**Scottish Parliament Region: North East Scotland**

**Case 200800508: Tayside NHS Board**

**Summary of Investigation**

***Category***

Health: Hospital (respiratory and immunology); diagnosis, treatment delays and complaint handling

***Overview***

The complainant (Mr C) raised a number of concerns about the care and treatment provided by Tayside NHS Board (the Board) to his father (Mr A) in the months before his death in October 2007. Mr C also complained about delays in diagnosis and treatment of Mr A and the handling of his complaint about these matters.

***Specific complaints and conclusions***

The complaints which have been investigated are that the Board:

(a) delayed in diagnosing Mr A (*upheld*);
(b) failed to provide timely treatment following diagnosis (*not upheld*);
(c) did not provide adequate care to Mr A in the respiratory ward (the Ward) of Ninewells Hospital, Dundee (*upheld*); and
(d) failed to handle Mr C's complaint appropriately (*not upheld*).

***Redress and recommendations***

The Ombudsman recommends that the Board:

(i) ask the consultant responsible for Mr A's care in the Ward to apologise to Mr C for any contribution he may have made to the misunderstanding with Mr A about visiting him on 28 September 2007;
(ii) apologise to Mr C for the failure to provide adequate care to Mr A as identified in this report; and
(iii) review the current arrangements for selecting patients for consultant out-of-hours review, including processes for communication and handover between doctors.

The Board have accepted the recommendations and will act on them accordingly.

## Main Investigation Report

### Introduction

1. On 21 May 2008, the Ombudsman received a complaint from Mr C about the care and treatment provided to his father (Mr A) by Ninewells Hospital, Dundee (the Hospital) between July 2007 and 5 October 2007. Mr A was transferred to the Intensive Care Unit (ICU) at the Hospital on 5 October 2007 and sadly he died there on 11 October 2007. In particular Mr C was concerned about delays in diagnosing Mr A's medical problems and in providing treatment for these once identified, and the quality of care delivered to Mr A in the respiratory ward (the Ward) of the Hospital prior to his transfer to ICU. Mr C complained to Tayside NHS Board (the Board) in January 2008 about the delays in diagnosis and the care provided to Mr A on the Ward by nursing and medical staff. Mr C raised concerns about an apparent lack of medical cover over the long weekend of 28 September 2007 to 2 October 2007. Mr C received a written response on 2 April 2008 but remained dissatisfied by the response and complained to this office. Mr C also complained to the Ombudsman that the staff who had investigated his complaint were those he had complained about.

2. The complaints from Mr C which I have investigated are that the Board:

(a) delayed in diagnosing Mr A;
(b) failed to provide timely treatment following diagnosis;
(c) did not provide adequate care to Mr A in the Ward; and
(d) failed to handle Mr C's complaint appropriately.

### Investigation

3. Investigation of this complaint involved obtaining and reviewing the complaints correspondence of the Board and Mr A's clinical records alongside Mr C's correspondence. A medical adviser to the Ombudsman (the Adviser) reviewed the files and provided me with his clinical opinion. I have also discussed a number of aspects of this case with Mr C.

4. At the time of Mr A's death his family were advised that his cause of death was extensive lung damage caused by Dermatomyositis (DM), a rare autoimmune connective tissue disease. A post mortem (PM) was conducted very shortly after Mr A's death which concluded that the principle cause of death was 'Respiratory Failure due to Pneumocystis Pneumonia' (PCP), an inflammatory infection of the lungs caused by a yeast like fungus, with

'Connective Tissue Disease' (CTD) listed as the secondary cause. Following receipt of the clinical opinion of the Adviser it became apparent that Mr A's family had not had been made aware of this actual cause of death and much of their complaint had been directed at the diagnosis and treatment for DM and CTD which, while present at Mr A's death, were not the principal causes of death. The Adviser provided me with more detailed explanations of these conditions (see Annex 2) and was very critical of this lack of information sharing with the family as he felt that it would have been of significant assistance to the family in understanding both Mr A's illness and the complaints responses. This has also impacted on our investigation of Mr A's complaint as Mr C has, understandably, raised further new issues in light of this new information.

5. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mr C and the Board were given an opportunity to comment on a draft of this report.

*Medical Background*

6. Mr A first became ill while on holiday in June 2007. His symptoms included skin inflammation around the eyes and on his return he visited his GP a number of times and was referred to Ophthalmology and Dermatology at the Hospital on 26 July 2007. At that time a physical examination (including the chest) showed no other problems. Blood tests were also done for a specific CTD, Systemic Lupus Erythemaosus (SLE), but these were negative. A chest x-ray was clear. A working diagnosis of Rosacea was made and an antibiotic was prescribed. A skin biopsy was done on 3 August 2007 and reported on 15 August 2007 with a strong suggestion that SLE might in fact be the cause. An anti-inflammatory treatment was commenced.

7. Mr A was reviewed by Dermatology on 30 August 2007 as his rash was progressing and there was a concern that he may have had an allergic reaction to the anti-inflammatory treatment. A chest examination noted that lung crackles were heard and it was suggested that Mr A may have DM and steroid tablets were commenced as treatment for this.

8. Mr A continued to have difficulties and attended his GP who tried a number of treatments including antibiotics for a possible chest infection, all without success. His GP then made an appointment for Mr A with Rheumatology (this eventually took place following Mr A's admission to hospital).

9. On 25 September 2007 Mr A was admitted to the Hospital by his GP after calling the ambulance twice because of increasing breathlessness and general deterioration. A number of tests and examinations were conducted with crackles noted in the base of both lungs. A dermatology review on 27 September repeated the view that Mr A had DM and secondary interstitial lung disease. A CT scan was arranged and reported at 16:00 on Friday 28 September 2007. The radiologist reported appearances in keeping with 'acute interstitial lung disease with a differential diagnosis of UIP [Usual Interstitial Pneumonia]'. The results were not seen by the consultant then responsible for Mr A (the Consultant) until Tuesday 2 October 2007.

10. The nursing observation records for this latter period are missing from the clinical records and there was no medical review at this time.

11. Mr A had deteriorated by 2 October 2007 when he was reviewed by the Consultant who decided to commence treatment for severe connective tissue disease with a very powerful drug, cyclophosphamide. A further review of the CT scan of 28 September 2007 on 3 October 2007 reiterated the first opinion of interstitial lung disease or UIP. Treatment at this time was high dosage intravenous steroids and cyclophosphamide (for DM/connective tissue disease), a number of antibiotics (for UIP) and a further drug co-trimoxazole. The Adviser had told me that this latter drug was given as a prophylactic as cyclophosphamide carries a number of risks including an increased risk of contracting PCP and co-trimoxazole is a treatment for PCP.

12. Mr A continued to deteriorate and became acutely ill overnight and was transferred to ICU early on 5 October 2007. His admission notes for that day list his problems as 'interstitial lung disease, respiratory failure,? PCP pneumonia'. This record also noted '? PCP pneumonia on cxr [chest x-ray]'.

13. Active treatment continued with a further dose of cyclophosphamide on 10 October 2007 but Mr A's overall condition did not respond to treatment and he continued to deteriorate. Mr A died in ICU on 11 October 2007.

**(a) The Board delayed in diagnosing Mr A**

14. Mr C complained that it had taken until the end of August 2007 for any mention to be made of DM and that it was only after the CT scan on 28 September 2007 that significant lung damage was diagnosed, despite the

fact there was evidence of lung damage earlier. Following sight of the Adviser's report Mr C also expressed concern that PCP had not been definitively diagnosed earlier and that a CT scan should have been arranged far sooner if lung symptoms might indicate a complication of DM. Mr C was also concerned that the actual cause of death had never been explained to Mr A's family or his GP.

15. With respect to the diagnosis of DM, the Adviser told me that this diagnosis was not straightforward as Mr A's symptoms were not entirely consistent with DM and SLE was initially equally a possibility. DM was being actively considered from 30 August 2007 and appropriate treatment for this was also give from that point onwards. He regarded this aspect of diagnosis as reasonable.

