continuing care funding. We are disappointed to have been told by the Department that they have not collected central statistics relating to the retrospective reviews since July 2004 and, at present, have no plans to do so. They could, therefore, be unable to round off the exercise by giving final figures for the number of cases reviewed and their outcome. This is unfortunate and we recommend that the Department keep an overview of the exercise and use the information from it to inform their handling of future claims.

6. Many of the complaints about continuing care that we received in 2003 and in the early part of 2004 concerned delays in carrying out retrospective reviews of eligibility. In the main, those strategic health authorities with the largest number of cases had the greatest difficulty completing them on time. It is clear that some primary care trusts took a long time to get started. For example, one primary care trust did not send out forms on which to apply for a retrospective review until nearly a year after we published our report in February 2003. They then said that the reviews would only take place 12 weeks after the completed forms were received. In other places, there is evidence that NHS bodies took too long to recruit, train and convene review panels. In one case, a primary care trust said in June 2003 that they were waiting for DOH guidance before they could proceed, although this had been issued the previous month. A number of others said that they were awaiting instructions from their strategic health authorities.

7. We recognise that, in some cases, primary care trusts had to wait for the relevant records and evidence to be made available. We also understand that a proportion of requests for review were not received, or at least recorded, until after the December 2003 deadline for completing reviews had passed. In many places, though, the number of claims simply surpassed the local capacity to deal with them.

Delay

Mrs Z first complained to the Ombudsman on behalf of her late mother, Mrs H, in March 2003. That same month we wrote to the strategic health authority and, as the DoH had asked, invited them to hold a retrospective review. Despite reminders from us, a review did not take place until April 2004. The delay was caused, in part, by a delay in receiving nursing records

from Mrs H's nursing home, but there was evidence that the authority and the trust, to whom they had passed the request for a review, did not take any effective action on the case during 2003, apparently due to the number of requests for review received. (The authority was one that those that had the highest number of requests, according to Department of Health figures.)

Delay and failure to communicate

In March 2003, Mr N wrote to the strategic health authority applying for a refund of nursing home fees for his late mother; having noted the publicity following the Ombudsman's special report the previous month. The authority wrote back to Mr N later that month saying that the case had been transferred to the appropriate trust, which had been asked to take action.

In April 2003 the trust wrote to Mr N saying that they were unable to proceed with his claim until they had received guidance from the Department of Health.

In October 2003 Mr N complained to the Ombudsman that he had heard nothing from the trust. We made enquiries of the trust which then replied to Mr N in November, saying that they would send him a questionnaire to facilitate the processing of his application. The trust said that a review would take place within 12 weeks of their receiving the completed form. Mr N did not receive the questionnaire until 20 February 2004, 11 months after his first approach, and returned it within a few days. A review panel did not take place within 12 weeks and once again we made enquiries to find out what was happening.

It transpired that the nursing home which had been caring for Mr N's mother had closed down, and the trust had failed to follow up its original request to the home for its nursing records. A review panel was finally arranged for the end of September 2004.

Local capacity

8. It was clear to us well before December 2003 that large numbers of people were affected and that capacity at a local level to deliver the extensive and detailed reviews required was severely stretched. It was evident that NHS bodies needed support and guidance to enable them to carry out the reviews promptly and thoroughly if the deadlines

were to be met. Yet adequate training for assessors and panel members was delayed or minimal in many primary care trusts and strategic health authorities.

9. The Department provided extra funding for the purposes of restitution (£180 million), but this did not cover the administrative resources needed to set up the retrospective assessment process. Furthermore, it was not until well into 2004 that the Department's Recovery and Support Unit was mobilised to address the situation in those strategic health authorities that were lagging behind. The delays resulted in our receiving a large number of complaints from claimants and their representatives, including Members of Parliament, whose expectations had been raised by the Department's deadlines.

10. In view of the delays in completing reviews, and after discussion with the Department of Health and the Healthcare Commission, from 12 July 2004 we exercised our discretion to look at complaints which had been through all the stages of the local review processes, rather than expecting complainants then to go through the full NHS complaints procedure. This was mainly to avoid prolonging the delay for many frail, elderly complainants who had already had to wait long enough. But it was also in recognition of the level of independent, specialist assessment of the claim that had already been given by the trusts and/or authorities in their review procedures. Many primary care trusts told us that they had exhausted the assessors available locally and could not identify people competent to undertake a further independent review. To deal with this additional work we set up a dedicated continuing care unit of investigators to concentrate the considerable knowledge and expertise that we have developed in this area.

