

The investigation of a complaint by Mr F against Aneurin Bevan Health Board and Caerphilly County Borough Council

A report by the Public Services Ombudsman for Wales

Cases: 201001820 and 201002050

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#### Introduction

This report is issued under section 21 of the Public Services Ombudsman (Wales) Act 2005.

In accordance with the provisions of the Act, the report has been anonymised so that, as far as possible, any details which might cause individuals to be identified have been amended or omitted. The report therefore refers to the complainant as Mr F.

Whilst the initial part of this complaint occurred prior to October 2009, when Aneurin Bevan Health Board ("the Health Board") came into being, the majority of the complaint occurred after 1 October 2009 when the Health Board had assumed the responsibilities of the former Caerphilly Local Health Board and Gwent Healthcare NHS Trust. The complaint has therefore been logged against Aneurin Bevan Health Board, rather than its predecessor organisations, and the report refers to the Health Board throughout.

## **Summary**

Mr F cared for his wife, Mrs F, at home with assistance on a daily basis from carers provided and funded by the Council. Mrs F suffered with alzheimer's disease. An application was made for continuing health care (CHC) funding for Mrs F because the Council considered that her needs had increased. No decision on eligibility was made for over a year by the Health Board until just prior to Mrs F's death. The Ombudsman found that there were shortcomings in the Health Board's systems that resulted in its failure to reach a decision on Mrs F's eligibility. This failure and the delays overall in this case were unacceptable. There was also a lack of clarity about the need for night care for Mrs F and/or a night sitting service to Mr F as a carer. The Ombudsman recommended that the Health Board apologise to Mr F for the identified failings and that it should ensure that improvements were made to its systems for considering all CHC eligibility applications.

## The complaint

1. Mr F complained about the manner in which the consideration of his wife's eligibility for continuing health care funding was dealt with. The process involved both Aneurin Bevan Health Board ("the Health Board") and Caerphilly County Borough Council ("the Council").

## Investigation

- 2. I obtained comments and copies of relevant documents from the Health Board and the Council and considered these in conjunction with the evidence provided by Mr F. The Health Board, the Council and Mr F are aware of the history of this complaint so I have not included every detail investigated in this report, rather a summary of the events in question. I have also not set out Mrs F's care needs in any detail as these were comprehensively considered during a retrospective review which concluded in November 2011 following Mr F's complaint to the Ombudsman.
- 3. Mr F, the Health Board and the Council were given the opportunity to see and comment on a draft of this report before the final version was issued.
- 4. I am issuing this report under the authority delegated to me by the Ombudsman under paragraph 13(1) of schedule 1 to the Public Services Ombudsman (Wales) Act 2005.

## **Relevant legislation**

5. Community care services in the home are provided by a council's social services department under several different legislative provisions<sup>1</sup>. The provision of these community care services is means-tested. Where someone's needs are such that their primary need is for health care rather than social care, the funding of all the services to meet those needs rests with the NHS. This funding is known as continuing health care ("CHC") funding and is not means-tested. The decision as to whether someone's need is primarily a health need (and therefore the

<sup>&</sup>lt;sup>1</sup> Chronically Sick and Disabled Persons Act 1970, s2 and National Assistance Act 1948, s29

services are provided and funded by the NHS) is a decision for the Health Board<sup>2</sup>. It is based on an assessment which considers an applicant's needs against specific eligibility criteria set out by the Health Board. National guidance in place at the start of the complaint<sup>3</sup> ("the 2004 guidance") set out that the decision on eligibility should be based on a multi-disciplinary assessment of the total amount of care required by an applicant<sup>4</sup>. This is reflected in the new national framework ("the national framework") which came into effect on August 2010<sup>5</sup>. It states that, in reaching any decision on eligibility "the totality of overall needs and the effects of the interaction of needs should be carefully considered."

6. A council can also offer a service specifically to carers where it is satisfied that the service "will help the carer care for the person cared for and may take the form of physical help or other forms of support. It can take the form of a service delivered to the cared for person (as a community service) but it may not be any service of an intimate nature". Night sitting services can therefore be provided as a carer's service, but night care (such as continence care or moving a patient's position) can only be provided as a community care service to the patient, not as a carer's service.

