Northern Ireland
Public Services
Ombudsman

Investigation Report

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

NIPSO Reference: 18612

The Northern Ireland Public Services Ombudsman
33 Wellington Place
BELFAST
BT1 6HN
Tel: 028 9023 3821
Email: nipso@nipso.org.uk
Web: www.nipso.org.uk
@NIPSO_Comms

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, and 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.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

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.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

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Appendix 1 – The Principles of Good Administration

SUMMARY

I received a complaint about the actions of the Belfast Health and Social Care Trust (the Trust). The complaint concerned the care and treatment provided to the complainant's late wife following her diagnosis of Bile Duct cancer in November 2015. Her disease remained stable until early October 2016 when she began to complain of an increase in pain. She sadly passed away on 5 May 2017. The complainant was concerned that the care and treatment his wife received between 7 November 2016 and 10 April 2017 was not appropriate or reasonable. In particular, he was concerned about how her pain was managed. He also considered that there was a delay in her being referred for palliative care, and that her medical oncologist[1] focused too much on how his wife managed day to day and how she looked rather than considering her pain management and carrying out examinations.

The investigation established that the care and treatment provided in respect of pain management, referral to palliative care and review of pain at appointments was reasonable. I therefore did not uphold these aspects of the complaint.

However, the investigation identified a failing in relation to the Trust not allocating the patient a clinical nurse specialist/keyworker which I consider would have assisted the patient and her family during the final stages of her cancer.

I am satisfied the failure I have identified caused the patient the injustice of loss of opportunity to have additional specialist support. I am also satisfied the failure I have identified caused the complainant the injustice of frustration and annoyance. I recommended that the Trust apologise to the complainant for the injustice caused by the failure to allocate the patient a clinical nurse specialist.

I am pleased to note the Belfast Health and Social Care Trust accepted my findings and recommendation.

[1] An **oncologist** is a doctor who treats cancer and provides **medical** care for a person diagnosed with cancer. The field of **oncology** has three major areas: **medical**, surgical, and radiation. A **medical oncologist** treats cancer using chemotherapy or other medications, such as targeted therapy or immunotherapy.

THE COMPLAINT

1. The complainant said that the care and treatment provided to his wife (the patient) between November 2016 and April 2017 in respect of her pain management and referral for palliative care, was not appropriate or reasonable. He also complained that his wife's consultant oncologist focused too much on her appearance rather than her pain management.

Background

2. The patient was diagnosed with bile duct cancer on 26 November 2015. She was referred to oncology where she underwent six cycles of chemotherapy treatment between 13 January 2016 and 25 May 2016. Her disease remained stable until October 2016. She attended a review appointment with the consultant on 5 September 2016 where he arranged for her tumour marker levels to be taken, assessed and reviewed. The results indicated an increase in the patient's tumour marker level. Therefore, the consultant referred the patient for a CT scan which was performed on 18 October 2016. He met with the patient on 7 November 2016 to discuss her latest CT scan results which had identified there was a very slow progressive disease indicating the patient may have bone metastasis[2].

3. The consultant arranged for the patient to have a further CT scan performed on 4 January 2017. The CT scan performed on 4 January 2017 indicated secondary bone cancer in the patient's spine. She was reviewed by a Specialist Registrar[3] at the oncology clinic on 23 January 2017. The Registrar discussed the patient's CT scan results from 4 January 2017 and the patient's overall wellbeing. The complainant indicated his wife was experiencing pain from October 2016; however he believes her pain became much worse in November 2016. The patient attended her GP complaining of new symptoms on 7 March 2017. The GP contacted the oncologist on that same day to advise that she was complaining of new symptoms. Subsequently, the oncologist made a referral for the patient to have a MRI scan

[2] The **bone** is a common site for **metastasis**. **Bone metastasis** or "**bone** mets" occurs when cancer cells from the primary tumor relocate to the **bone**.
[3] A specialist registrar is a doctor who is receiving advanced training in a specialist field of medicine in order to eventually become a consultant.

which was performed on 9 March 2017. The patient's MRI confirmed she had secondary bone cancer. She also underwent a further CT scan on 28 March 2017 which confirmed the secondary bone cancer had spread to her abdomen. She was reviewed by the oncologist on 10 April 2017 and he referred the patient for palliative radiotherapy on that same day.

Issues of complaint

4. The issues of the complaint which I accepted for investigation were:

Issue 1: Whether the care and treatment afforded to the patient was appropriate and reasonable? In particular,

(i) Whether the patient's pain management was appropriate and reasonable

(ii) Whether there was a delay in the patient having a palliative care referral and

(iii) Whether the oncologist focused too much on the patient's appearance rather than her pain management

INVESTIGATION METHODOLOGY

5. In order to investigate the complainant's complaint, the Investigating Officer obtained from the Trust all relevant documentation relating to the patient's clinical records together with the Trust's comments on the issues raised by the complainant. This documentation included information relating to the Trust's handling of the complainant's complaint.

Independent Professional Advice Sought

6. After further consideration of the issues, I obtained independent professional advice from the following independent professional advisors (IPA):

- A Consultant Clinical Oncologist with a special interest in hepato-biliary and pancreatic tumours (MO IPA 1)
- A Consultant Medical Oncologist (MO IPA 2)

7. As part of the NIPSO process clinical advice received is shared with the healthcare organisation and clinicians for comment. Having considered the comments by the Trust in this case in relation to the independent professional advice obtained on 16 January 2019 from the medical oncologist MO IPA 1 and being unable to come to a conclusion I decided to further explore the difference in opinion between the Trust and MO IPA 1. I therefore obtained advice from a second medical oncologist MO IPA 2.

8. The information and advice which have informed my findings and conclusions are included within the body of my report. The IPA's have provided me with 'advice'; however how I have weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards

9. 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.

10. The general standards are the Ombudsman's Principles[4]:

- The Principles of Good Administration
- The Principles of Good Complaints Handling
- The Public Services Ombudsman's Principles for Remedy

11. The specific standards are those which applied at the time the events occurred and which governed the exercise of the functions of the Trust staff whose actions are the subject of this complaint.

12. The specific standards relevant to this complaint are:

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

- World Health Organisation (WHO): Guidelines for the Pharmacological and Radiotherapeutic Management of Cancer Pain in Adults and Adolescents (1996/2008) (WHO Guidelines);
- National Institute for Clinical Excellence (NICE) Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer - The Manual (2004) (Guidance on Adults with Cancer);
- British Pain Society: Cancer Pain Management – A Perspective from the British Pain Society (2010);
- Guidelines and Audit Implementation Network (GAIN) General Palliative Care Guidelines for the Management of Pain at the End of Life in Adult Patients (February 2011) (Palliative Care Guidelines);
- National Institute for Clinical Excellence (NICE) Guidelines End of Life Care for Adults (2011) (NICE 2011);
- General Medical Council Guidelines (2013) (GMC Guidelines);
- European Society for Medical Oncology (ESMO) Clinical Practice Guidelines: Management of Cancer Pain in Adult Patients (2012);

13. 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. I have included information from the patient's GP records. However, the investigation is only considering the actions of the Trust.

15. A draft copy of this report was shared with the Trust and the complainant for comments on factual accuracy and the reasonableness of the findings and recommendations.

INVESTIGATION

Issue 1 **Whether the care and treatment afforded to the patient was appropriate and reasonable? In particular,**

(i) Whether the patient's pain management was appropriate and

reasonable

(ii) Whether there was a delay in the patient having a palliative care referral and

(iii) Whether the oncologist focused too much on the patient's appearance rather than her pain management

Detail of Complaint

16. The complainant believed his wife was experiencing a great deal of pain between November 2016 and April 2017 and her medical team should have known the level of pain she was experiencing. In particular, he complained her pain management between 7 November 2016 and 10 April 2017 was not appropriate and there was a delay in her being referred for palliative care including palliative radiotherapy. He believes the opportunity to have palliative radiotherapy would have spared her unnecessary pain. He also complained that the oncologist focused too much on his wife's appearance rather than her pain management.