11. We recommend that the Department support training and development to expand local capacity and ensure that new continuing care cases are assessed and decided properly and promptly.

Case finding

12. Despite the large numbers of people who did come forward, we would like assurance that sufficient efforts have been made in all cases to locate everyone who might be affected. Our February 2003 report recommended that strategic health authorities should '...attempt to locate any patients in their area who may wrongly have been made to pay for their care in a home...'. We know that some strategic health authorities made extensive and comprehensive efforts to locate

patients and their relatives. From the evidence available to us, we are not able to say with certainty if these efforts have been replicated throughout the country. We note, however, that new cases for retrospective review are still coming to light. The Department's own independent review also raises this issue:

'The approach to case finding in most SHAs had relied in the first instance on cases presenting themselves for review, and on those who had come forward as a result of the advertising and publicity of the restitution exercise. It was widely recognised that there could be a further task still to be completed that would entail seeking out cases. There was a concern that many of the most disadvantaged cases might have been overlooked by a process that had favoured the articulate and well-informed' (Executive summary).

13. We recommend that the Department of Health should therefore seek reassurance that strategic health authorities have made sufficient efforts to trace and contact those potentially affected.

Reviewing and revising eligibility criteria

Developments since February 2003

14. Our February 2003 report recommended that strategic health authorities and primary care trusts should 'review the criteria used by their predecessor bodies, and the way those criteria were applied, since 1996. They will need to take into account the Coughlan judgment, guidance issued by the Department of Health and my findings' (paragraphs 26 and 39). The report also recommended that 'The Department of Health should review the national guidance on eligibility for continuing NHS health care, making it much clearer in new guidance the situations when the NHS must provide funding and those where it is left to the discretion of NHS bodies locally' (paragraphs 32 and 40).

15. In response to the first of these recommendations, the Department of Health asked all strategic health authorities to review whether continuing care criteria in use in their area since 1996 were consistent with the Coughlan judgment. This was a landmark judgment in continuing care (*R v. North and East Devon Health Authority ex-parte Pamela Coughlan*, July 1999). It considered whether nursing care for a chronically ill patient might lawfully be provided by a local authority as a social service (in which case the patient would pay according to their means) or whether it should be provided free of charge by the NHS. This depended on whether the nursing services were merely incidental or ancillary to the provision of accommodation that a local authority has a duty to provide and of a nature that an authority whose primary responsibility is to provide social services could be expected to provide. The overriding test is whether the person's need is primarily a health care or a social care need, although the Coughlan judgment did not draw a hard and fast line between the two.

16. In response to our second recommendation the Department of Health, instead of updating its own national guidance, required authorities to complete the integration of their continuing care criteria into a single set of criteria applicable across each strategic health authority area and legally compliant with the Coughlan judgment. Our report in February 2003 observed that national guidance issued post-Coughlan in June 2001 (Continuing Care:

NHS and local councils' responsibilities - HSC 2001/015, LAC(2001)28) did not clearly define when continuing NHS health care should be provided - hence our recommendation that this should be reviewed at a national level.

17. All strategic health authorities have now reviewed their criteria and have developed revised, integrated criteria. We recognise that this was a difficult task. Authorities were inheriting variable approaches and attempting to integrate several often-diverging sets of criteria from the former health authorities. It was also a task undertaken in parallel with carrying out the retrospective reviews and in some cases proved to be a factor in the delays. Individual strategic health authorities have expended considerable effort on this task and we are concerned that much good practice that could be shared more widely might have been overlooked.

18. It is clear that the process of reviewing eligibility criteria and carrying out retrospective reviews has helped to raise the profile, and increase the understanding, of continuing care. The Department of Health's independent review of nine strategic health authorities confirms that there is now greater acknowledgement that it is a patient's overall health care needs that should determine eligibility for continuing care funding, that those needs may change over time and that care can be provided in a range of settings, not just in an NHS hospital. In particular, it is the complexity or intensity or unpredictability of the presenting needs that determine eligibility and not the condition itself. Some of these principles were reinforced by the case of Mr Pointon (see below).

