Investigation Report

Investigation of a complaint against the Southern Health and Social Care Trust

NIPSO Reference: 17349

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Publication date: February 2018

The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities. She may also investigate and report on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

Where the Ombudsman finds maladministration or questions the merits of a decision taken in consequence of the exercise of professional judgment she must also consider whether this has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. The Ombudsman may recommend a remedy where she finds injustice as a consequence of the failings identified in her report.

The Ombudsman has discretion to determine the procedure for investigating a complaint to her Office.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

Before the Ombudsman decides to publish a report under section 44 she will take into account the interests of the person aggrieved and any other person she considers appropriate.

As far as possible any personal details which might cause individuals to be identified in this report have been removed.

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EXECUTIVE SUMMARY

1. I received a complaint about the care and treatment provided to a patient of the Southern Health and Social Care Trust (the Trust), prior to the patient's death in December 2014 aged 60.

2. The complainant stated that the patient (his wife) was not made aware of a serious heart condition and that no care was provided to her for this from 2010 until her death.

3. My investigation of the complaint did not identify a failure in the care and treatment provided by the Trust.

THE COMPLAINT

4. The complaint is in relation to the care and treatment the complainant's late wife (the patient) received from the Trust prior to her death in December 2014 aged 60.

Background

5. The patient was diagnosed with a high grade Non-Hodgkin's Lymphoma[1] in 2009. She was successfully treated with chemotherapy through a PICC[2] line and entered remission. She was admitted to Daisy Hill Hospital, Newry in September 2014 with respiratory failure. During this admission the complainant contends that his wife discovered that her heart had been damaged as a result of an infection through the PICC line dating back to 2010. He contends that if his wife had received a follow up or had a treatment plan for her condition that it may have improved her quality of life.

6. The complainant also contends that during his wife's admission in September 2014, he was advised by medical staff that his wife had Chronic Lymphedema (CL), a form of oedema[3] from 2010. He states that his wife was discharged without any aftercare for this condition. The Trust stated that the patient received treatment for this up until her death in December 2014. The complainant refutes this and complains that it was not until September 2014 that his wife began to receive specific treatment for CL but she was unfortunately too ill at this stage.

7. The complainant states that the Trust failed his late wife as she was not made aware of the serious heart condition and that no after care was provided to her.

[1] A type of blood cancer

[2] Peripherally inserted central catheter (PICC or PIC line), is a form of intravenous access that can be used for a prolonged period of time

[3] Oedema is an accumulation of fluid causing swelling, usually in the lower limbs. The condition is commonly associated with aging, but can be caused by many other conditions, including congestive heart failure, trauma, altitude sickness, pregnancy, hypertension, compromised lymphatic system, or merely long periods of time sitting or standing without moving.

Issues of complaint

8. The issues of complaint which I accepted for investigation are:

1. Whether the treatment and care afforded to the patient was appropriate and reasonable following an episode of infective endocarditis in 2010.

2. Whether the treatment and follow up of the patient's condition of Chronic Lymphoedema was reasonable.

INVESTIGATION METHODOLOGY

9. In order to investigate the complaint the Investigating Officer obtained from the Trust all relevant documentation, including medical records, together with the Trust's comments on the issues raised by the complainant. The Investigating Officer also met with the complainant at his home.

10. I have not included all of the information obtained in the course of the investigation in this report but I am satisfied that everything that I consider to be relevant and important has been taken into account in reaching my findings. The complainant and the authority were both given the opportunity to see and comment on a draft of this report before the final version was issued.

Independent Professional Advice Sought

11. After consideration of the issues, I obtained advice (IPA) from an Independent Professional Advisor (IPA), a consultant cardiologist of almost 30 years' experience.

13. The information and advice which have informed my findings and conclusions are included within the body of my report. The IPA has provided me with "advice", however how I weigh this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards

14. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case.

15. The general standards relevant to this complaint are the Ombudsman's Principles:

- The Principles of Good Administration[4]

These principles are set out in full in an Appendix to this report.

16. The specific standards are those which applied at the time the events occurred and which governed the exercise of the administrative functions and professional judgement of the Trust and the individuals whose actions are the subject of this complaint.