Evidence Considered

Guidance

17. I examined the Palliative Care Guidelines and I considered the following sections relevant to the investigation:

Principles of Pain Management states '*Comprehensive, individualized and holistic assessment and treatment planning, including regular review and assessment with involvement of the wider multi professional team as appropriate'*.

Assessment of pain states '*accurate assessment of pain is essential to plan appropriate interventions or treatments. Uncontrolled pain limits a person's ability to self-care, affects their response to illness and reduces their quality of life. In keeping with the "total pain" model, assessment should consider the following domains:*

Physical: Related to underlying disease e.g. cancer, abdominal distension from ascites. Related to treatment e.g. surgery, chemotherapy, radiotherapy, drug related

neuropathies. Associated factors e.g. constipation, pressure sores, bladder spasm, stiff joints, postherpetic neuralgia. Co-existent conditions e.g. osteoarthritis, angina

Psychosocial: Psychosocial factors may have a profound influence on an individual's perception and experience of pain and can affect how the patient's responds emotionally and behaviourally. There is a large body of scientific evidence to support the role of anxiety and depression, fear, pain related beliefs and coping styles in the mediation of pain perception in chronic non-malignant pain.

Spiritual: Pain suffering from chronic unremitting pain can experience spiritual distress/pain. The spiritual dimension of an individual includes meaning, relatedness, hope and forgiveness – this may or may not include a religious belief system

It is imperative that patients' anxieties and frequent misconceptions related to the above factors are explored. Pain will not be adequately controlled unless patients feel a degree of control over their situation. To ignore psychological and spiritual aspects of care may often be the reason for seemingly intractable pain. The patient, if competent and able to communicate, is the most reliable assessor of pain, and where possible should be the prime judge of their pain'.

18. I examined the NICE guidelines for end of life care for adults and I considered the following sections relevant to the investigation:

Quality statement 8: co-ordinated care states '*people approaching the end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences'.*

Quality statement 10: specialist palliative care states '*people approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night'.*

The Trust's response to investigation enquiries

19. The Trust stated '*at the patient's appointments on 5 September 2016 and 7 October 2016, [the patient] was not describing symptoms that were likely to benefit from palliative radiotherapy treatment. [She] was not referred for palliative radiotherapy treatment at this time'.* The Trust stated '*the key appointment date in relation to this is the one which the patient attended on 23 January 2017 at the oncologist's clinic. [She] was reviewed by a speciality registrar[5] in oncology who then discussed her intended management with the oncologist. There is clear documentation relating to that consultation, including detail with the patient's reported symptoms, which included new upper right quadrant abdominal pain. [The patient] also advised that she was keeping well and was able to eat and drink and carry on with all activities. The speciality registrar who reviewed the patient did not recall the patient complaining of back pain during this appointment. It is our view that given the extent of the detail documented in the notes that had the patient mentioned any back pain, the speciality registrar would have undertaken an examination and recorded both the mentioned symptoms and any findings from the examination in the notes. It is also our view that the speciality registrar would have highlighted the issue of new back pain to the oncologist when discussing with him the management plan for the patient at the clinic'.*

20. The Trust further stated *'[The oncologist] has advised that had it been known that the patient was suffering back pain when she attended her outpatient on 23 January 2017, further investigation would have been organized and she may have been referred for palliative radiotherapy sooner. Palliative radiotherapy will relieve pain in about 50% of patients with pain related to bone metastases, but unfortunately it is not possible to know whether it would have helped to address the patient's pain'.*

21. The Trust confirmed '*at the clinic (oncology review clinic) on 23 January 2017 the patient reported she had been commenced on a Butec[6] patch of 5mgs/hr which she did not feel helped. She was also taking co-codomol[7] 8/500mgs tablets, which did*

[5] A **specialist registrar** (SpR) is a doctor in the Republic of Ireland or in the United Kingdom who is receiving advanced training in a specialist field of medicine

[6] **Butec** patches contain the active ingredient buprenorphine which belongs to a group of medicines called strong analgesics or 'painkillers'

[7] Codeine/acetaminophen or co-codamol is a compound analgesic consisting of a combination of codeine

appear to be helping her with her pain. Her pain was being managed in the community by her GP. We assume that the increase in her Butec patch referenced (by the complainant) was at some point following her clinic attendance (on 23 January 2017) given her pain management was supervised by her GP. [The patient's] pain assessment at clinic was scored at 3/10 on the pain scale suggesting her pain was largely controlled'. The Trust reiterated '*the patient's pain control was largely satisfactory and this was being managed by her GP in the community'.*

22. The Trust also confirmed that the patient's '*GP contacted the oncology service on 7 March 2017 to advise that the patient was experiencing back pain which was radiating to her right thigh. As a result, the oncologist requested an MRI scan which was performed two days later on 9 March 2017. This scan result unfortunately showed evidence of metastatic disease in the first lumbar vertebrae with evidence of partial collapse of the vertebrae. As it did not show evidence of spinal cord compression, which would have necessitated emergency radiotherapy, [the patient] was offered the next available review appointment at the oncologist's clinic on 10 April 2017.* The Trust stated '*during the patient's appointment on 10 April 2017, she described symptoms that the oncologist felt could benefit from palliative radiotherapy and the oncologist referred the patient to a consultant in palliative medicine for consideration of palliative radiotherapy treatment. Unfortunately, the patient was admitted to the Ulster Hospital in the interim period and sadly her condition deteriorated very rapidly such that she became too unwell to attend for radiotherapy'.*

23. The Trust reiterated '*there is no record that the patient complained of back pain when she was seen at the clinic in January 2017….following her clinic appointment on 10 April 2017 where she did complain of back pain the patient was offered palliative radiotherapy and was referred for consideration……the oncologist had planned to review the patient following the radiotherapy'.*

24. In response to enquiries made regarding the oncologist focusing on the patient's appearance, the Trust state '*assessment of patients when considering treatment options is not limited to a review of scan results. Such assessment must also take*

phosphate and paracetamol.

into account the patient's symptoms, their ability to carry out daily activities, the likely benefit of further treatment and the likely toxicity of further treatment which may impact on the patient's quality of life. How each patient feels is an important part of this assessment and an important consideration when determining what is in their best interests'.

Clinical Records

25. I examined the patient's clinical records and considered the following extracts relevant:

6 September 2016: correspondence from the oncologist to the patient's GP '*I reviewed this lady in the oncology clinic today. She remains well in herself after completing chemotherapy for her metastatic adenocarcinoma possibly of the ampulla of vater*[8] *in June 2016. CT scan on completion of treatment suggested her disease was stable and there had been significant reduction in her Ca19-9*[9] *level during chemotherapy treatment. She has been well since completing chemotherapy and has no new symptoms or problems today. On abdominal examination there were no abnormal findings. I have rechecked Ca19-9 today and I have requested a repeat CT scan for early October. She will be reviewed again in a further 2 months'.*

11 November 2016: correspondence from the oncologist to the patient's GP '*I reviewed this lady in Oncology clinic today* [7 November 2017]*. She remains reasonably well in herself and currently has no symptoms from her metastatic ampullary/lower common bile duct tumour…CT scan performed in mid-October has shown that her disease is very slowly progressive, with some increase in the extent of peritoneal nodularity*[10] *seen, this is mirrored by a rise in her CA 19.9. However as she is asymptomatic*[11] *at present, I do not feel that there is a strong rationale for rushing in to second line chemotherapy at this point.*

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[8] Ampullary carcinoma is a rare malignant tumor originating at the ampulla of Vater, in the last centimeter of the common bile duct, where it passes through the wall of the duodenum and ampullary papilla. Patients typically present with symptoms related to biliary obstruction.

[9] Carbohydrate antigen (**CA) 19-9** is a type of antigen released by pancreatic cancer cells. ... After diagnosis, the **CA 19-9** Radioimmunoassay (RIA) blood test can be used for some patients to watch the disease's development

[10] *Peritoneal nodularity* - cancer cells that multiply and form small tumor **nodules** (between 2 to 5 mm) on the **peritoneum**. The **peritoneal** cancer **nodules** may occur anywhere in the abdominal cavity, but the most common sites include the right diaphragm, the small pelvis, the omentum and the surface of the intestine

[11] (of a condition or a person) producing or showing no symptoms.