16. The Adviser told me that Mr A's cause of death was principally PCP although he also had DM and interstitial lung disease at the time he died. PCP was not definitively diagnosed until the PM. DM is a rare disease, as is PCP in those without risk factors for HIV infection. The Adviser emphasised that his review was made with the benefit of hindsight and as a doctor who has dealt with more cases of PCP than most doctors would see. Nonetheless he was critical of some aspects of Mr A's diagnosis. The Adviser told me that while the x-ray of 26 July 2007 was normal, at the appointment on 30 August 2007 when DM was first raised as a possibility, lung crackles were heard. At that time Mr A had had a recent viral infection and this was considered to be the cause. The Adviser told me that in his view a more astute doctor would have requested a CT scan and detailed lung function tests at that time but that while he considered this to be an example of 'below average care' he would not go as far as to say it was unreasonable care. The Adviser also noted that in any event even if ordered in August, the test would probably not have been carried out any sooner than the four weeks later it was actually done (when Mr A was already an in-patient).

17. The Adviser told me that in his view the CT scan on 28 September 2007 was not suggestive of either of the two given possible diagnosis namely UIP or CTD. He considered that the differential diagnosis would rather include lung haemorrhage, drug related pneumonitis or PCP. Because of the rarity of PCP in a patient with no significant risk factors he was not critical of the radiologist for not making this differential diagnosis, but was strongly of the view that the differential diagnosis given was not supported by the image reviewed.

*(a) Conclusion*

18. The Adviser has told me that Mr A had a rarely seen presentation of an unusual condition and that it was reasonable that the actual diagnosis took time with more likely conditions being considered first. However, he has also told me that the failure to investigate the lung crackles heard on 30 August 2007 was an example of below average care and the radiology reports of the CT scan of 28 September did not reflect the nature of the image (although he did not expect that the radiologist should have made the correct diagnosis). I am concerned that both these errors mean that opportunities to explore further what the true diagnosis might be, were lost. The Adviser has also been very clear that he cannot say that an earlier diagnosis would have altered the outcome in this case. However, below average care was given and there were errors in reporting the CT scan and to this extent I uphold this aspect of Mr C's complaint.

*(a) Recommendations*

19. The Ombudsman has no specific recommendation to make but the recommendations relating to complaint heading (c) are relevant here.

**(b) The Board failed to provide timely treatment following diagnosis**

20. Mr A was given steroid treatment from 30 August 2007 as a treatment for possible DM. PCP was first considered a possibility in the clinical records from 5 October 2007 but in fact treatment for it commenced on 2 October 2007 because of the increased risk from the high dose steroids also prescribed from 2 October 2007.

21. Mr C expressed concern that although the scan results were available by 16:00 on Friday 28 September 2007, nothing was done to review the scan by the Consultant until Tuesday 2 October 2007 because there was a bank holiday weekend. Mr C felt that if such powerful treatment were needed so urgently on 2 October 2007 it would have had a far better chance of working if it had been introduced on 28 September 2007.

22. The Board's view is that the cyclophosaphamide being used was very powerful and had significant side effects and should only be used where needed. The Board noted that Mr A deteriorated on 2 October 2007 (this is disputed by Mr C, see complaint heading (c)) and at that point the balance

tipped in favour of use of cylophosaphamide, but that Mr A's condition over the weekend did not indicate their use earlier.

23. The Adviser noted that treatment for DM was being given in a timely manner and in fact in advance of the definitive diagnosis. He has also told me that if the correct diagnosis of PCP had been made from the CT scan on 28 September 2007 then it is likely the cylophosaphamide would not have been prescribed, but that in the event the correct treatment for what was then considered to be the diagnosis was given on 2 October 2007. The Adviser told me that cyclophosaphamide has a real potential to do harm and should only be considered for use when a number of criteria are fulfilled including a diagnosis of interstitial lung disease confirmed on CT scan, clarity that the deterioration was due to interstitial lung disease and not other causes, clarity that the disease would not respond to routine steroids and no evidence of infection. While the Adviser is of the view that the PCP was already sufficiently advanced on the CT scan for it to be considered a cause of the deterioration and an infection, in the circumstances where the PCP had not been diagnosed, the Adviser considered that not commencing the cylophosaphamide until 2 October 2007 (when Mr A was considered to be deteriorating) was reasonable.