17. The details of the National Standards relating to the issues raised in respect of the care and treatment the late patient received are:

- Working party of British Society for Antimicrobial Chemotherapy, 2004
- European Society of Cardiology Guidelines on prevention, diagnosis and treatment of Endocarditis, 2009

MY INVESTIGATION

Evidence considered

18. As part of my investigation I have considered the following relevant extracts from the relevant correspondence and clinical records:

[4] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

2009/2010 records

September 2009 – Document titled 'Consent for Examination Treatment or Care' signed by patient and a staff nurse regarding PICC insertion - 'serious or frequently occurring risks – infection, blockage, bleeding, breaking, bruising, phlebitis, migration…..' The patient was also provided with a leaflet titled 'A patients guide to a PICC'. The same form was signed by the patient in September 2009, October 2009 and February 2010.

January 2010 – Department of Haematology letter to GP '*Patient was admitted January 2010….She had recently grown Staph aureus*[5] *from her PICC exit site ….*'

January 2010 - Chemotherapy review clinic to GP, '*Patient was discharged a week ago following an inpatient stay for staph aureus bacteraemia…… A transthoracic echo also showed no evidence of endocarditis*[6] *although the views were suboptimal…'*

February 2010 – Clinical notes "*long standing leg swelling, calves soft*"

February 2010 – Clinical notes "*main problem today is increased swelling of legs, feels fluid in legs is getting worse."*

March 2010 - Discharge letter to GP '*Patient was readmitted approximately a fortnight after completing therapy for staph aureus bacteraemia……..A TOE was performed which showed a small mobile echo adjacent to the mitral valve in keeping with possible bacterial endocarditis…Patient's condition has improved greatly and her inflammatory marker has almost normalised'*

April 2010 – Chemotherapy review clinic to GP, '*Patient has been well and it is now 3 weeks since she completed her course of antibiotics….*'

[5] Staphylococcus aureus - a type of bacterium frequently found in the nose, respiratory tract, and on the skin.
[6] Endocarditis - Inflammation of the inner layer of the heart, the endocardium, usually involving the heart valves

2014 records

September 2014 – Clinical records - '*Type 2 respiratory failure on basis of obesity hypoventilation/OSA (obstructive sleep apnoea) and therefore not fully reversible'*

'*D/W (discussed with) husband son and daughter. Family aware of current condition. Explained ICU (intensive care) and decision not to intubate + ventilate should she deteriorate/not respond to current management….Aware of minimal progress with niv (Non-invasive ventilation) and that prognosis remains guarded'*

'Ceiling of care HDU (high dependency unit) and DNAR (do not artificially resuscitate) form complete.

'Spoke with patient's daughter …explained issues hypoventilation due to weight and apnoea. Irregular heart beat AF (Atrial Fibrillation[7]) ? (don't know) duration it has been present but plan is to control rate..….. Explained risk of stroke with AF…..'

September 2014 – '*discussed situation with daughter and husband. Bleak prognosis due to generally poor baseline and weight. Worsened by current infection…currently at high risk of cardiorespiratory deterioration and arrest*'.

September 2014 – Discharge notification to GP. '*Principle discharge diagnosis – Type 2 respiratory failure secondary to obesity hypoventilation and obstructive sleep apnoea. Right ventricular failure and pulmonary hypertension[8]…..Investigations – severely dilated right heart, right ventricular failure – severely impaired. Findings suggestive significant pulmonary hypertension.'*

[7] Abnormal heart rhythm

[8] Pulmonary hypertension - A condition of increased blood pressure within the arteries of the lungs. Symptoms include shortness of breath, tiredness, chest pain, swelling of the legs, and a fast heartbeat. Onset is typically gradual.