# The background events (summarised from the records and Mr F's account)

7. Mr F had been caring for his wife, Mrs F, at home for some time. In 2008, she was hospitalised following a fall but was later discharged with a package of care to enable Mr F to care for her at home. Mrs F had Alzheimer's disease, was immobile and was unable to communicate. Mr F took care of all her daily care needs, and carers provided by the Council's Social Services Department undertook her daily personal care needs. A district nurse attended once a week to assist with Mrs F's health needs. The service provided by the Council's carers was, as all

<sup>&</sup>lt;sup>2</sup> St Helens Borough Council v Manchester Primary Care Trust, Court of Appeal, August 2008

<sup>&</sup>lt;sup>3</sup> WHC (2004) 54; NAFWC 41/2004 – NHS Responsibilities for meeting continuing NHS health care needs; Guidance 2004.

<sup>&</sup>lt;sup>4</sup> Paragraph 14 of the above guidance

<sup>&</sup>lt;sup>5</sup> Continuing NHS Healthcare; The National Framework for Implementation in Wales, May 2010

<sup>&</sup>lt;sup>6</sup> Paragraph 4.3 of the above framework

<sup>&</sup>lt;sup>7</sup> Carers and Disabled Children Act 2000

community care services provided by the Council, means tested. However, due to Mr F's income, this service was fully funded by the Council. Mr F has always stated that he was very happy with the service that the carers and the district nurses provided to Mrs F.

- 8. In January 2009, Mrs F's social worker ("the social worker") undertook a community care assessment of Mrs F's needs. The social worker's case notes indicated that she was going to arrange a multidisciplinary team ("MDT") meeting with health professionals to consider Mrs F's eligibility for continuing health care. This was due to the complexity of Mrs F's condition. The social worker's notes stated that "a nursing assessment needs to be undertaken to look into night support re: toileting and prevention of pressure sores, as [Mrs F] is immobile and currently only has assistance with changing position and toileting during the day." A further entry on 21 January 2009 recorded the district nurse as saying "[Mrs F] does not need support at night time with toileting and changing position. Her skin is intact. She wears highly absorbent pads at night time and she is on an air flow mattress."
- 9. The MDT took place on 27 January 2009, though Mrs F's social worker was unable to attend. Another social worker attended along with a district nurse, community psychiatric nurse ("CPN") and the consultant psychiatrist. The assessment matrix (which is the framework document which details the level of someone's needs) was completed and indicated that Mrs F's needs were in the low or medium category for most of the care domains but were categorised as medium/high in 2 care domains. The minutes of that meeting, written by the consultant psychiatrist, state that:

"The health care trigger put forward from social services was the need for Mrs [F] to be turned and receive incontinence care at night. The health professionals disagreed with this as Mrs [F] is on a pressure relieving mattress and at present this along with cream applied by carers is preventing pressure areas. There has been recent intervention by district nurses but at present they are visiting on a weekly basis. Mrs [F]'s incontinence products are currently meeting her needs by night. After discussion, the social worker agreed that Mrs [F]'s needs

are currently being met. All agreed that this was subject to possible change in the future. Mr [F] is happy with the care package and would not want this to change unless absolutely necessary. All agreed that Mrs [F] does not meet the Continuing Health Care criteria at present.

The health care trigger was the fact that essentially one of turning during the night. There was a difference of opinion over the clinical facts where the health staff felt that her pressure sores has improved. Therefore we did not feel that she met the continuing health care criteria."

- 10. Having discussed the matter with Mr F, the social worker requested another MDT meeting. A request for a retrospective review was also subsequently made in writing by Mr F's solicitors.
- 11. A second MDT was scheduled for 22 September 2009. The district nurses were still visiting on a weekly basis. The nursing assessment noted that Mr F attended to Mrs F's needs at night and that he felt he would need increased support at night. He did not wish Mrs F to be admitted to residential care. The assessment matrix indicated that Mrs F was considered to have low needs in 9 categories, medium needs in 11 categories and high needs in 4 categories.

## 12. The MDT meeting concluded that:

"After going through the domains at the MDT meeting, it was felt that there are increasing health triggers due to the nature of [Mrs F]'s condition, the unpredictability of advanced stages of Alzheimer's disease. [Mrs F] will need regular ongoing monitoring and meets criteria 1 of the eligibility criteria."

This assessment was forwarded to the Health Board. Further information was requested by the commissioning manager about Mrs F's needs and the package of care that she would require.

13. The district nurse responded on 24 November with further details of what was currently provided (2 carers visiting four times a day). In

addition, support was requested for a night time visit to prevent pressure sores and maintenance of skin integrity. The commissioning manager wrote again to the district nurse on 2 December requesting specific details about the package of care being requested including night calls. This was so that the case could be progressed to the funding panel. The district nurse responded with these details on 7 December.

