

Investigation Report

Investigation of a complaint against Southern Health & Social Care Trust

NIPSO Reference: 201916096

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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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SUMMARY

I received a complaint about the actions of the Southern Health and Social care Trust (the Trust). The complainant believed that surgery performed at Craigavon Area Hospital (CAH) caused her injury and enduring symptoms which have not been properly investigated or treated.

I obtained all relevant information, including the Trust's response to the complaint and the complainant's medical records. I also obtained Independent Professional advice from a number of different clinicians.

My investigation found no evidence that surgery to remove lymph nodes injured the complainant or caused the symptoms she described and I did not uphold this issue of complaint.

I also found that subsequent surgery carried out to remove her thyroid was necessary to relieve symptoms of Grave's disease. I considered that the oral surgeon's follow up was satisfactory. However, I concluded that there was a failure to arrange and deliver endocrine follow up following the surgery. This was a lost opportunity to take action to advise the complainant when it became evident that she was not taking her medication as prescribed. I upheld this element of the complaint. I recommended that the Chief Executive apologises to the complainant for this failing.

I also investigated whether neurological investigations, referrals and subsequent actions were carried out appropriately when the complainant attended as an outpatient at CAH. I found that the care and treatment the consultant neurologist provided met good medical practice standards and I did not uphold this issue of complaint.

The Trust accepted my findings and recommendations.

THE COMPLAINT

1. I received a complaint about the actions of the Southern Health and Social care Trust (the Trust). The complainant said that surgery performed at Craigavon Area Hospital (CAH) in 2014 caused her serious and enduring injuries which have not been recognised or treated.

Background

2. The complainant received a diagnosis of hyperthyroidism in March 2014 at Daisy Hill hospital. In June 2014. She was referred to an endocrinologist at CAH who diagnosed Grave's disease.
3. She received treatment at the Ear Nose and Throat (ENT) department at CAH. Oral surgeon A removed a lymph node on 1 July 2014. She experienced a swelling in her throat following the surgery and symptoms of hypertension¹ and haematuria². She reported hearing loss as well as unpleasant sensations in her mouth. The Trust carried out investigations including nerve conduction tests that recorded a normal sensory response.
4. The consultant ENT surgeon CAH performed a total thyroidectomy on 15 June 2016 at CAH and prescribed thyroid medication. The complainant reported that the sensations in her mouth worsened and included a weight sensation, loss of swallow reflex, metallic taste in the mouth and a crawling sensation around her body.
5. A consultant neurologist at CAH saw the complainant in September 2016 as an outpatient. He diagnosed sensory neuropathy and chronic folic acid deficiency, which was treated.
6. An ENT surgeon at the Royal Victoria Hospital (RVH) who saw her on 15 November 2016 reported no obvious ENT cause for her symptoms and suggested an opinion from 'Health Psychology'.

¹ High blood pressure

² Blood in her urine

7. The consultant neurologist at CAH referred the complainant to the neurology department of the RVH. She was an inpatient from 17 May to 8 June 2017. This attendance is the subject of a separate complaint.
8. The consultant neurologist at CAH also referred the complainant to the National Hospital for Neurology and Neurosurgery in London for an independent assessment. She attended as an inpatient between 22 October 2018 and 9 November 2018. The diagnosis was '*profound central sensitisation*'. She was discharged for '*follow up by her local team for further neuropsychological assessment and management*'.
9. The consultant neurologist at CAH reviewed the complainant on 7 February 2019 and referred her to a consultant in anaesthesia and pain management at CAH.
10. The consultant neurologist at the CAH saw the complainant on 30 August 2019 for final review. He stated '*In summary she has chronic severe pain which is refractory to intervention and having attended the pain clinic they feel they do not have anything more to offer her.*' He referred her to the mental health team at CAH.
11. The complainant remained under the care of her GP for her distressing symptoms. He made several referrals, specifically to the ED and neurology at the RVH, spinal surgery at Musgrave Park Hospital and general surgery at CAH.

Issues of complaint

12. The issues of complaint accepted for investigation were:

Issue one:

Whether the care and treatment provided to the complainant from March 2014 to June 2016 following the diagnoses of hyperthyroidism and Grave's disease was appropriate?