I have discussed this with the patient, who also does not feel that she wishes to rush in to further chemotherapy at this stage, as she is well with no symptoms or problems. She does wish however to consider further chemotherapy in the future should this be appropriate. In view of this I have arranged for her to have to repeat CT scan performed early in the new year and will review her again in the oncology clinic with the result of this once this is available to discuss further treatment options with her at that stage'.

23 January 2017: '*surgical trainee 3* [in oncology] *(ST3)*[12]*….Pain review pain constant ache and can be sharp 7/10* [pain score] (1 being least amount of pain and 10 being most amount of pain) *more so last couple of weeks takes co-codamol 8/500*[13] *– 3/10* [pain score]. *Sometimes need 30/500. GP gave Butec 5 micrograms, no real benefit….patient keeping well, eating and drinking and mobilising'.*

27 January 2017: correspondence from the Specialist Registrar to the patient's GP '*CT scan on the 4 January 2017 showed soft tissue thickening and nodularity within omental*[14] *and peritoneal fat plans consistent with metastatic disease*[15]*. This is mixed lytic and sclerotic disease*[16] *involving L1 vertebra*[17]*, presumably metastatic disease and left adnexal cyst is slightly larger. The patient is complaining of right upper quadrant pain, which is constant ache and sometimes can be sharp and is 7 out of 10. The pain has been more constant over the last few weeks and she takes 8/500*

[12] ST3. Specialty training is the final stage of surgical training before obtaining your CCT (Certificate of Completion of Training) which grants you entry to the Specialist Register, and allows you to practise as a substantive consultant surgeon in the NHS.

[13] Co-codamol tablets and capsules come in 3 different strengths.They contain 8mg, 15mg or 30mg of codeine.All strengths contain 500mg of paracetamol - the same as in a standard paracetamol tablet or capsule. The strength of co-codamol appears as 2 numbers on the packet. For example, the strength may be written as 8/500. This means it contains 8mg of codeine and 500mg of paracetamol.

[14] Omental: The greater **omentum** (also the great **omentum**, **omentum** majus, gastrocolic **omentum**, epiploon, or, especially in animals, caul) is a large apron-like fold of visceral peritoneum that hangs down from the stomach.

[15] In **metastasis**, **cancer** cells break away from where they first formed (primary **cancer**), travel through the blood or lymph system, and form new tumors (**metastatic** tumors) in other parts of the body. The **metastatic** tumor is the same type of **cancer** as the primary tumor

[16] *Lytic and sclerotic disease*: **sclerotic** lesions are spots of unusual thickness on your bones. Bone disease

[17] The lumbar **spine** has 5 intervertebral segments, termed lumbar segment 1 through 5 (e.g. **L1**, L2, **L3**, L4, and L5). Each lumbar **spine** segment is comprised of: Two **vertebrae**, such as L4-L5, stacked vertically with an intervertebral disc between them. ... They pass through small holes in the back of the lower **spine**.

which brings pain down to about 3 out of 10. She has no pleuritic pain[18] and the pain isn't associated with eating.

She feels if she sits for long periods of time that can aggravate the pain. Her bowels are normal with dietary fibre. She is keeping well, is eating and drinking and able to do activities of daily living. I discussed the scan result with the oncologist today who reviewed it but couldn't see any obvious progressions from the scan in October 2016. On examination today her chest was clear, abdomen soft and non-tender, bowel sounds present, heart sounds 1 & 2 +0 calves were soft and non-tender and no oedema[19]. Since the patient is feeling well and there is no obvious progression on the CT scan, the plan would be to do a repeat CT scan in 3 months and to consider second line chemotherapy if necessary'.

5 April 2017: correspondence from the patient's GP to the oncologist 't*he patient is ampullary carcinoma, ascites and metastatic spinal disease was recently admitted to Ulster Hospital for control metastatic back pain…she is due for review with yourself on 24 May 2017 but is anxious to see you before this to discuss any other treatment options'.*

10 April 2017*:* correspondence from the oncologist to the patient's GP *'I reviewed the patient in the oncology clinic today following a recent MRI and CT scan of chest, abdomen and pelvis. The MRI scan was requested as she had been having problems with back pain which culminated in emergency admission to the Ulster Hospital (UH) on 30 March 2017. The back pain had been managed at home with increasing doses of pregbalin[20] and this had been withdrawn due to confusion. On the night of admission to hospital she had been unable to sleep due to severe pain*. *MRI scan on 9 March 2017 showed metastatic bone marrow infiltration on L1 and*

[18] **Pleuritic** chest **pain** is characterized by sudden and intense sharp, stabbing, or burning **pain** in the chest when inhaling and exhaling. It is exacerbated by deep breathing, coughing, sneezing, or laughing. ... **Pleuritic** chest **pain** is caused by inflammation of the parietal pleura and can be triggered by a variety of causes

[19] a condition characterized by an excess of watery fluid collecting in the cavities or tissues of the body.

[20] **Pregabalin** is used to treat some types of persistent pain. It is especially good for nerve pain, such as burning, shooting or stabbing pain.

L3…she was commenced on MST[21] 5 mg twice daily with oramorph[22] 3 mg for breakthrough pain as well as paracetamol 1g as required for breakthrough pain. She was also commenced on dexamethsone[23] 4 mg per day which was reduced to 2 mg per day on 4 April 2017….currently her pain control is substantially improved although she is still sore on movement, particularly on climbing stairs at home.

In the first instance as her main symptom from her progressive disease is back pain related to metastases…I feel it would be appropriate to consider palliative radiotherapy and have referred her to my colleague […] for consideration of this. It may be appropriate to consider second line chemotherapy and I have discussed this in broad terms with the patient and her husband today….I have explained that the benefits of second line chemotherapy are relatively of the balance between the risks and benefits of further chemotherapy. I plan to review her again in the clinic following her palliative radiotherapy to discuss this in more detail'.

11 April 2017: correspondence from the oncologist to the Consultant in Palliative Medicine - *'I would be grateful if you could arrange to see this lady with a view to palliative radiotherapy to L1 to L3. She has a metastatic ampullary carcinoma with known bone metastasis which were diagnosed in 2015…she received palliative chemotherapy between January 2016 and June 2016 with stable disease which remained relatively stable until January 2017. More recently, she has presented with worsening back pain and an MRI scan has shown marrow infiltration and replacement of L1 without evidence of cord compression but some evidence of compression of the left L1 root. This has required admission to the Ulster Hospital on 30 March 2017 for pain control. Her pain is much better on her current analgesic regimen. However she dislikes opiates due to dissociative effects she feels with them and is reluctant to increase the dose of these and is still experiencing pain on mobilisation'.*

[21] **MST is** a salicylate (sa-LIS-il-ate). It works by reducing substances in the body that cause pain, fever, and inflammation. **MST is** used to treat mild-to-moderate pain, fever, inflammatory conditions, and pain, swelling, or stiffness associated with arthritis

[22] Oramorph is a liquid form of morphine, which is often used as a pain killer, in small doses oramorph is used for the relief of long term or chronic breathlessness.

[23] Dexamethasone is a type of corticosteroid medication.