- 14. On 21 December the commissioning manager wrote to the district nurse to say that Mrs F's case had been discussed at the Case Review Group on 18 December, but it had decided not to put it forward to the Funding Panel because further information about the risk of aspiration was requested. The district nurse responded on 4 January stating that "as indicated in the SALT [speech and language therapy] report enclosed, SALT therapist felt that there is no significant risk of aspiration. According to [Mr F], his wife is continuing to have occasional difficulty with choking, therefore I feel there is a risk of aspirating. Please advise"
- 15. The response was considered by the Case Review Group on 29 January 2010. The Group asked for a re-assessment of Mrs F's risk of aspiration by specialist SALT staff.
- 16. A report from SALT was considered at the Case Review Group on 9 April 2010. No specific risk of aspiration was noted. The Case Review Group notes stated that "no evidence to suggest a primary health need; assessment now out of date, a new assessment to be requested." Despite an agreement that another nursing assessment would be carried out and a further MDT would be convened, it seems that this never happened.
- 17. Throughout these events, the social worker had been carrying out regular reassessments of Mrs F's care plan (7 January, 28 July, 12 October, 27 November 2009 and 9 March and 13 October 2010) and care plan reviews on 21 September 2009 and 22 June 2010. As part of his carers assessment, carried out in January 2010, Mr F said that he found "having to wake up in the night to check on [Mrs F's] safety"

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<sup>&</sup>lt;sup>8</sup> Inhaling food or fluid into the respiratory tract involuntarily and thereby creating a risk of choking or infection

particularly difficult. The assessment indicated that Mr F would most like "night sits" to assist him in continuing to care for Mrs F.

18. On 14 October, there was a significant deterioration in Mrs F's condition. She was referred on the fast track pathway for continuing healthcare funding because she was deemed to be in the terminal phase of life. The Health Board agreed that it would fund the Council's carers to ensure continuity of care. However, Mrs F sadly died on 18 October before this agreement took effect.

## What the Council had to say

- 19. In its response to the Ombudsman, the Council said that the social worker had referred Mrs F for consideration for CHC eligibility because of the growing intensity and complexity of her needs. The referral was not due to any specific concern about the need for pressure relief at night, rather that she would benefit from input and care being available from qualified nursing staff (and more specialist staff, such as SALT, Occupational Therapy etc). It was not necessary for a patient to be eligible for CHC funding to receive night time care; this is a service that the Council could provide if it was deemed necessary. However, as the MDT had agreed Mrs F's eligibility, the Council had expected any assessed night care needs to be included as part of this package so it had not given any further consideration to providing night time care.
- 20. The Council explained that eligibility for CHC would not necessarily have led to a change in Mrs F's care package. Indeed, the Council pointed out that the request for the MDT in September 2009 was for the care package to remain the same to ensure continuity. However, the Council explained that there were benefits to CHC provision for patients who had deteriorating conditions such as Mrs F. These included that the care co-ordinator would be a health professional rather than a social worker, that the patients would have access to a team of health professionals who are trained beyond the skill level of social services carers. This would have increased the care options for Mrs F as the complexity of her needs increased. It would also give greater flexibility for care provision, including respite, and access to more specialist care services for additional advice and support. It specifically cited the

contractures<sup>9</sup>that Mrs F suffered with. These became particularly difficult for care staff to deal with as they did not have the specialist skills or knowledge to deal with this type of complex presentation.

- 21. In discussion with the Council's Continuing Health Care coordinator ("the CHC coordinator"), she considered that the delay for the second MDT in September had been unacceptable. This was in part due to the difficulty getting specialist opinion; in this case an assessment from SALT. Once the eligibility had been agreed by the MDT, the matter was referred to the Health Board and it was assumed that provision of care would be agreed.
- 22. The CHC coordinator said that one of the issues in Mrs F's case was around diet and Mrs F's ability to swallow. She felt that the Health Board were looking solely at Mrs F's physical ability to swallow whereas Mrs F's difficulties seemed to relate to her cognitive processes in recognising food, and determining when to swallow. She felt that Mrs F needed specialist input into her diet and hydration regime.
- 23. The CHC coordinator confirmed that the process had changed since the events of this complaint<sup>10</sup>. Cases which had been agreed at MDT are now referred to a Locality Panel (which has both Council and Health Board representation) before referral to a funding panel. Therefore, whilst cases could be referred back at that stage, it was very unlikely as any issues or concerns would have been thoroughly discussed and addressed at the Locality Panel stage. There was also a dispute resolution process which was not in place at the time that Mrs F's case was being considered.

# What the Health Board had to say

24. In its response, the Health Board accepted that there were shortcomings in the process which had led to delays. It acknowledged the following:

<sup>&</sup>lt;sup>9</sup> Chronic tightening of the joints and muscles leading to an inability to move or be moved.