Comprehensive needs assessment and location of care

Mrs Pointon complained to the Ombudsman that her husband, who suffers from severe dementia, had been wrongly refused NHS funding for respite care. Mrs Pointon subsequently waived her anonymity to talk to the press and the Alzheimer's Society. We upheld Mrs Pointon's complaint, as the former Cambridgeshire Health Authority's assessments concentrated solely on Mr Pointon's physical, and not his psychological, needs. Neither did they take account of the care provided by Mrs Pointon at home. We made a general recommendation that eligibility criteria for funding at home should be clearly defined and that assessments should include recognition of patients' psychological as

well as physical needs. Before we issued our report, the primary care trust agreed to fund the whole of Mr Pointon's care at home.

This case raised important issues around eligibility and assessment. However, our recommendations did not extend, as some commentators have maintained, to providing continuing care funding to all those who suffer from dementia. It is the healthcare needs, not the diagnosis, that determine whether the criteria for funding are met.

Setting of care: residential home

Mrs H, who had Alzheimer's disease, a pulmonary embolism, a chest infection and frequently wandered, was placed from hospital in a residential home for the elderly, mentally infirm in April 2002. Her son, Mr H, requested funding following the Ombudsman's special report in February 2003. The trust sent Mr H a letter in September 2003 telling him that they would conduct a retrospective review, saying:

"We will be gathering the information necessary about your relative's health and abilities at the time of admission to the residential home as part of that review"

Assessments were carried out in December 2003, and in January 2004, Mr H was told that the trust had concluded that his mother was not eligible for funding. The rationale for this was that she was in a residential home. We asked the trust to clarify the basis of their decision and a further response was sent, setting out other reasons for refusal, but identifying Mrs H's placement in a residential home as the significant factor in refusing funding.

Once again we told the trust that the place of care was not relevant, and suggested that, in line with DoH guidance, a full and proper review of Mrs H's health care needs should be carried out, particularly as there had been no discharge assessments when she had left hospital, and it was unclear whether original contemporaneous hospital, GP and residential home records had been gathered and considered. In our dealings with the trust we also acknowledged that our clinical advisers were of the opinion that, from the papers they had seen, it was unlikely that Mrs H

had unpredictable, complex or intense health care needs.

Finally we asked the trust to confirm that no other requests for funding on behalf of people in residential homes had been screened out of the retrospective review process. Each case should merit a full assessment of their health care needs.

19. Despite some welcome rationalisation and clarification, we have found a continuing lack of clarity around the interpretation of words such as 'unpredictability', 'complexity' and 'intensity', causing difficulties for health care professionals as well as for patients, carers and relatives. There are also multiple sets of eligibility criteria across the country and complainants question why this should be so in a national health service. As the independent review has identified, many of the local criteria in place in different strategic health authorities appear to be similarly worded. But there are strategic health authorities where the content and interpretation of their criteria differs significantly from those of others. The result has been that some cases have been assessed using what appear to be overly-restrictive or poorly applied criteria. In the absence of national criteria, a degree of variation in the wording of local criteria may be acceptable in order to explain or interpret Departmental guidance, but this flexibility cannot be used to restrict that guidance. The addition of words such as 'specialist' restricts the guidance rather than interpreting it. We have written to a number of strategic health authorities expressing our concerns and have also raised the matter with the Department.

Application of criteria

Mrs F was resident in a nursing home from August 1998 to October 2003, when she died. She was initially self-funded and later social services means tested. Due to her mental and physical deterioration, her funding was shared equally by the NHS and social services from July 2002.

Our 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. We 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. We asked the strategic health authority to carry out another review, taking into account DoH guidance and our concerns about criteria which include specialist intervention.

20. We cannot make a definitive judgment about whether an individual authority's new criteria are lawful or otherwise; that is for the courts. We can only investigate if maladministration has been alleged, either in individual cases or because of systemic faults. However, judging by what we have seen from some of the complaints we have received about the retrospective reviews, some NHS bodies have still failed to establish or maintain a logical, fair and transparent system for making decisions about continuing care funding retrospectively. In these circumstances, we are concerned that scope may still exist for some patients to be disadvantaged.

Poor process and delay

Mr A cared for his wife, who had suffered from multiple sclerosis since 1982, at home until September 2001, when Mrs A moved to a residential home. At the request of the matron, in April 2002 Mrs A was transferred to a nursing home as her condition was deteriorating and her needs could not be met at the residential home. By this time, in addition to multiple sclerosis, Mrs A was diagnosed with epilepsy, anaemia, contractures and fractures of her left arm and leg due to falls, and frequent urinary tract infections which made her confused and agitated.