Issue two:

Whether the surgery for removal of the thyroid in June 2016 was performed to the required standard?

Issue three:

Whether Neurological investigations and subsequent actions were carried out appropriately at CAH?

INVESTIGATION METHODOLOGY

13. In order to investigate this complaint, the Investigating Officer obtained from the Trust all relevant documentation together with its comments on the issues raised by the complainant.

Independent Professional Advice Sought

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

- Pain Management IPA, BM BCh DSMEP 36 years as a GP having developed an interest in Sports Medicine (Diploma) and thence musculo-skeletal problems (Pain management IPA);
- ENT IPA, Consultant Otolaryngologist-Head, Neck and Thyroid Surgeon, Clinical Lead for Head and Neck Cancer Services, Honorary Senior Lecturer;
- Consultant endocrinologist IPA, MD, FRCP, FRCP with over 30 years' specialist experience in the management of thyroid disease; and
- Consultant neurologist IPA, MA DPhil FRCP, with over 25 years extensive experience of patients with physically and emotionally-generated symptoms.

I enclose the clinical advice received at Appendix three to this report.

15. I included the information and advice that informed the findings and conclusions within the body of this report. The IPAs provided 'advice'; however how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

16. I attach a chronology at appendix five, which details much, but not necessarily all of the treatment the complainant received from 2014 to 2021 in this Trust and also in the Belfast Trust Area. The latter Trust is the subject of separate complaints.
17. The London Hospital for Neurology and Neurosurgery is outside my jurisdiction. However, issue three of this investigation references the referral and follow up by the consultant neurologist at CAH.
18. Following several GP referrals, the complaint was seen recently by spinal consultants at Musgrave Park Hospital Belfast. Neither the actions of the GP nor the spinal consultants are within the scope of this complaint.

Relevant Standards and Guidance

19. 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. I also refer to relevant regulatory, professional and statutory guidance.

The general standards are the Ombudsman's Principles³:

- The Principles of Good Administration
- The Principles of Good Complaints Handling

20. The specific standards and guidance referred to are those that applied at the time the events occurred. These governed the exercise of the administrative functions and professional judgement of those individuals whose actions are the subject of this complaint.

The specific standards and guidance relevant to this complaint are:

- The General Medical Council's (GMC) Good Medical Practice, as updated April 2014 (the GMC Guidance);

I enclose relevant sections of this guidance considered at appendix three.

³ These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association.

21. I did not include 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 was taken into account in reaching my findings.
22. A draft copy of this report was shared with the complainant and the Trust for comment on factual accuracy and the reasonableness of the findings and recommendations. The Trust accepted my findings and recommendations. The complainant did not agree with all my findings. The complainant made some points of factual accuracy which I am happy to correct in this report.

THE INVESTIGATION

Issue one:

Whether the care and treatment provided to the complainant from March 2014 to June 2016 following the diagnoses of hyperthyroidism and Grave's disease was appropriate? This includes consideration of:

- i. **Whether the surgery for removal of a lymph node on 1 July 2014 was performed to the required standard?**
- ii. **Whether the complainant's symptoms following the surgery on 1 July 2014, including swelling, hypertension and haematuria were appropriately managed?**
- iii. **Whether it was appropriate to perform a thyroidectomy in June 2016?**

Background and detail of Complaint (please refer to appendix five for further details)

23. The complainant was diagnosed in March 2014 at Daisy Hill hospital with hyperthyroidism
24. She was referred to oral surgeon A at CAH who reported a benign gland in October 2014; and an endocrinologist who diagnosed Grave's disease.
25. The endocrinologist, referred her on 22 December 2014 to a Consultant Ophthalmic Surgeon at the Royal Victoria Hospital (RVH) for advice regarding the merits of iodine treatment versus thyroidectomy to treat Grave's disease. He first saw her on