*(b) Conclusion*

24. The Adviser's view is that the treatment provided following the working diagnosis of DM and acute interstitial lung disease was given in a timely manner. The apparent delay in not administering the cyclophosaphamide until 2 October 2007 would, in the Adviser's view, have occurred irrespective of whether or not the CT scan report had been reviewed by the Consultant on Friday 28 September 2007 and would match the experience in most hospitals. Based on the Adviser's clinical opinion I do not uphold this aspect of the complaint but would note that the dispute about when Mr A began to deteriorate referred to in complaint heading (c) is significant here.

**(c) The Board did not provide adequate care to Mr A in the Ward**

25. Mr C told me that he had a number of concerns about the care provided to Mr A on the Ward but in particular he was concerned that Mr A had had to ask for temperature-reducing medication every day and nursing staff were not proactive in this area. This caused Mr A distress because he felt he was always having to trouble staff and being a nuisance to them. Mr C also noted that over the long weekend of 28 September 2007 to 2 October 2007 nursing staff failed to react to Mr A's deterioration. His family felt that he took a significant turn for

the worse on 30 September 2007 but nursing staff did nothing to contact a doctor to have Mr A reviewed and no medical staff were on duty as it was a bank holiday weekend. Mr C was also concerned that the Consultant had promised Mr A that he would speak with him on 28 September 2007 to discuss the results of the CT scan but he did not see Mr A until 2 October 2007. This caused Mr A added anxiety while waiting for the results particularly as his health was deteriorating at this time.

26. The Board responded that an arrangement had been made by nursing staff directly with Mr A that he would let them know when his temperature was raised and he needed paracetamol. The Board also advised that the Consultant could not recall having arranged to speak with Mr A on 28 September 2007. The Board advised that there was medical cover on the Ward over the bank holiday weekend and nursing staff were also aware that they should call a doctor if they had any concerns about a patient's condition in between doctor's rounds and knew which doctor was on call. Mr A's condition over the weekend did not give rise to any concern as his observations were all stable.

27. Unfortunately the nursing records for the long weekend are missing and it is not possible to review the nursing observations for that time. Mr A was not reviewed by a doctor during that time so no medical notes are available either. The available nursing records contain no reference to a discussion between Mr A and nursing staff regarding paracetamol to reduce his temperature. I have raised this matter with a nursing adviser to the Ombudsman and she advised me that while such an arrangement as the Board described is possible and can represent good practice in involving a patient in their care, there should be a record of any special arrangements made in the nursing records and this did not exist in this case.

28. The Adviser told me that the consultant cover over the weekend is theoretically adequate but appears to rely on a patient deterioration showing up in observations to agreed criteria. In this case the Adviser's view is that Mr A would not have suddenly deteriorated on 2 October 2007 to the extent he did without there being evidence of deterioration in the immediately preceding days.

*(c) Conclusion*

29. If a special arrangement were made with Mr A then this should have been recorded. In the absence of such a record and Mr C's evidence that he

discussed this concern directly with Mr A, I conclude there was no such arrangement and there was a failure to deliver care to Mr A. In the absence of nursing notes I cannot draw any conclusion about Mr A's deterioration or otherwise over the weekend. However, the absence of records is of itself a failure and in combination with the Adviser's clinical opinion that Mr A would have shown signs of deterioration at an earlier stage than was recognised, I conclude there was a failure to note a deterioration in Mr A's condition and to obtain appropriate medical review. The Consultant does not recall making an arrangement with Mr A to discuss his review on 28 September 2007 but I am satisfied that Mr A did expect such a meeting. However, miscommunications can and do occur without fault; the significant issue here is the absence of any medical input directly to Mr A over the long weekend, which gave him no opportunity to ask the questions that were troubling him and his family. I conclude that this was a failure in care. For all these reasons I uphold this aspect of the complaint.