In January 2004, the trust assessed Mrs A as being eligible for high band RNCC funding, but there was no evidence or rationale presented as to why Mrs A did not qualify for continuing care funding.

Mr A complained to the Ombudsman about the decision not to fund, and the fact that it had taken the trust nine months to provide him with a copy of the eligibility criteria on which the decision had been made.

One of our clinical advisers said:

"Due process in cases where there is high level and borderline need such as this warrants the presentation of underpinning clinical evidence to support any decision of the PCT in declining to fund Mrs A."

The assessment of the health care needs as presented from the papers received by our

adviser was that "...Mrs A's health status is complex, unstable and unpredictable, in relationship to management of her epilepsy, renal function, dietary intake, swallow reflex, and behaviour should she develop a urinary tract infection".

We also learned at this time that Mr A had been diagnosed with cancer, and that his daughter would take over the complaint. The trust undertook to re-review the case in June 2004.

The review did not take place until 22 October and the decision to refuse funding remained unchanged. Furthermore Mr A's daughter was told that neither she, nor her father was entitled to be present at the review panel meeting.

Mr A's daughter complained again to the Ombudsman. Our investigation is continuing.

NHS Funded continuing care vs free nursing care

21. We have also found continuing misconceptions about the distinction between NHS funded continuing care and 'free' nursing care. Registered Nursing Care Contribution (RNCC - also known as 'free' nursing care) funding was introduced in October 2001 to fund care in nursing homes by a registered nurse for people who would otherwise fund the full cost of their care themselves. It was extended in April 2003 to all care home residents (Guidance on NHS funded nursing care - HSC2003/006, LAC(2003)7). There are three levels (bands) of nursing care, high, medium and low, each of which attracts a different level of NHS funding, following an assessment by an NHS nurse. Department of Health Guidance accompanying the introduction of RNCC attempted to make it clear that responsibilities for providing continuing NHS health care (defined as where the totality of a patient's care should be arranged and funded by the NHS) were unchanged.

22. However, some NHS bodies appear to regard entitlement for NHS continuing care funding as simply a 'top band' above the higher band of RNCC funding. This may mean that they are not considering the totality of a patient's healthcare needs **before** assessing eligibility for RNCC funding. This is borne out by the fact that, in many instances, we have found only nursing assessments considered in retrospective reviews and not comprehensive, multi-disciplinary continuing care funding assessments that cover health care needs falling outside the scope of Registered

Nurses to provide. The wording of guidance relating to healthcare needs at the highest band of RNCC funding is very similar to the Department of Health's guidance as to who might be eligible for NHS funding, which may be contributing to the uncertainty at local level.

23. There are therefore a number of areas of uncertainty that need to be addressed in order that a level playing field exists across the country. This leads us to believe there is a compelling case for introducing consistent clear national, minimum criteria for determining eligibility for continuing care funding. This is reinforced by the independent review commissioned by the Department of Health, which showed that all nine strategic health authorities reviewed were in favour of national criteria. As our report said in February 2003:

'I do not underestimate the difficulty of setting fair, comprehensive and easily comprehensible criteria. The criteria have to be applied to people of all ages, with a wide range of physical, psychological and other difficulties. There are no obvious, simple, objective criteria that can be used. But that is all the more reason for the Department to take a strong lead in the matter: developing a very clear, well-defined national framework' (paragraph 31).

24. We recommend the establishment of clear, national minimum eligibility criteria which are understandable to health professionals and patients and carers alike.

The process of retrospective assessment and review

25. Our report in February 2003 recommended that strategic health authorities and primary care trusts should 'Make efforts to remedy any consequent financial injustice to patients, where the criteria, or the way they were applied, were not clearly appropriate or fair' (paragraphs 26 and 39). We also recommended that the Department of Health should 'Consider how they can support and monitor the performance of authorities and primary care trusts in this work' (paragraphs 27 and 40).

26. The process of retrospective review has produced positive results. First, in a written Ministerial statement to the House of Commons on 16 September 2004, it was announced that "almost 20% of cases have been granted recompense". Secondly, in a written statement to the House on 22 June 2004 (amended on 24 June), Dr Ladyman said that further cases for retrospective funding which had come to light should be decided within two months of all the information being received by the NHS body concerned. We very much hope that this will be the case. Finally, the experience of conducting reviews and making decisions has resulted in a higher profile for, and a better understanding of, the issues involved in continuing care - a previously largely neglected area.