18 March 2015 and again on 13 May 2015. He diagnosed mildly active thyroid disease.

26. The complainant saw an ENT consultant privately on 4 June 2015. He recommended a CT scan. She was referred to oral surgeon A at CAH who saw her on 8 July 2015 and booked a CT scan which was performed on 26 August 2015. It showed bilateral cervical lymph nodes.
27. A locum medical consultant at CAH saw her and requested MRI of the head/spine on 3 August 2015. Oral surgeon A saw her again on 14 October 2015 and reported to C's GP that the MRI showed '*no new changes*'. He discharged her from his care.
28. On 5 August 2015, following review and consultation with the consultant ophthalmic surgeon he advised that it would be safer to pursue with total thyroidectomy as radioactive iodine was contraindicated because of active thyroid eye disease.
29. The endocrinologist referred the complainant to the consultant ENT surgeon CAH at CAH on 17 September 2015. He saw her on 16 November 2015. His clinic record to the endocrinologist stated:

'I had a long conversation with [the complainant] and explained to her that total thyroidectomy means lifelong thyroxine supplements and she understands that there is roughly 10% chance of permanent hypoparathyroidism⁴ with associated hypocalcaemia. She is quite keen to proceed and I have added her name to my waiting list for total thyroidectomy.'
30. Her case was discussed at a thyroid/head and neck MDM on 20 November 2015 and the operation was scheduled for March 2016. However, the complainant said that this was deferred as she had '*cold like symptoms*'.
31. The complainant reported to her GP symptoms of an unpleasant sensation in her oral cavity. She described a sensation or coating which moves around her mouth

⁴ Hypoparathyroidism is a rare condition where the **parathyroid** glands, which are in the neck near the thyroid gland, produce too little parathyroid hormone. This makes blood calcium levels fall (hypocalcaemia) and blood phosphorus levels rise (hyperphosphataemia), which can cause a wide range of symptoms, including muscle cramps, pain and twitching.

and can feel like metal, plastic or wires in her mouth. Her GP made referrals back to ENT at CAH in April and May 2016.

32. The complainant said:

'Due to have thyroid removed late April 2016, deferred again as had grave concerns due to oral symptoms that I was experiencing. Finally allowed procedure to go ahead June 15th 2016 only after speaking to the consultant ENT surgeon CAH, regarding oral symptoms and also with regards to benign growth on tonsil bed, was concerned re intubation and aspiration also discussed with Anaesthetist, and asked for same to be recorded in the notes. Also asked to be referred to someone regarding oral symptoms as no one could give me an explanation for same.' I note that she signed a consent form for thyroid removal on 15 June 2016

33. Her GP and dentist also requested urgent referrals to consultant oral and maxillofacial surgeon in the Ulster Hospital Dundonald (UHD) in April and July 2016. The complainant was unhappy that this was triaged as routine

34. I note that an ENT surgeon at the RVH, reviewed her on 14 April 2016. His letter to her GP states *'This lady persuaded my secretary that I should see her urgently.'* He *'reassured her that there is nothing wrong with her ear, nose and throat and suggest she continue with the planned surgery for Grave's disease.'*

Issue one

- i. Whether the surgery for removal of a lymph node on 1 July 2014 was performed to the required standard?**

Detail of complaint

35. The complainant believed that removal of her lymph gland in 2014 led to her symptoms which worsened following the thyroidectomy. She attributed her symptoms to the surgery in 2014, which she believed caused swelling which pressed on her arteries and veins.

Evidence Considered

Legislation/Policies/Guidance

36. I considered the following guidance:

- GMC Guidance

Relevant Trust's records

37. I reviewed the complainant's medical records and referred these to a number of Independent professional advisors (IPA).

Relevant Independent Professional Advice

ENT surgeon IPA (ENT IPA)

38. The investigating Officer asked the ENT IPA whether the care and treatment provided to the complainant during this admission to Daisy Hill hospital in March/April 2014 met the standards of good medical practice. He advised:
'C was referred to the ENT department and seen in May 2014 with a persistently enlarged lymph node in the right side of the neck. Initial investigations in the form of an ultrasound scan and a fine needle aspirate for cytology were appropriately performed and resulted in an exclusion of high-grade lymphoma or other cancers. Low-grade lymphoma could not be excluded and therefore C was consulted, and an excisional biopsy was arranged.'