26. I examined the patient's GP records and considered the following extracts relevant:

8 November 2016: '*oncology yesterday, disease progression. Going to be re-scanned in January and decision re further chemotherapy…reduced appetite, pain in back, bloating all related to disease progression'.*

24 January 2017: *'seen by oncology yesterday, took pain patch off, not helping. On co-codamol 30/500, possibly has suggested oramorph. Minimal disease progression. Due another scan in 3 months…co-codamol 30/500 tablets'.*

23 February 2017: '*looks well…main issue is l.sided lower back pain, when sitting straight. Last scan 04/01/2017 possible metastases in L1. Gets ease by stretching out legs and sitting to L side. Butec 5 patch ineffective. Taking 4-6 30/500 per day can cause nausea. Butec Transdermal patches 10 mgrams/hour. Paracetamol tablets 500mg. Will increase patch to Butec 10 with ref paracetomol. Ongoing rv with me to review analgesic requirements'.*

6 March 2017: '*still r sided lower back pain sclerotic lesion L1. Pain into R ant thigh. Increase butrans to 20. Not toxic. Add in trial pregabalin neuropathic pain. Update bloods....voicemail left with the oncologist secretary'.*

7 March 2017: '*d/w oncology Spr (Specialist Registrar) [A Hamilton], re-staging scan end of March. Will request MRI scan (this week) and try to expedite CT scan. Sounds like disease progression'.*

10 March 2017: '*spoke with [the complainant] this morning…[the patient] had her MRI yesterday, was told GP would have results today, no results through. Also analgesia not optimal at present, was going to increase pregabalin, advised to speak to GP first for appropriate advice'.*

13 March 2017: *'has had MRI, still back pain, will refer to community palliative care team'.* '[GP referral] *Referral to palliative care service'.*

20 March 2017: '*palliative care review last week, nurse mentioned palliative radiotherapy. Awaiting the oncologist review…On steroids, appetite improved, pregabalin dose increase has helped slightly'.*

11 April 2017: '*hospice nurse called out to see today but [patient] declined to see as emotionally not ready for hospice nurses to call and see at home. Seen by the*

oncologist yesterday, lined up for palliative radiotherapy. Can be re-referred to community hospice team if needs be. Pain controlled. [The oncologist] stopped steroids yesterday'.

Independent Professional Advice

27. In response to enquiries made regarding the patient's pain relief, the MO IPA 1 advised '*The clinical notes on 4 July 2016 and 5 September 2016 state no pain. Clinical notes from 7 November 2016 mentions progression of disease on CT scan without any symptoms. However, the next clinical appointment on 23 January 2017 states "pain for several weeks*". The MO IPA 1 further advised ''*the patient was started on co-codamol on 9 January 2017 which was changed to Butec 5 microgram/hr on 18 January 2017 and increased again to 10 microgram with paracetomol on 23 February 2017. It was increased to 20 micrograms* [by GP] *on 6 March 2017 and pregabalin was added. the patient also received morphine from 3 April 2017'.* The MO IPA 1 further advised *'the patient's pain medication was being prescribed by her GP….it is not clear whether it was a joint care by GP and the hospital consultant. Depending on the circumstances of patients and local arrangements, pain management is generally by GP's community Macmillan team or hospital specialist'.* The MO IPA 1 confirmed '*since 9 January 2017, there* was *regular reviews and adjustments of medications, however it is difficult to assess from the notes whether the increase and adjustments were appropriate for the intensity of pain'.*

28. In response to enquiries made in regards to the patient's review appointment with the oncologist on 7 November 2016, the MO IPA 1 advised '*the patient was reviewed by the oncologist on 7 November 2016. The letter states "she remains reasonably well in herself and currently has no symptoms from …. the patient who also does not feel that she wishes to push into further chemotherapy at this stage as she is well with no symptoms or problems. Therefore, it is reasonable to assume that no pain management is offered'.* The MO IPA 1 highlighted '*however, the note from* GP, *on the next day* [8 November 2016] *states 'reduced appetite, pain in back, bloating all related to disease progression'. It is unlikely that the symptoms could have developed overnight'.*

29. The MO IPA 1 further advised '*the patient was started on co-codamol on 9 January 2017 by her GP and therefore, I assume pain started during early January 2017'*. The MO IPA 1 advised '*the patient was reviewed at the clinic on 23 January 2017. [She] had constant right upper quadrant pain "over the last few weeks" for which she was taking co-codamol 8/500. GP started BUTEC at this time "which feels is of no benefit at all". The letter notes […] discussed the scan results (CT scan 4 January 2017) with the oncologist who could not see any obvious progression. Even though the patient stated that pain control was not optimal, she was not offered better/alternative pain medication in this clinic'. The clinical letter on 23 January 2017 indicates that she has pain which is not optimally controlled…the GP has increased BUTEC from 5mg on 18 January 2017 to 10mg on 23 February 2017 and to 20 mg on 6 March 2017. While the letter on 23 January 2017 acknowledges uncontrolled pain, no alternative or stronger medication was offered. Since pain needed constant increase in medication the pain could have been evident to clinicians'.*

30. In response to enquiries made regarding the level of pain the patient was experiencing based on her prescribed pain medication, the MO IPA 1 advised '*It is not clear from the notes who was in overall charge of pain management. It is often difficult to anticipate levels of pain and therefore, patients often need regular assessment and adjustment of pain medications'.* The MO IPA 1 further advised '*Palliative radiotherapy is often an effective method of pain management in patients with metastatic bone disease. Pain control is often achieved in 8 out of 10 patients within 2 weeks of radiotherapy. Since there was radiological progression of bone metastases and uncontrolled pain, the patient should have been referred to palliative radiotherapy earlier. Ideally after the clinic consultation on 23 January 2017…she should have been offered palliative radiotherapy earlier'.*

31. The Investigating Officer enquired as to whether the oncologist had focused too much on the patient's appearance during his assessment and reviews of her condition. The MO IPA 1 advised '*I could not find any documentation on "appearance" in the notes.* The MO IPA 1 concluded '*the patient should have had better pain control and less suffering during her last days. Therefore, the regional health providers are advised to critically review the pain management pathways and treatment guidelines urgently to avoid similar situations in the future'*.

The Trust's response to Independent Professional Advice

32. The Investigating Officer provided the opportunity for the Trust, the oncologist and the Registrar to provide comment on the MO IPA 1 advice.

33. The oncologist referenced the MO IPA 1 who advised *"It is not clear whether it was a joint care by her GP".* However, the oncologist states *'that the GP was leading the patient's pain management as he initiated and managed changes in her analgesia'.*

34. The oncologist referenced the MO IPA 1 who advised *"The clinical letter on 23 January 2017 indicates that she has pain, which is not optimally controlled. The GP has increased BUTEC from 5 mg on 18 January 2017 to 10mg on acknowledges uncontrolled pain, no alternative or stronger pain medication was offered. Since pain needed constant increase in medication, the pain could have been evident to clinicians*." However, the oncologist states '*while the patient reported that Butec was not helping, she also reported that Co-codamol 8/500 was helping to control her pain. The following is an extract from the medical notes of 23 January 2017: 'The pain has been more constant over the last few weeks and she takes 8/500, which brings the pain down to about 3 out of 10. She sometimes requires 30/500. GP commenced her on BUTEC 5mcgs, which she feels is of not benefit at all'.* The oncologist also states that *'the patient's pain was not severe enough or poorly controlled enough to interfere with activities of daily living at this time'.*

35. The oncologist referenced the MO IPA 1 who advised *"It appears that GP has increased the pain relief. The GP has increased BUTEC from 5 micrograms/hr. on 18 January 2017 to 10mg on 23 February 2017 and to 20mg (along with pregabalin) 6 March 2017"*. However, the oncologist states '*that it is clear that the patient's pain had worsened however comments that BUTEC is delivered as a patch, which is changed at 7-day intervals. The patch had been commenced only 5 days before her appointment on 23 January and it would have been premature to recommend an increase in dose at this stage. There was a period of 4 weeks between 18 January 2017 and 23 February 2017 which meant that there would have been a weekly*

opportunity to review/increase the strength of the patient's pain management if her pain was poorly controlled'.