27. We know that many strategic health authorities have made considerable efforts to review and integrate their local criteria and to apply them consistently and fairly to individual cases. We also recognise that, because of the sheer volume of cases and the lack of resources and support, the process of carrying out the retrospective reviews has often been demanding for staff and frustrating for patients and relatives. In view of this, on several occasions where we have received complaints that concern the same primary care trust or strategic health authority, we have made informal approaches to the body concerned to encourage them to put things right before we considered taking things further. This has often achieved a positive response and agreement to re-review individual cases. For example, in response to our letter pointing out some flaws in their retrospective review of a patient, one strategic health authority replied, 'The panel have recognised that

more supporting information would be helpful, and we now therefore obtain as much documentation as is possible to support the appeals. It is our intention to formally review the process to incorporate lessons learned over the past year.' That attitude is encouraging and welcome news for complainants.

28. However, we currently have over 430 unresolved cases where retrospective reviews have been carried out, but complaints have been made that the review process was flawed, or that the decision made was unreasonable or that there were problems in obtaining payment of the monies owed to those granted full funding. The trust and strategic health authority assessments and reviews we have already examined run the full spectrum from meticulous and searching to those where claims have been rejected summarily, in some instances without any attempt to look at the patient's health care needs or to obtain their health care records or simply because of the setting in which the care was delivered.

29. In more than half of the cases that we have examined, we have found that assessments have not been carried out properly. There are a number of aspects of the review process where complaints have revealed systemic problems. They include problems with:

- Lack of consistency of approach to reviews;
- Non-robust assessment methods;
- Confused and inconsistent panel procedures and failures to obtain documentation and record reasons for decisions;
- Poor communication with, and involvement of, patients and relatives; and
- Delays in payment of restitution.

Consistency of approach to reviews

30. In April 2003 the Department of Health issued guidance to strategic health authorities in the form of a template, which contained a suggested procedure for carrying out retrospective reviews. This has been interpreted by most strategic health authorities as involving a re-assessment of the patient against the eligibility criteria, using the available evidence, followed by a hearing by a primary care trust panel, which makes a decision. In some areas, if the claimant contests the outcome of the first panel, this is followed by an appeal heard by a different panel at the strategic health authority.

31. However, it emerged that few primary care trusts were aware of the existence of the template. In any case, the suggested procedure was not

compulsory, although there was an expectation that retrospective reviews would follow the two-tier process outlined in the previous paragraph. In our investigations we have therefore had to take a view on whether the procedure followed and the decision reached were reasonable - that is, robust, transparent and fair. In many cases, we have concluded that they were not. Complaints we have examined show that there was much variation between primary care trusts and strategic health authorities in the way they approached reviews and that in some cases they were poorly carried out. This variation is reflected in the diverse titles given to the different tiers of the process. We found them variously referred to as 'restitution panels', 'independent review panels', 'Ombudsman panels', 'appeal panels' or 'retrospective care panels'. This caused confusion for patients, relatives, their representatives and our investigators alike in trying to ascertain whether cases had been reviewed more than once, and the degree of independence of the second tier, if one existed.

32. In the absence of support and leadership from the Department of Health and from some strategic health authorities, our investigators were regularly receiving requests from staff at trust level, where the majority of retrospective reviews were carried out, for advice, interpretation of Department of Health guidance and even training. We also received many requests from patients, relatives and patient advice and pressure groups for clarification of the review process. Where appropriate we were as helpful as we could be. However, in our view it was a matter for the Department, not the Ombudsman, to clarify procedures which the Department, itself, had initiated. We raised this in meetings with the Department.

Opaque and unfair appeal process

Mr J had successfully appealed on 1 August 2003 against a decision of the primary care trust that his mother, an Alzheimer's sufferer, did not qualify for NHS funding. However, the Chief Executive of the strategic health authority (who had initially endorsed the appeal decision) intervened to prevent the funding being paid because she considered that the decision was flawed, even though payments had already commenced.

Our enquiries revealed that the decision not to pay had originated from the primary care trust. Having disagreed with the appeal decision, they had asked two other strategic health authorities to undertake assessments of Mrs J's entitlement to continuing care

funding using those other authorities' criteria. The strategic health authorities decided that, under their criteria, Mrs J would not have qualified for funding, but Mr J was not informed that they had been asked to do this and was therefore unable to be present or make representations.