39. In relation to the surgery, the ENT IPA advised:

'Whilst I do not have access to the operation notes from the 1st July 2014, at the post-operative clinic follow up on the 17th July 2014, it was noted by Oral surgeon A that the 'operated site has healed well without any complications'. Therefore, I infer from this clinic letter that the surgery was performed to the required standard.'

Issue one

- ii. **Whether the complainant's symptoms following the surgery on 1 July 2014, including swelling, hypertension and haematuria were appropriately managed?**

Relevant Independent professional advice

40. The Investigating Officer asked the ENT IPA if subsequent consultations with the oral surgeon A at CAH adequately addressed the complainant's ongoing issues and results of investigations. He reviewed the consultations and clinic letters dated, 17 July 2014, 5 August 2014, 5 August 2014, 17 October 2014 and advised:
'On review of the provided clinical notes, I am unable to identify any documentation pertaining to post-operative swelling, hypertension or haematuria, and therefore I cannot comment on the appropriateness of the management of these symptoms.'
41. The complainant attended oral surgeon A again on 23 October 2014 complaining of a lump. The Investigating Officer asked the ENT IPA if oral surgeon A addressed this appropriately. He advised:
'At the clinical consultation on the 23rd October, C was concerned regarding the return of the neck lump. Oral surgeon A was able to examine C and was unable to feel any lumps in the neck. Therefore, no further ultrasound scans appear to have been requested and C was reassured and discharged. This is in line with acceptable clinical practice.'
42. The complainant believed the swelling put pressure on her arteries and veins and this led to symptoms of hypertension in April 2015 and haematuria. The ENT IPA advised:
'The hypertension is likely to have been related to poorly controlled hyperthyroidism. There is no evidence of swelling in the neck. The haematuria may have been due to the later identified renal calculi.'
He also advised there was no evidence of anything left in the complainant's mouth following surgery.
43. The complainant was seen on 8 July 2015 and discharged on 14 October 2015 by consultant oral surgeon B at CAH. The ENT IPA reviewed the records:
'Clinical history, examination, hearing test and CT scan. This was then followed up by an ultrasound scan due to the detection of some long-standing minor neck nodes. The ultrasound scan showed no concerning signs.'
The ENT IPA advised this was appropriate.

Issue one

iii. Whether it was appropriate to perform a thyroidectomy in June 2016?

Detail of complaint

44. The complainant believed her thyroid symptoms were stable prior to surgery therefore the thyroidectomy was unnecessary. She thinks the thyroid was removed to access her throat to find out the cause of the symptoms that arose when the lymph nodes were removed on 1 July 2014.

Trust response to investigation enquiries

45. The Trust commented on the Consultant endocrinologist's referral to oral surgeon the consultant ENT surgeon CAH on 17 September 2015:

'[The complainant's] referral clearly states that she suffered from Grave's disease and that it had not been easy to control because of non-compliance with medication and altering doses by herself. She also had mild to moderately severe active thyroid eye disease and therefore was not suitable for radioactive iodine. Her thyroid eye disease was confirmed following MRI 03 October 2014. Consultant Ophthalmic Surgeon, on 05 August 2015 following review and consultation with the complainant advised that it would be safer to pursue with total thyroidectomy as radioactive iodine was contraindicated in her case. The consultant ENT surgeon CAH saw the complainant on 16 November 2015. The consultant ENT surgeon CAH explained to the complainant that unstable Grave's disease, with thyroid eye disease is absolute indications for total thyroidectomy. The consultant ENT surgeon CAH also explained the potential complications associated with this type of surgery. She agreed to proceed to having surgery.'

46. The Trust also stated:

'Whilst waiting for surgery [the complainant] was also seen by Consultant ENT Surgeon in Royal Victoria Hospital [on 14 April 2016] who confirmed her decision to have thyroid gland removed.'

47. I reviewed the complainant's medical records and referred these to a number of Independent professional advisors (IPA). I attach the entire advice at appendix three. I refer to relevant extracts below.