36. The oncologist referenced the MO IPA 1 who advised "*according to the clinic letter she has pain for several weeks and the pain was not well controlled with Butec 5mglhr*". However, the oncologist states '*that this is a misrepresentation of what was noted in [the Registrar's] clinical letter, where it was described that BUTEC, started less than 5 days previously, was not helping pain much, but that co-codamol was'.*

37. The oncologist referenced the MO IPA 1 who advised "*it is not clear from the notes who was in overall charge of the pain management. It is often difficult to anticipate levels of pain and therefore, patients often need regular assessment and adjustment of pain medication".* The oncologist stated that '*the patient's GP was in overall charge of her pain management. The oncology service would ordinarily only make recommendations to change pain medication if a patient was experiencing sustained poor control of their pain, and/or if it appeared that a GP needed assistance with offering alternative options'.*

38. The oncologist referenced the MO IPA 1 who advised "*palliative radiotherapy is often an effective method of pain management in patients with metastatic bone disease. Pain control is often achieved in 8 out of 10 patients within 2 weeks of radiotherapy*." However, the oncologist states *'that this is an overestimate of the efficacy of pain control with radiotherapy. In clinical reports, complete relief of pain is only seen in around 30% of patients with improvement in pain noted in between 50 - 80% of patients.'*

39. The oncologist referenced the MO IPA 1 who advised "*since there was radiological progression of bone metastases and uncontrolled pain, the patient should have been referred to palliative radiotherapy earlier. Ideally after the clinic consultation on 23 January 2017."* However, the oncologist stated '*that it is not clear that the pain the patient complained of on 23 January 2017 was related to bone metastases. The patient described right hypochondrial pain*[24] *and it is his view that a*

[24] Hypochondrium. In anatomy, the division of the abdomen into regions can employ a nine-region scheme, in

metastasis in the L1 vertebral body would be unlikely to result in hypochondrial pain. Back pain would be more typical than hypochondrial pain. If the patient had nerve root involvement, then the pain would have been felt in the lower abdomen and groin (rather than the upper abdomen) and therefore radiotherapy to her back would not have relieved this pain. The oncologist contests the IPA's statement, and would contend that on 23 January 2017 there was no indication for radiotherapy'.

40. The oncologist referenced the MO IPA 1 who advised "*she* [the patient] *complained about 'pain for several weeks' during the clinic on 23 January 2017."* However, the oncologist wishes to clarify that *'this comment did not relate to back pain, it instead related to hypochondrial pain on the right hand side, i.e. upper abdominal pain, as is detailed in the Registrar's clinic letter of the same date'.*

41. The oncologist indicated that he disagreed with the following advice provided by MO IPA 1 "*according to the clinic letters, there was no pain on the clinic visit on 7 November 2016. Patient was asked to return to clinic offer a scan 'early in the new year'. When she* [the patient] *returned to clinic on 23 January 2017, she had already developed pain which was managed by her GP. However, she should have been referred for palliative radiotherapy during the clinic consultation on 23 January 2017, as she had uncontrolled pain at that time."* The oncologist stated '*[the Registrar] does not recall the patient complaining of back pain on 23 January 2017, but rather of hypochondrial pain as is detailed in the clinic letter'.*

42. The oncologist referenced the MO IPA 1 who advised "*there was some discrepancy in the medical notes between hospital and GP surgery. The oncologist's letter on 7 November 2016 states 'she remains reasonably well in herself and currently has no symptoms from ... ' However, the note from GP , on the next day states 'reduced appetite, pain in back, bloating all related to disease progression'. It is unlikely that the symptoms could have developed overnight."* However, the oncologist stated '*he was only able to document and consider the symptoms the patient reported to him during the consultation'*. The oncologist stated he '*discussed*

which the hypochondrium is the upper part of the abdomen on either side, inferior to (below) the thorax, in the area of the lower ribs. The liver is in the right hypochondrium; the spleen and much of the stomach are in the left hypochondrium.

further palliative chemotherapy with the patient at this visit in light of the CT findings and she decided that this was not what she wanted to do'.

43. The oncologist referenced the MO IPA 1 who advised "*it appears from the notes that GPs had tried to help the patient with regular reviews and constant modification of analgesics. Unfortunately, none of the attempts were satisfactory and it is sad to notice that GP notes of the patient mention uncontrolled pain in most of the entries from 24 January 2017 to 19 April 2017. In retrospect, she should have had a better pain control and less suffering during her last days."* In response to the MO IPA 1 comments, the oncologist has expressed his sympathy that the patient was described by her GP as having uncontrolled pain throughout January 2017 to April 2017. However, the oncologist states '*he remains of the view that it is not clear that the pain the patient complained of in January 2017 was back pain, which would have been helped by radiotherapy. It is clear the patient developed back pain at some point in February 2017 and right anterior thigh pain, which was definitely related to her bone metastases, and it was for this pain that she was offered palliative radiotherapy.'*

44. The Investigating Officer provided the opportunity for the MO IPA 1 to comment on the oncologist's response. The MO IPA 1 advised *'Even after considering the limitations of the retrospective nature of this review, pain control for the patient was inadequate, which led to this complaint. The Trust maintains the position that optimal pain control was GP's responsibility. I am not sure whether the GP was aware of this. It would be worth clarifying with the GP that there is an agreed pathway for pain management for patients who are being actively managed at hospital and community'.*

45. The Investigating Officer made telephone enquiries regarding this matter with the patient's GP on 16 April 2019. The GP states "*that if a patient is attending hospital as an outpatient, as a GP he would work in conjunction with the Consultant or specialist who is caring for his patient in regards to pain management'.* The GP further stated '*they would work in partnership and the GP would be guided by what they are told by the Consultant to prescribe or administer to the patient. If an alteration to pain*

medication was required and if they felt it necessary to do so they would inform or consult with the Consultant accordingly”.

46. After consideration of the comments of the oncologist, the Trust and the further advice provided by the MO IPA 1, the Investigating Officer sought additional advice from another medical oncologist MO IPA 2 on the patient’s pain management and referrals for palliative care and palliative radiotherapy.

47. In relation to the patient’s pain management, the MO IPA 2 advised ‘*From the clinical records provided there is evidence that when the patient was reviewed in clinic on the 23 January 2017 a physical examination to determine the nature of her pain took place and this is recorded in the notes. This was performed as part of the assessment of her pain which included a pain history….the notes document that on examination "the chest was clear, abdomen soft and non-tender, bowel sounds present……calves were soft and non-tender and no oedema’.*

48. *There was no documentation that a musculoskeletal examination or neurological examination took place to determine the cause of pain; this was performed at a subsequent review and was normal therefore its omission is unlikely to have altered the patient’s management. Examination would not determine the level of pain - this would be determined from the pain history and use of a pain score as previously described. Within the clinical records a numerical rating scale is documented as being used to determine the patient's level of pain. It is stated that "the patient is complaining of right upper quadrant pain which is a constant ache and can sometimes be sharp and is seven out of ten. The pain has been more constant over the last few weeks and she takes 8/500 (co-codamol) which brings the pain down to three out of ten. She sometimes requires 30/500 (co-codamol)". From this it appears that an assessment of the level of pain did occur.*

49. *The patient examination on the 23 January 2017 including her pain management assessment was in accordance with good medical practice. The pain history, examination and use of a pain scale were in keeping with*

recognised national and international practice. I note that there is no documentation that a neurological or musculoskeletal examination occurred on this date however this may not have been indicated in view of the description given of the pain by the patient which was describe as being abdominal; therefore the assessment was in keeping with good medical practice.

50*. In reference to the General Medical Council's (GMC) guidelines there is evidence from the consultation that there was appropriate application of knowledge and experience in practice, clear and accurate documentation and effective communication".*

51. In response to enquiries made in regards to the type of pain relief that the patient had been prescribed, the MO IPA 2 advised '*management of cancer related pain requires assessment to determine the underlying cause of the pain to help to guide the appropriate choice of pain relief for that individual patient. For patients that are pain killer naive ie have not been on regular pain relief previously it would be appropriate to start off initially with a simple non-opioid analgesic such as paracetamol on a regular basis. If this does not adequately control the pain the next step would be to add in an opioid for mild to moderate pain such as codeine phosphate or switching the patient to a combination pain killer such as co-codamol (containing paracetamol and codeine).*

52. *Stepwise increments in the strength of pain relief should be considered according to response. If a patient's pain was not adequately controlled by lower dose co- codamol (8/500) taken on a regular basis (two tablets four times a day) it would be appropriate to increase to higher dose co-codamol (30/500) particularly if some benefit had been seen with the lower dose. Ideally a "back up" analgesic should also be prescribed for a patient in case the patient finds themselves in pain despite taken the maximum dose of analgesic for example oromorph (liquid morphine) as required. Ongoing assessment of the patient's symptoms would then determine if further escalation of analgesics was required. At this point in her care 8/500 or 30/500 of co-codamol would have been a suitable and appropriate pain relief for the patient's type of diagnosis; it would however require ongoing review and assessment'.*