We were concerned that this process had been neither transparent nor fair. The strategic health authority accepted that Mr J should have been told what was happening. They agreed that another strategic health authority would be asked to make a fresh assessment (using the original authority's criteria) on the understanding that the original authority would be bound by the decision. They also agreed that funding should continue to be paid at least until that decision had been made.

Confusion about scope of retrospective reviews

Mr C complained about the funding arrangements for his mother, Mrs C, who had been in a nursing home from October 1994 until she died in February 2000. In a separate complaint, Mrs A complained about the funding arrangements for her father, Mr E, who was also in a nursing home from October 1995 until his death in June 2002.

The strategic health authority wrote to Mr C that '...Mrs C's placement falls outside the scope of the review because the review only relates to...placements made between April 1st 1996 and 1st October 2001'. They wrote to Mrs A that, '...Mr E's placement falls outside the scope of the review because: the review only relates to placements made between April 1996 and February 2003.' We contacted the authority and questioned whether this was reasonable. We suggested that the reviews should include those who were already in nursing homes in April 1996, and not just those who entered them afterwards. The authority agreed with our interpretation of the scope of the retrospective review programme, and agreed to consider these cases and others in the same situation.

Assessment methods

33. The quality of decision-making and of the clinical assessments on which those decisions are based has been very variable. We have found decisions made on scant evidence or on a nursing

assessment rather than a comprehensive, multi-disciplinary continuing care assessment. Some assessments have only considered a patient's needs at a single point in time rather than considering the issues of stability or complexity or intensity of need from all perspectives and over the full period following discharge from hospital. Patients' needs rarely remain unchanged for long periods of time.

34. Our previous report referred to the range of different approaches that existed for assessing eligibility for continuing care funding. Some authorities had detailed guidance and procedures to support their criteria, but others relied on clinical staff to interpret the criteria with little or no practical guidance. There had also been little national guidance on methods and tools for assessing against eligibility criteria. This was leading to inconsistencies in approach and decisions both within and between health authorities. Some of the complaints we have received about retrospective reviews indicate that there is still uncertainty about how to interpret, and carry out robust assessments against eligibility criteria. **We therefore recommend that, to support the application of national, minimum eligibility criteria, there should also be national good practice guidance and a set of accredited tools to assist with continuing care assessments.**

Communication

Following the Ombudsman's criticism of a trust's retrospective review, a letter detailing her concerns was sent to the trust, which agreed to do the review again.

We looked again at the case once the re-review had been completed, and found that, unlike the first review:

-there had been a full multi-disciplinary review group of appropriate practitioners with a sufficient level of independence and experience, who met and considered the case;

-all possible time frames for funding were reviewed;

-the review had examined all relevant clinical documents

-healthcare needs for each time frame were debated and recorded by the panel

-appropriate rationale for the decision not to fund had been presented,

and

-the decision reached appeared reasonable when compared to the eligibility criteria.

Although the review itself was done well, we noted that there had been a lack of communication with or involvement of the complainant in the review and re-review process, and that the initial shortcomings in the process warranted an apology from the Chief Executive of the trust. This is now being sought.

Panel procedures and documentation

35. In the cases we have seen, membership of the review panels has not been consistent between primary care trusts. In some cases, decisions were made by a single officer. Some panels did not include the relevant professional or clinical input to enable full consideration of whether the claimant was eligible from an informed clinical perspective. We are aware of one strategic health authority where a chair of an appeals panel routinely refused to convene panels; and where decisions were taken without taking clinical advice, even though the process set out in the authority's documents made it clear that panels would normally be held and that clinical advice was necessary.

36. Record keeping and documentation has been very inconsistent, both for original case records and the retrospective reviews themselves. Some NHS bodies have made every effort to trace the original records and documentation, although they have not been assisted by the absence of care home nursing records in many cases, which appear to have been destroyed after a minimal period. The quality of the original records, where they do exist, has also been variable. Other bodies have made only cursory attempts to trace documentation. One strategic health authority had initially refused to take into account a reliable but non-contemporaneous report, an approach which appeared to us to be unreasonably inflexible and was changed after our intervention.

Failure to consider all timeframes

In August 2004 the Ombudsman received a complaint from Mr A that the retrospective review panel had refused funding for his late mother, Mrs A.

We called for and reviewed the papers, and found that the assessment prepared by the trust's nurse assessor was well constructed and set out a clear chronology of events. It was accompanied by a comprehensive set of multi-disciplinary assessments, undertaken before Mrs A was discharged from hospital to a nursing home. However no nursing

home documents were sent to the review panel, and this was important as the nursing assessor had made reference to a rapid decline and terminal stage illness in Mrs A during January and February 2003.