Relevant Independent Professional Advice

ENT IPA

48. The consultant ENT surgeon CAH saw the complainant on 16 November 2015. The Investigating Officer asked the ENT IPA what rationale the consultant ENT surgeon CAH presented for the requirement for a thyroidectomy. He advised:
- 'The total thyroidectomy was undertaken to support the treatment of Grave's disease which was not controlled with Carbimazole. The clinical documentation suggests that this appears to be related to non-compliance with the medication. The option of treatment with radioactive iodine was considered by the endocrinology team as an alternative to surgery but after discussion with the Ophthalmology team, it was felt not to be appropriate due to the presence of the orbitopathy (hyperthyroidism related eye disease); therefore, a total thyroidectomy was entirely appropriate given the history of difficult to control Grave's disease. The decision to operate was made following a multidisciplinary meeting which took place on the 20th November 2015.'*
49. He also advised that *'the clinic letter outlines the impact of total thyroidectomy including the risks of the surgery'* and evidences that the consultant ENT surgeon CAH explained the implications of the thyroidectomy to the complainant.

Endocrine IPA

50. The Endocrine IPA explained that *'Grave's disease is an auto immune disease where the thyroid gland is stimulated by antibodies to produce too much thyroid hormone. The main symptoms of any cause of an over active thyroid can include anxiety, sweating, palpitations, weight loss, loose bowel motions, and occasionally muscle weakness'*.
51. The Investigating Officer asked the Endocrine IPA if the complainant's symptoms could be attributed to Grave's disease. He advised:
- 'The enlarged thyroid gland may in some people lead to a sensation with swallowing although in most cases as the thyroid disease responds to medication the gland would often become less prominent. As regards the other symptoms*

mentioned, the Carbimazole [CBZ] medication could be linked whilst taken with a metallic taste in the mouth. However, the other issues regarding swallowing and crawling sensation round the body cannot be ascribed to either the thyroid condition or its treatment.'

52. The Endocrine IPA advised that the diagnosis of hyperthyroidism was '*unequivocal*' and '*the management of the thyrotoxicosis was in line with standard practice in 2014, initially with standard anti thyroid medication (CBZ) and supplemented by beta blockers for symptom control. In addition, there is documentation of concern with [the complainant's] administration of the prescribed dosage with advice to not self-medicate on varying dosage according to how she felt and in particular according to the eye symptoms. There was later referral for more effective definitive therapy [thyroidectomy].'*
53. He advised that the referral to the ENT surgeon 17 September 2015 was appropriate. He advised '*As stated definitive treatment for thyroid over activity that is not coming under control is reasonable practice as stated in the more recent NICE guidelines and the earlier guidance from the American Thyroid Association and endorsed by the British Thyroid Association.'*
54. The endocrinologist referred the complainant to a consultant ophthalmic surgeon at the RVH for advice regarding iodine therapy. The Endocrine IPA advised: '*Given the concerns regarding the eye signs which can progress despite best efforts in managing the over active thyroid, referral for an ophthalmological perspective is good practice'*.
55. The endocrine IPA advised '*radioactive iodine is a preferred option for managing Graves' disease but in the context of active thyroid related eye disease is a cause of concern given the well recorded potential for the release of thyroid hormones with iodine to make the eye features much worse. This may be mitigated by a course of high dose steroids but it is not without its own downside and given smoking can also make the eye signs worse it was a reasonable option to refer for thyroid surgery as an alternative. As explained each option has pros and cons and these were pointed out to [the complainant] regards thyroid surgery which she consented to.'*