53. The MO IPA 2 further advised '*from review of the evidence specifically the GP records it would appear that the patient was first prescribed co-codamol on 12 November 2016 by her GP. This appears have been prescribed following a telephone consultation with her GP on the 8 November 2016 where back pain was noted. A palliative care plan review was undertaken by the GP on the 14 December where it was noted "stable". The GP subsequently reviewed the patient's pain relief on 24 January 2017, 23 February 2017, 1 March 2017 and 6 March 2017 - on each of these occasions the GP reviewed and amended the patients pain relief. The patient was reviewed in the oncologist's clinic on the 23 January 2017 - at this time the GP had already initiated appropriate pain relief and was reviewing the impact of them. In view of this it would seem reasonable that the oncologist and his medical team did not interfere with this at the time of review on 23 January 2017 in the patient's pain management as her GP was actively managing her pain relief'.*

54. The Investigating Officer made enquiries of the MO IPA 2 in regards to who is responsible for the management of a patients pain levels, particularly with the patient's type of diagnosis. The MO IPA 2 advised *'It is the responsibility of all health professionals involved in a patient's care to manage symptoms such as pain levels in patients with a diagnosis such as the patient. The overall responsibility can sit with any of the involved health professionals. From a practical perspective GP's or community palliative care services are well placed to lead on this as they are able to assess and review symptoms such as pain in the patient's home or local environment avoiding the need to attend hospital. Day to day management of a patient's supportive care needs is often met by their GP with the option to refer for specialist support if required. In the case of the patient the GP appropriately managed her pain relief and referred onto specialist palliative care services on 13 March 2017 due to ongoing back pain'.*

55. In response to enquiries made in regards to the patient being referred for palliative radiotherapy on 23 January 2017, the MO IPA advised '*The indication for radiotherapy in the case of a patient such as the patient would be painful bone metastases not adequately controlled with analgesics or evidence of*

neurological compromise due to nerve compression. At the time of the review on the 23 January 2017 the patient did not specifically complain of back pain - the complaint was of right upper quadrant pain (abdominal pain) and there were no symptoms to suggest neurological compromise. The conclusion of the review was that "the patient was feeling well" and there is evidence to suggest her pain management was being reviewed and optimised by her GP. In view of this I would concur with the statement that "on 23 January 2017 there was no indication for radiotherapy".

56. The MO IPA 2 further advised '*The indication for referral for radiotherapy at the time of the review on the 23 January 2017 would have been if the patient was symptomatic from her bone metastasis. Radiotherapy in this context would be used as an adjunct to optimisation of her pain relief. At the time of review on the 23 January 2017 there was no evidence to suggest that she was symptomatic from her bone metastases therefore it was reasonable to defer referral for radiotherapy. In the absence of symptoms radiotherapy would have been indicated at this time if on imaging concern was raised that there was a risk of neurological compromise from the bone metastases. The CT scan on the 4 January 2017 did not report any concern for neurological compromise. Although CT imaging would not be the optimal method of assessing this (MR scan is preferable) there were no findings from the consultation to suggest that this was a clinical concern. Again in view of this it was therefore reasonable to defer referral for radiotherapy'.*

57. The MO IPA 2 further advised that in regards to the pain experienced by the patient on 23 January 2017, the MO IPA 2 advised '*The clinical records relating to the consultation with the patient on the 23 January 2017 state that the patient was "complaining of right upper abdominal pain. The physical examination of the patient at this consultation is documented as " the abdomen being soft and non-tender" i.e. no pain was present when the patient was examined. The examination performed did not identify any pain in any location'.*

58. The MO IPA 2 further advised *'At the time of the examination on 23 January 2017 the patient did not have any pain it is possible her pain which fluctuated in*

severity - it is documented that her pain levels varied from seven out of ten to three out of ten. On the evidence contained in the notes it is difficult to ascertain whether her pain was right hypochondrial pain or back pain. Right hypochondrial pain is often associated with pain related to the liver and the patient was known to have cancer affecting that region. In the GP records it is documented on the 8 November 2016 that the patient was complaining of back pain. A GP consultation on the 24 January 2017 notes that she has pain but does not specify the location of the pain. On the 23 February 2017 the pain is present and described as being at the left side of the lower back. It is possible that the patient had two sites and therefore causes for her pain. At the review appointment on the 23 January 2017 there is no evidence within the notes to confirm that the patient complained of back pain. It is documented within the clinical notes that at the review appointment on the 23 January 2017 the patient complained of right upper quadrant pain which is the equivalent of right hypochondrial pain - the terms are interchangeable'.

59. In response to the patient's referral to palliative care, the MO IPA 2 advised *'Referral to community palliative care teams can potentially be made at any time point in a cancer patient's journey either by a patient's treating oncology team, general practitioner or in some cases patient self-referral. The timing of the referral varies depending upon the patients symptoms both physical and psychological and the specific needs of the patient. When the patient was seen in the oncology clinic on the 7 November 2016 following her scan in October 2016 it was documented that the patient was "well with no symptoms." In view of this there would have been no indication for referral to the community palliative care team at this time'.*

60. The MO IPA 2 further advised '*the patient was then seen again in the oncology clinic on 23 January 2017 following her scan on the 4 January 2017. At this review the patient was experiencing increasing symptoms namely right upper quadrant abdominal pain however she remained well. It was noted that she was taking co-codamol 8/500 which helped her pain but occasionally required a stronger dose of co-codamol 30/500. Her GP reviewed her painkillers and made adjustments to them prior to her review in the clinic which was noted*

and also subsequent to the oncology clinic review. Referral to the community palliative care team at this time point would have been appropriate if there was evidence that more specialist supportive /palliative care input was required. However both the GP and the oncology team were providing appropriate provision of supportive and palliative care needs to the patient. From the documented notes there appeared to be an appropriate pain management plan in keeping with recommended practice therefore there was nothing to indicate that at this time referral to the community palliative care team would have been indicated unless it had been requested by the patient'.

Responses to the Draft Report

61. In response to the draft report the complainant stated he '*does not agree with the contents of the draft report'.* The complainant stated '*his wife should have been referred for palliative care earlier and the oncologist should have been more involved in her pain management'*. He also stated that '*having a specialist nurse would have helped both he and the patient in dealing with her diagnosis'*. I have considered the complainant's comments and where appropriate commented on these within the analysis and findings section of the report.

62. In response to the draft report, the Trust stated '*they have no comment to make on the draft report and staff accept the findings'.*

Analysis and Findings

(i) Pain management

63. In my consideration of this complaint and upon examination of the evidence, I shall focus my analysis and findings on three key dates, 7 November 2016, 23 January 2017 and 10 April 2017. I would highlight that the patient was also regularly attending her GP in between her review appointments at the Oncology clinic during this time. However, I shall be considering the actions of the Trust only.

64. The patient was examined and reviewed by the oncologist at the oncology clinic on 7 November 2016. I established the oncologist informed the patient's GP on 11 November 2016, '*she remains reasonably well in herself and currently has no symptoms from her metastatic ampullary/lower common bile duct tumour… she is asymptomatic at present'.* I also established the patient spoke to her GP on 8 November 2016, one day after her review with the oncologist. Her GP recorded '*reduced appetite, pain back, bloating all related to disease progression'.* I note from approximately 8 November 2016 until 10 April 2016 the patient was being prescribed pain medication by her GP. This included co-codamol, butec, paracetomol, pregabalin and morphine.

65. As the patient was feeling well with no symptoms on 7 November 2017 including both her and the oncologist's decision to not pursue further with chemotherapy at that time, I have considered and I accept the MO IPA 1 advice that *'it is reasonable to assume that no pain management was offered'.* However, I would highlight that the MO IPA 1 advised that '*there was some discrepancy in the medical notes between the oncologist's letter 7 November 2016 and GP record 8 November 2016…"she remains reasonably well in herself and currently has no symptoms from….however GP records state reduced appetite, pain in back, bloating all related to disease progression"…it is unlikely that the symptoms could have developed overnight*. Having considered the records it does not appear that the patient informed the oncologist of the symptoms which she has reported to her GP the day after her appointment with the oncologist.