2015

June 2015 – Letter of complaint from husband to the Trust: '*Point 2, In September 2014 whilst in Daisy Hill the medical staff said that she had Chronic Lymphoedema, again since 2010…'*

The Trust response to investigation enquiries

19. In responding to the complaint the Trust stated that the patient had been diagnosed with infective endocarditis in 2010 but that this had been treated successfully with two courses of antibiotics. It stated that following the complaint a Consultant Cardiologist reviewed the patient's records. He confirmed that the treatment for endocarditis was appropriate and that it had been 'cured completely' and there were no subsequent cardiac complications related to this. The Trust stated that the poorly functioning heart problems experienced in 2014 were a direct complication of pulmonary hypertension secondary to obstructive sleep apnoea. With regard to being treated for Chronic Lymphoedema, the Trust stated that the patient was not diagnosed with this condition but rather had peripheral oedema and was treated for this with a standard diuretic up until the time of her death.
The Trust explained its position to the complainant in correspondence and facilitated a meeting for him to meet with senior clinicians.

IPA Advice

20. The IPA advised that infective endocarditis is inflammation of the inner lining of the heart muscle, particularly the heart valves, and arises from infection in the blood stream passing through the heart. The IPA advised that in the patient's case the PICC line was the obvious source of infection with the same bacterium being cultured from both the line and her blood. The IPA further advised that she was treated appropriately for this condition with a six week course of antibiotics. A follow up echocardiogram in October 2010 showed the right heart to be entirely normal and the IPA advised that it would be perfectly reasonable to say that her endocarditis was completely cured and there was complete resolution. As such there was no

need for continuing specialised care for this condition after 2010. The IPA advised that it was extremely unlikely that the endocarditis illness of 2010 contributed significantly to the right sided heart failure which the patient experienced in 2014.

21. With regard to the final heart problem experienced in September 2014 the IPA advised that the source of this problem was different from the endocarditis experienced in 2010. The IPA advised that the deterioration in the patient's condition at this time had its origins in the development of sleep apnoea and pulmonary hypertension in the intervening period. This was exacerbated by sustained obesity. The IPA advised that sleep apnoea involves pauses in breathing during sleep. These episodes can wake the sufferer as they gasp for air and it prevents restful sleep. It is associated with high blood pressure, arrhythmia[9], and heart failure. Pulmonary hypertension occurs in 17 – 53% of people with sleep apnoea and 82% of people with pulmonary hypertension have underlying sleep disordered breathing. Pulmonary hypertension eventually causes the right heart to fail as it tries to pump blood into a high pressure pulmonary circulation. The IPA advised that the patient's poor prognosis was explained to the family in September 2014. The IPA also advised that surgical intervention was not indicated and that the patient was treated medically with diuretics, anticoagulants and medication to control her heart rate.

22. With regard to whether the patient had peripheral oedema or chronic lymphoedema, the IPA confirmed that, as stated in the Trust's letter of 23 November 2015, that chronic lymphoedema was not diagnosed. The IPA advised that the occasional references regarding lymphoedema in the medical records were unsubstantiated. The IPA advised that the patient had peripheral oedema which in obese and poorly mobile patients can be very difficult to treat and is usually caused by a combination of factors. The IPA described how oedema had been recognised and treated from 2010 with diuretics and stated that this was the appropriate treatment. The IPA advised that by 2010 and her final admission to hospital, the patient was described as having gross oedema up to her sacrum (lower spine), as being severely obese, with obstructive sleep apnoea, secondary pulmonary hypertension and resultant heart failure. The IPA advised that the predominant

[9] Irregular heartbeat

cause of her 'peripheral oedema' at this time was her chronic pulmonary hypertension and right heart failure in addition to obesity which would also have contributed and which was an underlying risk factor to all her health problems. However the final peripheral oedema experienced in late 2014 was very much secondary to her right heart failure.

23. The IPA advised that while the complainant's frustration about his wife's continual decline in health in her final years may be understandable, this decline had multiple causes. These were prolonged obesity, the development of sleep apnoea and pulmonary hypertension leading to the development of breathlessness and eventual heart failure. The IPA advised that the development of these conditions was quite separate from previous conditions. Overall the IPA was satisfied that the patient had been appropriately and successfully treated for endocarditis in 2010 and that the Trust's diuretic therapy received to treat oedema was appropriate.

Issue 1 - Whether the treatment and care afforded to the patient was appropriate and reasonable following an episode of infective endocarditis in 2010.