56. The complainant's case was discussed at MDM on 20 November 2015. The Endocrine IPA advised *'The MDT states difficult to manage conservatively (i.e., with medication) and marked orbitopathy (eye signs linked to the thyroid Grave's disease) - thus the balanced view taken was that as radio iodine could make the eyes worse, then surgery would be a definitive procedure for the thyroid disease.'*
57. The Endocrine IPA added, as a learning point *'...MDT would also need to recognise the need for lifelong thyroxine replacement medication which would also need to be taken reliably for overall health and medium term to ensure stability of the eye signs. In this case there was no record in the MDT notes of the balancing concerns of long-term compliance with replacement thyroxine medication.'*
58. The Endocrine IPA advised that the complainant's thyroid biochemistry was normal in February 2016. The Investigating Officer asked him if the consultant ENT surgeon CAH ought to have reconsidered his decision to operate at that time. He advised:
'This is a balanced judgement as compliance was considered an issue. On balance a period of stable thyroid function for 6 months at least to define medical therapy working - or alternatively evidence that this was not achieved over a 6-month period to then determine need for alternative such as surgery.'
59. The consultant endocrinologist saw the complainant on 16 February and planned a further review after surgery. The Investigating Officer asked the Endocrine IPA if there was evidence that the endocrinologist explained the implications of thyroidectomy to the complainant. He advised *'It is clear from documentation that both [the endocrinologist] and [the surgeon] wrote and documented the potential implications of thyroidectomy.'*
60. In the Endocrine IPA's opinion, there is no substance to the complainant's belief that her thyroid was removed to facilitate examination of the damage to her throat during surgery on 1 July 2014. *'The issues of thyroidectomy for an over active thyroid in an individual with thyroid related eye disease is completely separate issue from the lymph node issue which raised concerns regarding a different condition unrelated to the thyroid ...The suggestion that thyroid surgery to repair damage from*

lymph node removal is to say the least bizarre, and has no basis in fact, not least based on the anatomy as to where such surgery would take place in the neck’.

61. The Endocrine IPA concluded ‘*My opinion is that on balance the definitive treatment offered was not necessarily the only option in 2016. In addition this was clearly a challenging case and it might have been prudent to ensure endocrine input formally after the thyroidectomy and ongoing review after May 2017 when the thyroid biochemistry was quite abnormal.*’

Analysis and Findings issue one

- i. Whether the surgery for removal of a lymph node on 1 July 2014 was performed to the required standard?**

62. I accept the advice of the IPA that it was appropriate to treat the complainant’s enlarged lymph node by way of ultrasound and cytology. I note that this ruled out high grade lymphoma⁵ or other cancers. However, a biopsy was required to rule out a low grade⁶ lymphoma. I consider that this was necessary to exclude malignancy. The records state that the wound healed with no complications. I am satisfied that this surgery met the standards of good medical practice and I do not uphold this element of complaint.

- ii. Whether the complainant’s symptoms following the surgery on 1 July 2014, including swelling, hypertension and haematuria were appropriately managed?**

63. The complainant stated that the swelling on the right side of her throat was present after surgery. However, the records of reviews with oral surgeon A on 17 July and 5 August 2014 do not include any reference to a complaint of swelling. The complainant attended again on 23 October 2014 complaining of a lump however the oral surgeon A was unable to detect this on examination. I accept the advice of the ENT IPA that she was reassured and discharged and this was ‘*in line with*

⁵ Cancer of the lymphatic system

⁶ Slow growing

acceptable clinical practice'.

64. The ENT IPA advised there is no record of swelling or that any material was left in the complainant's mouth following surgery and therefore no link to her complaints of hypertension or haematuria.
65. The ENT IPA also advised that further investigation between 8 July 2015 and 14 October 2015 by consultant ENT surgeon C at CAH were appropriate and *'Ultrasound showed no concerning signs'*.
66. I found no failings in care and treatment following the surgery in 2014 and I do not uphold this element of complaint.

iii. Whether it was appropriate to perform a thyroidectomy in June 2016?

67. I note that the decision to operate rather than to continue with therapy was multifactorial and informed by advice from ophthalmology, endocrinology, ENT and an oral surgeon from the RVH. I consider that this collaboration meets the GMC guidance at paragraph 16 which requires Doctors to
- *'provide effective treatments based on the best available evidence'*;
 - *'to consult colleagues where appropriate' and*
 - *'respect the patient's right to seek a second opinion.'*
68. The records and commentary provided by Trust shows that Thyroid tests in late 2015 were abnormal and there were concerns that iodine therapy would worsen her eye disease. The records show that the complainant was not compliant with her medication and that she was a smoker, another contraindication to iodine therapy.
69. I accept the advice of the ENT IPA that *'A total thyroidectomy was entirely appropriate given the history of difficult to control Grave's disease. The decision to operate was made following a multidisciplinary meeting which took place on the 20th November 2015.'*