66. I consider on the balance of probabilities the patient was in all likelihood experiencing back pain around the time of her review appointment with the oncologist on 7 November 2016. However, I am unable to establish if the patient informed the oncologist on 7 November 2016 she was experiencing these symptoms. I note the oncologist states '*he was only able to document and consider the symptoms the patient reported to him during the consultation*'. On the basis of the information available to the oncologist on 7 November 2016 it is evident that a review of her pain management was not considered necessary. I do not consider this was a failure by the oncologist.

67. The investigation established the patient was examined and reviewed at the oncology clinic on 23 January 2017. The records indicate the patient informed the Registrar she was experiencing new symptoms of pain in her '*right upper quadrant'* and she feels (*her current pain medication*) '*is of no benefit at all'.* I note the Registrar wrote to the patient's GP on 27 January 2017 and advised the patient had complained of right upper quadrant pain which sometimes had been a 7/10 with 8/500 co-codamol but with an increase in her co-codamol to 30/500, her pain was brought down to a 3/10. I note confirmation of the record of examination and assessment of pain levels on 23 January 2017 was a view supported by the MO IPA's 1 and 2.

68. The MO IPA 1 advised '*the patient had constant pain over the last few weeks for which she was taking 8/500 co-codamol…the clinic letter from 23 January 2017 indicates that she has pain which is not optimally controlled…the GP had increased BUTEC from 5mg on 18 January 2017 to 10 mg on 23 February 2017'*. However, I note the oncologist stated the patient '*reported her pain was being controlled by 8/500 co-codamol and sometimes required 30/500….the patient's pain was not severe enough or poorly controlled enough…'.* I note the MO IPA 1 also stated '*By 23 January 2018 she was on pain medication that had been adjusted three times* [by GP]*'*.

69. As explained previously at paragraph 47, as I was unable to reconcile the differences in opinion on this matter I obtained advice from a second advisor MO IPA 2. I have considered and I accept the MO IPA 2 advice that '*at this point in her* [the

patient's] *care 8/500 or 30/500 of co-codamol would have been a suitable and appropriate pain relief for the patient's type of diagnosis',* highlighting that it would however require ongoing review and assessment. I also established the patient attended her GP on 24 January 2017, the day after the Registrar reviewed her. I note her GP recorded '*seen by oncology yesterday, took pain patch off not helping…on co-codamol 30/500, possibly has suggested oramorph'.*

70. I have considered and I accept the MO IPA 2 advice that '[the patient] *was reviewed at the clinic on 23 January 2017 where a physical examination to determine the nature of her pain took place….this was performed as part of the assessment of her pain.…examination would not determine the level of pain, this would be determined from the pain history and use of a pain score….the examination including pain management assessment was in accordance with good medical practice'.* I note the MO IPA 2 has reflected upon GMC guidance and advised there was evidence the consultation on 23 January 2017 was in keeping with good medical practice by ensuring the appropriate application of knowledge and experience was applied particular in regards to clear and accurate documentation and effective communication with a patient.

71. In regards to the patient being referred for palliative radiotherapy, I note the Trust state '*the key appointment date in relation to this is 23 January 2017 at the oncologist's clinic.… had it been known that the patient was suffering back pain…further investigation would have been organised sooner and she may have been referred for palliative radiotherapy sooner'*. The MO IPA 1 advised palliative radiotherapy can often be used as an effective method of pain control for someone with the patient's illness. The MO IPA 1 further advised '*since there was radiological progression of bone metastases the patient should have been referred to palliative radiotherapy earlier'.* However, I note the oncologist's response to this element of the complaint was ' *it was not clear the pain the patient was experiencing in January was that of back pain…however it is clear at some point in February 2017 the patient developed back pain and it was for this pain she was offered palliative radiotherapy'.*

72. I have considered and I accept the MO IPA 2 advice that had there been an indication the patient required a referral to palliative radiotherapy, her medical team

would have sought evidence of '*painful bone metastases not adequately controlled with analgesics or evidence of neurological compromise due to nerve compression'.* Subsequently, the MO IPA 2 advised that palliative radiotherapy would have been indicated had '*on imaging'* concerns been raised that there was a risk of '*neurological compromise'* however a CT scan of 4 January 2017 did not report any concern for neurological compromise.

73. It is my view that a referral for the patient for palliative radiotherapy would have been in addition to her already existing pain relief. However, as previously indicated the patient's pain relief was appropriate and suitable at this time. I consider there was no evidence to suggest the patient was symptomatic from her bone metastases at the consultation on 23 January 2017 and her CT scan from 4 January 2017 did not identify any neurological concerns. Therefore, it is reasonable that the oncology team did not refer the patient for palliative radiotherapy on or immediately after her review appointment on 23 January 2017.

74. I note the patient was reviewed at the oncologist's clinic on 10 April 2017 and in response to the patient's new symptom of back pain, the oncologist referred the patient for palliative radiotherapy on 10 April 2017. I considered the oncologist's comments regarding the patient "*developing back pain at some point in February 2017 and right anterior thigh pain, which was definitely related to bone metastases and it was for this pain that she was offered palliative radiotherapy".* I have considered and I accept the MO IPA 2 advice in response to the oncologist's claims that '*I would agree that it became clear that back pain described subsequently in February 2017 was related to bone metastases…at this point there was a clear indication for referral for radiotherapy which was subsequently made*'. I further acknowledge the MO IPA 2 advice that '*on 30 March 2017 it is documented that the patient was complaining of pain that is described as being bother back pain and right upper abdominal pain…it is therefore possible that there were dual processes underlying her symptoms relating to her bone metastases and cancer in the upper abdominal region'.* Therefore, I am satisfied that upon reviewing the patient and considering her new symptom of back pain and upper abdominal pain, she was referred appropriately by the oncologist at that time for palliative radiotherapy as an effective method for her pain management, a view supported by the MO IPA 2.

75. In response to enquiries made regarding who was responsible for managing the patient's pain levels, I note the Trust state '*the patient's pain was being managed in the community by her GP*. This was a view supported by the oncologist who also stated '*the patient's pain was not severe enough or poorly controlled enough to interfere with activities of daily living at this time…the patient's GP was in overall charge of her pain management'.* Upon further investigation into this element of the complaint with the patient's GP, the GP also advised "*as a GP he would work in conjunction with the consultant or specialist who is caring for his patient in regards to pain management".*

76. I note the MO IPA 1 advised that '*it was not clear who had been in overall charge of the patient's pain management….most of the time patients with advanced cancers are jointly managed by hospital specialists and GP's'.* However, the oncologist in response to this element of the complaint stated '*the patient's GP was in overall charge of her pain management…the oncology service would ordinarily only make recommendations to change pain medication if a patient was experiencing sustained poor control of their pain…'.* However, I refer to the NICE guidelines for end of life care for adults quality statement 8; co-ordinated care states '*people approaching the end of life receive consistent care that is co-ordinated effectively across all relevant settings and services at any time of day or night and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences'.* Furthermore, upon examining the palliative care guidelines I note the principles of pain management state '*Comprehensive, individualized and holistic assessment and treatment planning, including regular review and assessment with involvement of the wider multi professional team as appropriate'*. With that in mind, I consider the oncologist and his team formed part of the patient's wider multi professional team.

77. In light of this difference of opinion between the Trust and MO IPA 1, I obtained advice on this issue from MO IPA 2. I considered and I accept the MO IPA 2 advice that all of the patient's health professionals whether that be her GP, consultant or community palliative care services are responsible for the patient's care including pain levels albeit the day to day management of her care can be led by her GP. I note in response to the draft report the complainant has reiterated that he feels the oncologist should have been more involved in the patient's pain management.