<sup>&</sup>lt;sup>10</sup> For older adults and those with physical disabilities. The process for assessing eligibility for children and those with learning disabilities and mental health problems remained the same.

- That there was little formal correspondence with Mr F during the process,
- That case review panels were not minuted, therefore there was no formal record of the discussion and the reasons why Mrs F's case did not meet the criteria for referral to the funding panel (only the additional information requested was recorded),
- There did not appear to be a central point of contact through which information would flow, nor was there one complete, centrally-held set of case records for Mrs F's application,
- That there was no evidence of any interim discussions about joint funding for the periods whilst the application was being discussed and further information was being sought,
- That there were significant delays (of several months) in actioning requests for reviews or for specialist assessment. The Health Board acknowledged that this was unacceptable. The Health Board also noted the delay in engaging Mrs F's GP in the process. The Health Board noted that this was a recurring problem.
- 25. The Health Board subsequently carried out a retrospective review of Mrs F's case. It acknowledged that it had failed to ratify the decision of the MDT on 22 September 2009 in relation to Mrs F's care needs and it had not provided any written rationale to Mr F or to the members of the MDT as to why the Health Board had not ratified their decision on eligibility. The Health Board acknowledged that communication between the central team and the locality office was poor during its quality assurance process. It offered Mr F its apologies for any distress that was caused to him and his wife during this period.
- 26. The Health Board outlined the action that it had taken as a result of reviewing the circumstances of Mr F's complaint:
  - A single point of contact should be agreed as soon as a complaint or appeal was identified. Formal processes for handling first stage complaints have been put in place to ensure compliance with the

Health Board's complaints procedures. This would enable an audit trail to be established, an awareness of timeframes to be followed and the need for clear documentation to be kept.

- The Health Board will keep one identified core set of notes which must contain all relevant information for a service user identified for complex care. These are the files held by the central team. This will avoid information being stored elsewhere which could have a bearing on the decision making or review process.
- The use of email for information requests within the Health Board to minimise delays
- The system for consideration of CHC applications now consists of Locality Quality Assurance Panels which contain representatives from both the Council and the Health Board. Cases are discussed at these Locality Panels and any issues resolved at this level before referral for central funding agreement. All Locality Panel meetings are minuted.
- If there are unavoidable delays in the process, which mean that a
  further assessment is required, the information gathered up to that
  day can be considered by the Locality Panel for it to reach a
  decision (either ineligibility or agreeing CHC or joint funding) until a
  further MDT can be held. There is also now a dispute process
  which can be followed where there is disagreement between the
  Health Board and the Council.

# **Analysis and conclusions**

27. I should start by saying that there seems to have been an overall lack of clarity as to why Mrs F was being put forward for CHC funding and how this related to the provision of night time care. From my conversations with Mr F, he certainly believed that the provision of night care depended on Mrs F's eligibility for CHC. The notes of the first MDT stated that the trigger for Mrs F's application for CHC was that she needed assistance during the night to have her position changed. However the Council's view, both in its response to this office and in the contemporaneous social work case records, was that it was because of

the increasing complexity of Mrs F's needs. The Council has stated that it could provide a night service if the need was assessed; this did not rely on Mrs F being eligible for CHC. In addition, the Council could have provided a night sitting service to Mr F as part of its service to carers. It stated to this office that it did not provide this as the expectation was that the Health Board would provide this as part of the CHC application (which had already been assessed at MDT). I accept, from the evidence that I have seen, that the initial reason for the CHC application was Mrs F's increasing needs and the complexity of those needs, rather than a specific need for night-time care. However, as time went on and Mrs F's condition deteriorated, it seems clear that Mrs F became increasingly frail and immobile and the need for additional assistance for Mr F during the night was becoming rather more pressing.

#### **Health Board**

28. A decision on eligibility for CHC funding is solely a matter for the Health Board. It is accepted that the delay in this case and the Health Board's failure to reach a decision on Mrs F's CHC eligibility amounts to maladministration. It follows that I **uphold** Mr F's complaint against the Health Board. Had the Health Board reached a decision that Mrs F was ineligible for CHC funding, Mr F would have been able to challenge this decision, had he so wished, through his right of appeal. The Health Board's failure to reach a decision denied Mr F this opportunity. It also appears that the Health Board did not have a dispute resolution process in place at the time of the complaint which is a requirement of both the 2004 guidance and the national framework.