24. The patient first noticed swelling in her right cheek in February/March 2009 and following investigations was diagnosed with Non-Hodgkin's Lymphoma in September 2009. She then received chemotherapy over a period of months, receiving the chemotherapy drugs through a PICC line in her chest. The treatment was successful and by March 2010, she was considered to have entered remission. For the period March 2010 to June 2014 she was reviewed, first weekly then monthly, then three monthly and six monthly by the Haematology team.

25. In order to receive the chemotherapy, the patient had a PICC line inserted in September 2009 and subsequently had the line replaced or recited on 18 September 2009, 8 October 2009 and 19 February 2010. On each of these occasions she signed a document titled 'Consent for Examination Treatment or Care' which listed the risks regarding PICC insertion. These were stated to be 'infection, blockage, bleeding,

breaking, bruising, phlebitis, migration…..' On each occasion the patient was also provided with a leaflet titled 'A patients guide to a PICC'. I am therefore satisfied that the risks of a PICC insertion were adequately communicated to the patient and that her consent was fully informed and given to this mode of treatment.

26. Unfortunately during January 2010 she acquired an infection causing infective endocarditis. The bacterium causing the infection, staphylococcus areus, was considered to have been introduced through the PICC line. The patient initially received two weeks of antibiotic treatment then a further four weeks, giving a total of six weeks to treat the endocarditis. In considering this matter, I accept that despite the best efforts of the clinicians and staff involved and precautions and efforts to limit its spread, infections in confined settings such as hospitals can and do occur. In this case I make no criticism of the Trust for the fact that the patient acquired infective endocarditis. I am mindful that the risk of infection was communicated and explained to her. My investigation has therefore focused on how this condition was treated. The IPA has advised that the endocarditis was accurately assessed and treated appropriately. Based on the IPA's examination of the correspondence, the medical records and the results of echocardiograms, the IPA has advised that as a result of the treatment received, the patient's endocarditis was cured completely in 2010. As such, the IPA concluded, there was no need for continuing care for this condition after this time. I accept this opinion and therefore consider that the care and treatment received by the patient was appropriate and reasonable following an episode of infective endocarditis in 2010. **I do not uphold this element of the complaint.**

27. The complainant informed the Investigating Officer that the family had been told by a female doctor in September 2014, during his wife's admission to Daisy Hill Hospital, that his wife's heart had suffered long term damage from the endocarditis of 2010. Unfortunately he did not recall the doctor's name or any other details of the conversation. An examination of the medical records does not evidence any indication to this conversation. I am not questioning the truth of the complainants' assertion. However in the absence of a contemporaneous record of this conversation I am unable to conclude on the detail of the Trust's communication with the family. However as referenced in the preceding paragraph I am satisfied that the

endocarditis suffered by the patient in 2010 was resolved. I am therefore also satisfied that she did not suffer any long term consequences from this condition. The IPA has advised, and I accept, that the final heart problem which she experienced prior to her death in December 2014 came from a different source.

Issue 2 - Whether the treatment and follow up of the patient's condition of Chronic Lymphoedema was reasonable.

28. The patient had a longstanding problem with oedema, an accumulation of fluid causing swelling in her legs. This was noted in the medical records following an admission in February 2010 which stated '*long standing leg swelling, calves soft'*. Shortly after it was noted '*main problem today is increased swelling of legs, feels fluid in legs is getting worse*'. The same was noted in March 2010. The IPA advised that oedema in obese and poorly mobile people can be caused by many factors and is difficult to treat. One of the factors involved in the patient's problem in this area may have been her longstanding obesity which the IPA described as an underlying risk factor to all her health problems. An additional factor may have been the cancer treatment which she was undergoing at that time which the IPA advised can cause localised fluid retention. Whatever the cause of the oedema at this time, the patient was commenced on diuretic therapy in 2010 and continued taking this medication (Furosemide) until her death in December 2014. I accept the IPA advice that this was the appropriate treatment for oedema and that she was appropriately treated for this condition.