We wrote to the trust, commenting on the positive aspects of the assessment. Mrs A may have qualified for funding during January and February 2003. The review panel had not identified this as a possible time frame for funding, nor had they debated the intensity and rapid decline in healthcare needs that may have been present during this period. We asked the trust to re-review Mrs A's eligibility for funding for this period, which the trust agreed to do.

37. Records and documentation generated during the retrospective review process have also varied considerably in quality. Since there has sometimes been a lack of documentation about panel membership, assessment data, proceedings and decisions in some cases, it has not been clear what evidence those panels examined. This flawed process has made it impossible for us to judge the reasonableness of decisions made in these circumstances. **We recommend the clarification of standards for record keeping and documentation both by health care providers and those involved in the review process.**

Poor process

Solicitors complained on behalf of Mrs V, about the refusal to fund her mother, Mrs T. We considered the case and in our letter to the trust in September 2004, we pointed out that their refusal provided no explanation about how the decision was reached. In particular that:

- there was insufficient reference to Mrs T's medical, health and social care needs;
- the source of the information about her needs was not identified;
- the rationale for refusing funding referred to the providers of the care ("unqualified carers" and "no input from specialist clinicians") and not Mrs T's care needs, and
- sufficient consideration had not been given to Mrs T's changing needs.

Furthermore, we noted that the rationale used by the PCT for refusing funding stated

that Mrs T "does not have any specialist nursing needs", but in the papers we received was an undated assessment, seen by an independent review panel which stated:

"fluctuations in Mrs T's mental state are unpredictable which would cause management problems in a setting where specialist skills and experience were not available".

We requested a fresh, properly conducted review.

Communication with, and involvement of, patients and relatives

38. Poor communication is a recurring theme in our investigations. It has also proved to be an issue in complaints about retrospective reviews. They have confirmed that NHS bodies vary greatly in how well they communicate with patients and their relatives. Some patients and relatives were kept informed of progress; at least one strategic health authority's process specifically included the sustained involvement of relatives at all stages, which we welcomed. Others had to wait for months after submitting a request for a retrospective review before they heard anything. Some NHS bodies provided well-reasoned letters explaining the outcome of the review and including relevant evidence. Others sent one-paragraph rejection letters. For example, one primary care trust failed to explain the process or the rationale for their decision to refuse full funding, despite repeated requests to do so from relatives. Another failed to explain sensitively or in any detail the reasoning for prioritising particular retrospective cases. Some trusts also failed to advise complainants about the existence of the appeals process or the Ombudsman.

39. This is a difficult and complex area and some complainants were confronted with unexplained jargon when they wanted a simple explanation of a decision. Our investigators have frequently had to spend time trying to explain the background and the detail to relatives, who have understandably been confused by the complexities and misled by some commentators and the media. One claimant, whose case we did not uphold, although disappointed with the outcome, wrote to us saying:

"Your letter did make clearer the criteria used to assess the care funding requirements, a point which we did not fully appreciate at the beginning of the complaint procedure, i.e. "having needs sufficiently intense or complex or unpredictable". Although [relative] did need

“extensive caring and was unable to attend to the activities of daily living” I appreciate that this did not meet the criteria as specified.’

Restitution

40. The aim of carrying out the retrospective reviews was to identify any individuals who had been wrongly refused continuing care full funding in the past and to make appropriate restitution. The Department of Health have provided around £180 million in funding for restitution to date. However, we have received a number of complaints concerning delays on the part of some NHS bodies in paying monies owed or recompense agreed. In addition, some claimants have been required to sign a declaration that the payment is for ‘full and final settlement’ when the payment is for monies that should rightly have been paid to the patient or the relatives at the time. We are also considering some complaints that the rate of interest applied to some retrospective payments has not been appropriately calculated or that the level of restitution granted does not provide adequate compensation for the previous failure to grant continuing care funding.