However, in considering all of the evidence, I am satisfied that the oncologist, his team and the patient's GP all had a responsibility in co-ordinating the patient's care and I consider the patient's pain management was a fundamental element of that care. The investigation established that the patient's pain management was being kept under review by her GP including any adjustments that were required with her pain medication. I considered and I agree with the MO IPA 2 advice that '*it would seem reasonable that the oncologist and his medical team did not interfere with this* [pain management] *at the time of review on 23 January 2017 as her GP was actively managing her pain levels'.*

78. Overall, I am satisfied that the management of pain was a shared responsibility. While the Trust had a role in ensuring the patient's pain management was adequate, I have not identified evidence that the patient during her review appointments of 7 November 2016 and 23 January 2017 complained of symptoms of severe pain that would have led to the oncologist recommending and adjusting her current pain medication or that a referral to palliative radiotherapy was necessary. I also agree with the MO IPA 2 advice that the patient's clinical examination in regards to her pain assessment on 23 January 2017 was in accordance with good medical practice. I further note that when the patient's GP was made aware of her back pain on 7 March 2017 he highlighted her new symptoms to the oncologist who acted promptly to arrange for an MRI scan on 9 March 2017 and a review on 10 April 2017 which led to a referral for palliative radiotherapy. It was at this stage I consider the GP felt the input from the oncology team was necessary in order to manage the patient's pain. That said, I recognise that the patient's condition unfortunately deteriorated and she remained too unwell to receive palliative radiotherapy. However, upon examination of the clinical evidence and consideration of the Trust and the oncologist's responses and the advice I have received, **I do not uphold this element of the complaint.**

(ii) Referral for Palliative Care

79. I established that upon attending her GP on 7 March 2017, the patient's GP contacted the oncologist to advise she was presenting with new symptoms. I note the oncologist referred the patient for an MRI scan which was performed two days later on 9 March 2017. I note the patient's MRI scan showed evidence of '*metastatic disease'*. The investigation established the patient's GP referred her to the palliative care team on 13 March 2017 and the patient informed her GP on 20 March 2017 that '*she had been reviewed by the palliative care team on (16 March 2017)'*.

80. I note the patient's GP wrote to the oncologist on 5 April 2017 as he was due to review the patient on 24 May 2017. However, the patient's GP advised the oncologist *'(the patient) is anxious to see you before this to discuss any other treatment options'.* The patient was reviewed by the oncologist on 10 April 2017 approximately six weeks in advance of the planned review appointment. She complained of back pain to the oncologist on 10 April 2017 and he referred her to a consultant in palliative medicine for consideration of palliative care and radiotherapy. The investigation also established the patient was visited by the Northern Ireland Hospice on 11 April 2017 however, she declined to meet with them.

81. I considered and I accept the advice of the MO IPA 2 that '*referral to the community palliative care teams can potentially be made at any time in a cancer patients journey…the timing varies'.* The MO IPA 2 highlighted that at clinic on 7 November 2016, the patient had been well with no symptoms and therefore advised that a referral was not indicated at this time. Furthermore, the MO IPA 2 also advised that at clinic on 23 January 2017 the patient was taking co-codamol 8/500 which was helping her pain but occasionally need a stronger dosage of 30/500. With that in mind I have considered and accept the MO IPA 2 advice that a '*referral to the community palliative care team at this time would have been appropriate had there been more evidence that more specialist supportive/palliative care input required, however the GP and oncology team were providing appropriate provision of supportive and palliative care needs to the patient'.*

82. I accept the MO IPA 2 advice that on 23 January 2017, there was nothing to indicate both in terms of the patient's illness and pain levels that the oncologist or his medical team should have made a referral to the community palliative care team at this time. Specifically the MO IPA 2 advised '*referral to the community palliative care team at this time* [23 January 2017] *would have been appropriate if there was evidence that more specialist supportive/palliative care input was required…however the GP and oncology team were providing appropriate provision of supportive and palliative care needs….'.* I would highlight the patient was reviewed by palliative care services in advance of her planned review meeting with the oncologist on 10 April 2017. Therefore, I do not consider there was any delay by the Trust referring the patient for palliative care. **I do not uphold this element of the complaint.**

83. I note the advice of the MO IPA 2. In particular, he/she advised '*the patients management may have been improved by clearer communication between specialist services (oncology) and primary care in relation to the patient's ongoing management and responsibilities in relation to her symptoms'.* I have considered and I accept the MO IPA 2 advice that *'It was unclear from the records whether the patient had a clinical specialist nurse or keyworker involved in her care that could have helped to facilitate her management and support her and her family'.* I consider that by allocating the patient a clinical nurse specialist or a keyworker, this may have gone some way to support her and alleviate any concerns she had in regards to her pain management and palliative care referral. I note that the complainant in response to the draft report considers a clinical nurse specialist would have helped support the patient and him during this difficult time. In the absence of any evidence from the Trust that the patient had access to a clinical nurse specialist or was allocated a keyworker to facilitate her care management with her oncology team, I consider this a failing in the patient's care and treatment. I consider the patient to have suffered the injustice of loss of opportunity to have had additional specialist support provided which could have alleviated some of her concerns around her pain management. I also consider that access to this specialist support would have been a benefit to the complainant and likewise he lost the opportunity to raise any concerns he had about the management of the patient's symptoms.

(iii) the patient's appearance

84. The complainant said that the oncologist paid a great deal of attention his wife's appearance and how she "*was looking well*" in his determination of how well she was feeling at her review appointments on 7 November 2016 and 10 April 2017. In response to enquiries made regarding this element of the complaint, I note the Trust stated '*assessment of patients when considering treatment options is not limited to a review of scan results. Such assessment must also take into account the patient's symptoms….how each patient feels is an important part of this assessment and an important consideration when determining what is in their best interests'.* I further note the oncologist states '*it is his standard practice to enquire about appetite in patients with advanced cancer'.*

85. The investigation established the oncologist reviewed the patient on 7 November 2016 and 10 April 2017. I note at the oncologist's review of the patient on 7 November 2017, the oncologist recorded 's*he remains reasonably well in herself and currently has no symptoms from her metastatic ampullary/lower common bile duct tumour'.* I note there is no mention of the patient's appearance in the review notes. I further note at the oncologist's review of the patient on 10 April 2017 there is no record of the oncologist discussing the patient's appearance with her.

86. I have considered and I accept the MO IPA 1 advice that he *'could not find any documentation of the appearance in the notes….letters only mention presence or absence of symptoms and objective assessment. I could not come across any mention on 'appearance'.*

87. GMC guidelines on knowledge, skills and performance, paragraph 15 (a) states '*you must adequately assess the patient's conditions, taking account of their history (including the symptoms and psychological, spiritual, social and cultural factors), their views and values; where necessary, examine the patient'*. I consider a holistic examination of a patient is necessary for a clinician to deliver an appropriate and reasonable standard of practice and care. I am satisfied the appearance of a patient can assist a clinician when deciding how to treat a patient. I have not been presented with evidence that the oncologist focused too much on the patient's appearance

during his reviews and examinations on 7 November 2016 and 10 April 2017. **Therefore, I do not uphold this element of the complaint.**

CONCLUSION

88. The complainant submitted a complaint to me about the actions of the Belfast Health and Social Care Trust.

89. In considering the complaint I have examined the patient's GP records and the Trust's clinical records. The investigation established that the patient's GP was reviewing her pain medication and adjusting it accordingly with input from oncology when necessary.

90. Having considered all the information available including the GP records, Trust clinical records and responses alongside the advice of the two clinical advisors, I have not found failures in care and treatment in respect of the following matters:

i. the patient's pain management
ii. Referral to palliative care
iii. the oncologist focusing too much on the patient's appearance

I have found a failing in care and treatment in respect of the following matter:

iv. The Trust providing a clinical nurse specialist/keyworker.

I am satisfied the failure I have identified caused the patient the injustice of loss of opportunity to have additional specialist support. I am satisfied the failure I have identified caused the complainant a similar injustice.

Recommendations

I recommend the BHSCT undertake the following action:

i. In accordance with the Ombudsman's guidance on issuing an apology, provide a written apology to the complainant for the injustice identified in this report. The BHSCT should provide the apology to the complainant within one month of the date of my final report.

I am pleased to note the Belfast Health and Social Care Trust accepted my findings and recommendation.

PAUL MCFADDEN **March 2020**
Acting Ombudsman

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.