29. Confusion appears to have arisen over whether the patient had chronic (longstanding) lymphoedema (that is oedema, with the source being the lymphatic system) or the more general term describing fluid retention in the lower limbs, peripheral oedema. The complainant stated in a letter of complaint to the Trust that he had been informed by medical staff in 2014 that his wife had chronic lymphoedema. I have noted some use of the word lymphoedema in the medical notes from the admission in September 2014 but as the IPA advises these are unsubstantiated and do not amount to a definite diagnosis. I accept the advice of the IPA in that in September 2014 the patient had peripheral oedema, of which the predominant cause would have been a combination of obesity, longstanding (that is

from at least 2010) pulmonary hypertension and right heart failure. I also note the advice of the IPA that the focus of attention during treatment in September 2014 was the more serious and life threatening breathing difficulties and right heart failure. The treatment of oedema, which I have concluded was appropriate, was very much secondary to this. I note the record of a discussion with the complainant and his daughter in September 2014 when it was explained that the patient had a bleak prognosis and that she was at a high risk of cardiorespiratory deterioration and arrest.

30. The IPA has raised the question of primary care[10] involvement in the care of the patient over the course of her illnesses, however my investigation has focused on the secondary[11] care and treatment she received from the Trust. She was admitted to hospital in September 2014 with respiratory failure and right heart failure. The IPA has advised that the origin of this was the development over the previous years of sleep apnoea and associated development of pulmonary hypertension, that is, an increased blood pressure within the arteries of the lungs. This in turn led to increased pressure on the heart and its ultimate failure causing death in December 2014. These are entirely separate issues to her earlier presentation in 2010. The IPA advised that the patient's weight would also have played a part in the development of heart failure. When discharged in September 2014 she was prescribed heart medication and the provision of additional respiratory nurse follow up in the community was arranged for her.

The Trust's handling of the complaint

31. The IPA has commented on the evident lack of understanding experienced by the complainant of the sequence of events and of the underlying causes behind his wife's health problems. This understandably led to a breakdown of the necessary trust and confidence between the family and the Trust. The complainant explained to the Investigating officer that he did not understand much of what was being said to

[10] Primary health care – care provided by a GP or other professional who is the first point of contact
[11] Secondary health care – care provided by a hospital trust

him in correspondence. Further he complained that during a meeting he had with clinicians during the local resolution process under the HSC Complaints Procedure that his distrust was of such an extent that he didn't believe much of what he was told.

32. I have examined the Trust's correspondence to the complainant dated 9 July 2015 and 24 May 2016 regarding his complaint about the events surrounding his wife's death. I note that this correspondence covered the issues of concern raised by him. I also note that clinicians from the Trust met with the complainant on 25 April 2016 in a further attempt at local resolution. I consider the correspondence contains medical terminologies which may be difficult for a layman to understand. These terms were not clearly defined by the Trust in plain English. However the correspondence was followed up by a meeting between the complainant and senior clinicians from the Trust during which he had an opportunity to ask questions. I consider this to represent a genuine attempt on the part of the Trust to answer his concerns. I note the IPA's comments on this, that such was the level of the complainants' misunderstanding of the medical situation that his concerns focused on his wife's endocarditis and oedema. While I accept the IPA's advice that these conditions had little bearing on his wife's ultimate death, I consider this highlights the complainants' lack of understanding. I would remind the Trust that, in responding to complainants concerns, that correspondence to patients and their families, should be written, as far as possible, in terms easily understood by those who do not have a medical background. **However, having examined the documentation available to me, I am satisfied that the Trust did make a sincere and reasonable effort to address the complainants' concerns.**

CONCLUSION

33. The complainant complained to me regarding the care his late wife received from the Trust in relation to the treatment she received for an infection causing endocarditis in 2010 and oedema up until her death in December 2014. I have found that both these conditions were appropriately and correctly treated. I am satisfied that the endocarditis was resolved and that there was no need for continued medical

care for this condition. The patient's death in December 2014 was as a result of heart failure, the roots of which came from a different source.

34. I have noted in correspondence and from the visit of the Investigating Officer the distress which the complainant has experienced following the death of his much loved wife. He has stated that the pain which he experienced has been heightened by his conviction that his wife may not have died if the care and treatment she received had been better. I have not found a failure in the care and treatment received from the Trust, however I hope that my report has gone some way to address the concerns the complainant has raised in his complaint to me.

Marie Anderson
Ombudsman

February 2018

APPENDIX ONE

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating its criteria for decision making and giving reasons for decisions
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.

- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.