Delays in making restitution payments

Mrs Y complained about the funding arrangements for her mother, Mrs D, who died in November 2001 aged 85. Mrs D had a high intensity of health care needs. Having conducted a retrospective assessment, the primary care trust decided that Mrs D should have been deemed eligible for funding from February 2001 until she died. However, they refused to pay restitution until they had all the invoices. They accepted that payments had been made but a small number of the invoices from the eligible period were missing. The primary care trust tried to arrange a meeting with the Finance Director, the Head of Continuing Care and Mr and Mrs Y, but Mr Y felt this would be too upsetting for his wife. We discussed the matter with the primary care trust and explained that while we accepted the need for a clear audit trail, we felt there was sufficient information in this case and that it was unreasonable not to process Mrs Y’s claim. The primary care trust agreed to pay.

Conclusions and recommendations

41. Since the publication of our report in February 2003, there has been much effort locally to make restitution for previous failures to grant continuing care funding where patients had in fact been eligible. Progress would have been faster, and the process less onerous for claimants and NHS staff, if the Department of Health had provided clearer national guidance and stronger support in carrying out the reviews. We welcome recent actions taken by the Department to expedite the remaining retrospective reviews. We also appreciate the Department's willingness to tackle persistent problems at individual NHS bodies, and recognise that their intervention, at our request, in some individual cases has led to a swift resolution of the problem. We are pleased that the Department, at a senior level, is now engaging with us in a positive dialogue aimed at taking forward the issues we have raised with them.

42. For new (non-retrospective) requests for continuing care funding, there have been some improvements to the national framework for assessing eligibility since February 2003. The Continuing Care (NHS Responsibilities) Directions 2004 set out the procedure that must be followed for continuing care funding assessments and reviews, with effect from 27th February 2004. And the Delayed Discharge (Continuing Care) Directions 2004 strengthen the requirement that the NHS should assess a patient for continuing care before discharging them from hospital to social services. These developments provide clarification in areas where it was badly needed.

43. However, in our view these developments still fall short of the kind of guidance and support for healthcare professionals in this difficult area that we had envisaged when we published our previous report. **We recommend that the Department of Health needs to lead further work in six key areas to improve the national framework for continuing care, and its application by:**

- **Establishing clear, national, minimum eligibility criteria which are understandable to health professionals and patients and carers alike;**

- **Developing a set of accredited assessment tools and good practice guidance to support the criteria;**
- **Supporting training and development to expand local capacity and ensure that new continuing care cases are assessed and decided properly and promptly;**
- **Clarifying standards for record keeping and documentation both by health care providers and those involved in the review process;**
- **Seeking assurance that the retrospective reviews have covered all those who might be affected; and**
- **Monitoring the situation in relation to retrospective reviews and using the lessons learned to inform the handling of continuing care assessments in the future**

Annex A

Conclusions and recommendations from the Ombudsman's report, February 2003

Paragraph 38. The findings in the cases reported today and the themes emerging from those still under investigation lead me to conclude that:

- The Department of Health's guidance and support to date has not provided the secure foundation needed to enable a fair and transparent system of eligibility for funding for long term care to be operated across the country;
- What guidance there is has been misinterpreted and mis-applied by some health authorities when developing and reviewing their own eligibility criteria;
- Further problems have arisen in the application of local criteria to individuals;
- The effect has been to cause injustice and hardship to some people.

Paragraph 39. I therefore **recommend** that strategic health authorities and primary care trusts should:

- Review the criteria used by their predecessor bodies, and the way those criteria were applied, since 1996. They will need to take into account the Coughlan judgment, guidance issued by the Department of Health and my findings;
- Make efforts to remedy any consequent financial injustice to patients, where the criteria, or the way they were applied, were not clearly appropriate or fair. This will include attempting to identify any patients in their area who may wrongly have been made to pay for their care in a home and making appropriate recompense to them or their estates.

Paragraph 40. I also **recommend** that the Department of Health should:

- Consider how they can support and monitor the performance of authorities and primary care trusts in this work. That might involve the Department assessing whether, from 1996 to date, criteria being used were in line with the law and guidance. Where they were not, the Department might need to co-ordinate effort to remedy any financial injustice to patients affected;
- Review the national guidance on eligibility for continuing NHS health care, making it much clearer in new guidance the situations when the NHS must provide funding and those where it is left to the discretion of NHS bodies locally. This guidance may need to include detailed definitions of terms used and case examples of patterns of need likely to mean NHS funding should be provided;
- Consider being more proactive in checking that criteria used in the future follow that guidance;
- Consider how to link assessment of eligibility for continuing NHS health care into the single assessment process and whether the Department should provide further support to the development of reliable assessment methods.

Source: *NHS funding for long term care, the Health Service Ombudsman, 2nd report - session 2002-2003, HC399*

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