70. The Endocrine IPA advised that, by February 2016, the complainant's thyroid biochemistry tested normal. The Endocrine IPA advised that a further period of monitoring could have been carried out prior to proceeding with surgery. However, he also advised that given the complainant's history of non-compliance with medication and disinclination to stop smoking, there is no guarantee that the biochemistry would remain normal without surgery.
71. The records show that the consultant ENT surgeon CAH, the endocrinologist and the ophthalmologist explained the advantages and disadvantages of treatment to the complainant. They informed her that she would require lifelong medication to maintain thyroid function. The complainant requested an opinion from another ENT surgeon in the RVH in April 2016. He reassured her that there was no reason not to continue with surgery. The complainant also sought assurances from the consultant ENT surgeon CAH and also from the anaesthetist regarding intubation and the risks of aspiration during surgery.
72. The Endocrine IPA advised that Thyroidectomy was not '*the only option*' and that it was a '*balanced judgement*'. Informed consent is vital to any successful procedure. The Endocrine IPA advised '*each option has pros and cons and these were pointed out to [the complainant] regards thyroid surgery which she consented to.*' The ENT IPA also advised that '*the clinic letter outlines the impact of total thyroidectomy including the risks of the surgery*' and evidences that the consultant ENT surgeon CAH explained the implications of the thyroidectomy to the complainant. Therefore, I consider that the complainant was adequately informed about the implications of surgery versus iodine therapy and I am satisfied that she provided appropriate consent for the procedure, as required by paragraph 17 of the GMC guidance. I consider that it was appropriate to perform the thyroidectomy in 2016 and I do not uphold this issue of complaint.

Issue two:

Whether the surgery for removal of the thyroid in June 2016 was performed to the required standard? This will include consideration of:

- i. **Whether the complainant's symptoms following the thyroidectomy in June 2016 were appropriately addressed including referrals to ENT, dermatology and neurology?**

Background and detail of complaint (please refer to appendix five for further details)

73. The thyroidectomy took place on 15 June 2016. The consultant ENT surgeon CAH saw her again on 4 July 2016. He reported no malignancy. He altered her medication as she was '*heavily hypothyroid*' at that time. The Endocrinologist did not review the complainant.
74. The complainant said that her symptoms worsened following the thyroidectomy. She contacted the Maxillo Facial on call department directly on 24 August 2016, and then attended ED at the Ulster Hospital Dundonald on 31 August 2016. She was '*reassured and discharged*' and advised to keep a future appointment.
75. The consultant ENT surgeon CAH saw her again on 12 September 2016. He reported '*[The complainant] is very, very adamant and convinced that there is something that we don't want to tell her.*' He requested a MRI of the neck/floor of mouth which was carried out on 21 September 2016. This demonstrated lingual tonsils and lymph nodes appeared enlarged bilaterally.
76. The consultant ENT surgeon CAH saw her again on 10 October 2016 and decided on pharynoscopy and biopsy of the tongue base. The biopsy on 12 October 2016 showed no evidence of malignancy.
77. Mr Qudairat, Maxillofacial Consultant CAH saw the complainant on 7 October 2016 and '*reassured her that there is no pathology of disease I could see inside her mouth that requires surgical intervention*' and discharged her back to the care of her dentist.
78. The complainant developed a skin rash which she believed to be a hospital acquired infection. I note that her GP referred her to Dermatology at CAH where

she was seen on 23 December 2016 and again on 23 February 2017. The clinicians diagnosed intertrigo caused by a bacteria called staphylococcus aureus and assured her that this was not a hospital acquired infection.

79. The complainant was also treated by the consultant neurologist at CAH at this time, however he deferred further management to the consultant ENT surgeon CAH. Issue three of this complaint investigates the neurological aspects of this complaint.

Evidence Considered

Legislation/Policies/Guidance

80. I considered the following
- GMC Guidance

The Trust's response to investigation enquiries

81. The Trust stated:

'Total thyroidectomy was carried out 15 June 2016. According to [the complainant's] anaesthetic record surgery took 1 hour and 48mins and was uneventful. She was reviewed in the consultant ENT surgeon CAH's clinic on 04 July 2016. She was discharged on 17 June 2016 with her vocal cords being fully mobile, normal parathormone and calcium levels and her wound had healed without any signs of an infection.'