29. I would also like to express my concern about the level of detail in the minutes of the first MDT meeting in January 2009 and the reasons given for the decision that Mrs F was ineligible for CHC funding. The minutes state that Mrs F's 'needs are currently being met' as part of its reasoning why Mrs F was not eligible for CHC. This is not the test. The eligibility test relates solely to the level of someone's needs, not whether those needs are being met or not<sup>11</sup>. The minutes do not show any consideration of Mrs F's needs against the factors for eligibility. That

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<sup>&</sup>lt;sup>11</sup>Paragraph 4.5, Continuing NHS Healthcare: The National Framework for Implementation in Wales, May 2010

said, there seems to me to be a clear difference between the needs portrayed in the first nursing assessment for the MDT in January 2009 and the subsequent one of 22 September 2009, when the level of Mrs F's needs is recorded as being noticeably higher.

30. I am further concerned that the Health Board appeared to focus on the physical aspect of one particular issue, rather than looking at Mrs F's care needs holistically. The 2004 guidance and the national framework both indicate the need to consider the totality of someone's needs. The Health Board only considered Mrs F's physical ability to swallow, when in fact her difficulties related to cognitive problems in recognising food and when she needed to swallow, thus leading to food pooling in her mouth and a risk of choking. This impacted on how she needed to be assisted and monitored when eating, and affected her diet and her ability to maintain adequate weight and hydration. I cannot see that the Health Board took account of these factors.

### Council

I accept that the Council, and in particular the social worker and the continuing CHC co-ordinator, went to considerable lengths to try to elicit a decision from the Health Board. However, it was also open to the Council to provide a night service to Mrs F if her care needs assessment indicated that she was in sufficient need of it. The Council could also have considered providing a night sitting service to Mr F as a carer. I am not sure that the Council ever discussed with Mr F that it could provide such a service or could have considered him for some additional assistance as a carer. I accept that once Mrs F was deemed to be eligible by the MDT in September 2009, the social worker would have expected the responsibility for providing Mrs F's care to be transferred to the Health Board and so did not take steps to initiate these services. However, it seems to me that when matters dragged on and a decision from the Health Board was not forthcoming, the Council should have reviewed matters and in particular Mr F's need, as a carer, for a night sitting service. I therefore partly uphold the complaint against the Council. I have noted the detailed case notes kept by the social worker in this case which have greatly assisted in considering the circumstances of this complaint. I am also pleased to hear that Mr F was happy with the service that was provided by both the social worker

and the Council's team of carers. It is only right that his positive experiences of the Council's services and staff should be reflected in this report.

## **Overall Conclusion**

The MDT agreed that Mrs F was eligible for CHC funding in September 2009 and the Health Board has provided no rationale as to why it failed to ratify this decision until 14 October 2010 when it did so on an emergency basis due to Mrs F's significant deterioration. I have found that the Health Board's failure to reach a decision on Mrs F's eligibility amounts to maladministration. I also have to consider the effect that this maladministration had on Mr F and the care that was provided to Mrs F. This is rather more difficult to gauge. I have noted Mr F's satisfaction with the care that the Council provided to Mrs F. I have also noted the Council's comments that a Health Board funded care package may have enabled easier access to more specialist advice when needed. In practical terms, an earlier resolution may not have made a huge amount of difference to the care provided to Mrs F. The exact need for a night call/night sitting is not explored fully in the assessment or the case notes, and there is no guarantee that it would have been provided in line with Mr F's wishes, even had the Health Board been funding the care as opposed to Social Services. However, the lack of clarity, poor administrative processes and the failure to make a decision on the application for over a year in this case can only have led to additional uncertainty for Mr F at a time when he was already tired and struggling to ensure that he was able to care for his wife at home. This is completely unacceptable. It is also regrettable that the poor administrative handling of the CHC application has detracted from the excellent care that the carers provided to Mrs F and resulted in Mr F's complaint to this office.

#### Recommendations

33. I am pleased to note that the Health Board has made improvements to its systems which means that a recurrence of this situation would be unlikely. I understand that this is for cases which relate to older people and those with physical disabilities. However, it is noted that the process for CHC for children, those with learning disabilities and mental health problems does not follow the same format

and it seems to me that this also requires review to ensure that these processes are as robust and effective as they can be.

- 34. I therefore recommend that the Health Board:
  - a) Provides a full written apology to Mr F for the failings detailed in this report
  - b) Reviews its processes for considering eligibility in other cases (such as applications from children, and those with learning disabilities and mental health problems) to ensure that they are sufficiently robust that the delay and failure to reach a decision, as experienced in this case, could not occur. These processes should all mirror the improvements made in respect of this case.
- 35. I am pleased to note that both the Health Board and the Council have accepted the findings of this report and the Health Board has agreed to implement the above recommendations.

Sam Ward Senior Investigator

21 June 2012