*(c) Recommendations*

30. The Ombudsman recommends that the Board:

(i) ask the Consultant to apologise to Mr C for any contribution he may have made to the misunderstanding with Mr A about visiting him on 28 September 2007;

(ii) apologise to Mr C for the failure to provide adequate care to Mr A as identified in this report; and

(iii) review the current arrangements for selecting patients for consultant out-of-hours review, including processes for communication and handover between doctors.

**(d) The Board failed to handle Mr C's complaint appropriately**

31. Mr C complained to the Board in January 2008. His complaint was passed to the relevant clinical team manager for review and comment. The clinical team manager forwarded the request for comment and information to the senior charge nurse (the Nurse) for the Ward asking him to respond to the complaints team. The Nurse noted that a number of the issues raised were medical and mentioned this to the Consultant. A copy of the complaint was then forwarded to the Consultant by complaints staff for his comments. The response sent from the Board on 2 April 2008 noted that the Nurse and the Consultant had investigated Mr A's concerns. As the Nurse and the Consultant were both named in Mr C's complaint he was concerned that investigation of their own actions had been left to the individuals concerned.

32. The NHS complaints process would expect that the individuals mentioned in a complaint would be asked to comment on the issues raised. It is also important that these comments are reviewed by senior staff with management responsibility to ensure that the written response sent represents the views of the Board and not simply the justification of those complained against. In this case the comments of the Nurse and the Consultant were considered by the relevant clinical team manager and the letter itself prepared by the complaints team and signed off by the medical director. This is all in line with the NHS complaints process.

*(d) Conclusion*

33. Mr C's concern about the level of involvement of those he was complaining about in the investigation of his complaint is understandable. However, the actual involvement was in line with that expected by the NHS complaints process and was subject to management review. I would suggest though that it is not accurate to describe the Nurse and the Consultant's involvement in the process as having 'investigated' the complaint. It would have been both more accurate and more acceptable to Mr C had it been phrased to reflect their actual role of being asked for information and their comments on the complaint as part of the investigation being conducted by senior management and complaints staff. I conclude that Mr C's complaint was handled appropriately but that the response letter did not accurately reflect the handling of his complaint. I do not uphold this aspect of the complaint but would ask that the Board consider the impact of language used to describe the process of investigating a complaint in future responses to avoid the perception of bias that arose in this case.

34. The Board have accepted the recommendations and will act on them accordingly. The Ombudsman asks that the Board notify him when the recommendations have been implemented.

**Annex 1**

**Explanation of abbreviations used**

| | |
|---|---|
| Mr C | The complainant |
| Mr A | The aggrieved (Mr C's father) |
| The Hospital | Ninewells Hospital, Dundee |
| ICU | Intensive Care Unit |
| The Ward | Respiratory ward of the Hospital |
| The Board | Tayside NHS Board |
| The Adviser | A medical adviser to the Ombudsman |
| DM | Dermatomyositis |
| PM | Post Mortem |
| PCP | Pneumocystis pneumonia |
| CTD | Connective Tissue Disease |
| SLE | Systemic Lupus Erythemaosus |
| UIP | Usual Interstitial Pneumonia |
| The Consultant | The consultant responsible for Mr C's care in the Ward |
| The Nurse | The senior charge nurse for the Ward |

**Annex 2**

## Glossary of terms

| | |
|---|---|
| Dermatomyositis | A rare autoimmune connective tissue disease typically characterised by skin rash and muscle inflammation. It has a recognised association with interstitial lung disease |
| Interstitial pnuemonitis | An inflammatory process in the walls of the air sacs in the lung where gas exchange takes place (not known to be caused by infection which would otherwise be described as pneumonia). This is an unusual condition and often the cause is not known |
| Pneumocystis pneumonia | A fungal organism which does not cause disease in a healthy individual but which occurs in immunocompromised individuals. It is usually associated with HIV/AIDS and only very rarely found otherwise although it is a known complication of DM and has a very high mortality rate of up to 86 percent |
| Rosacea | A skin disease affecting the face which causes reddening of the skin |
| Usual interstitial pneumonia | A specific term used by lung pathologists as one of several interstitial pneumonias. UIP is the most common type of interstitial pneumonia |