82. The Trust added:

'Despite her complaint, the consultant ENT surgeon CAH was very pleased with the fact that she went through surgery smoothly and without complications. By removing her thyroid gland [the complainant's] eyes and vision have been saved for years to come. She was also referred to and seen by two other ENT Consultants outside of the Southern Trust namely the Royal Victoria Hospital who have advised that she has received the correct diagnosis and treatment and care.'

The Trust's response to the draft report

83. The Consultant ENT Surgeon CAH asked me to note :

‘[The complainant] had her surgery initially scheduled for 9th March 2016. She was seen by the Consultant Endocrinologist, on 16th February 2016 and a review appointment in the Endocrinology Outpatient Clinic was arranged for her post operatively in 2 months’ time (which would have been May 2016). This is routine practice in relation to patients who are having endocrine surgery. If the date of the surgery changes, patients are asked to contact the Endocrine Secretary who then arranges a different date for review in the clinic. The complainant postponed her surgery due to personal reasons and also that she wanted a second opinion.’

84. The Trust added *‘The Endocrinologist, would like it noted that as she was not informed of the change of the surgery date, nor was a discharge letter received by the Endocrinology Service from the discharging Consultant, there was no further prompt to give a new review date’.*
85. The Trust identified this as an error in the process and stated that *‘from now on any discharge letter following endocrine surgery will be copied and sent to Endocrinology Service so the same situation can be avoided in the future’.*
86. The Consultant ENT surgeon also asked that me to note *‘that Post-operative titration of the thyroid supplements is guided by the same NICE guideline in primary care, Endocrinology or ENT’.*

Relevant Trust’s records

87. I reviewed the complainant’s medical records and referred these to a number of Independent professional advisors (IPA). I attach the entire advice at appendix three. I refer to relevant extracts below.

Relevant Independent Professional Advice

ENT IPA

88. The ENT IPA advised:

'The total thyroidectomy surgery [on 16 June 2016] was performed to the required standard. At C's post-operative follow up appointment with the consultant ENT surgeon CAH on the 4th July 2016, the clinic letters confirms that her vocal cords were mobile bilaterally and her parathormone level and calcium levels were normal. Therefore, I would infer from this that there were no complications from surgery and therefore is no clinical information to suggest that the surgery was not performed to the required standard level.'

89. The consultant ENT surgeon CAH saw C again on 12 September 2016 and ordered further investigations. The ENT IPA advised:

'An MRI neck/floor of mouth requested by the consultant ENT surgeon CAH was carried out on 21 September 2016. This demonstrated lingual tonsils and lymph nodes appeared enlarged bilaterally. The consultant ENT surgeon CAH saw her again on 10 October 2016 and decided on pharynoscopy and biopsy of the tongue base. The biopsy on 12 October 2016 showed no evidence of malignancy. These investigations were appropriate.'

90. The ENT IPA advised that referrals to Neurology and Psychology were appropriate.

91. The complainant believed that the surgeon removed her thyroid to access and consider the cause of the swelling in the throat following the previous surgery. The ENT IPA advised there was no evidence of this and no link between the surgery and her symptoms.

92. The complainant said her symptoms became more pronounced following the biopsy of the tongue. Symptoms included a weight sensation, loss of swallow reflex, metallic taste in mouth, a crawling sensation round her body. The Investigating Officer asked the ENT IPA if there a possible link between these symptoms and the biopsy? He advised:

'Following an endoscopy and biopsy of the tongue base it is possible that a metallic taste may occur if there is some bleeding. It would be rare for a loss of swallow reflex and I am unable to explain the crawling sensation around her body.'

93. The consultant ENT surgeon CAH saw the complainant on 28 November 2016. He discharged her from ENT and made a referral to a health psychologist at CAH. The

ENT IPA advised that discharge was appropriate because *'she had been extensively investigated and nothing had been identified'* and there was no further action that the ENT surgeons could have taken in order to identify a physical cause for her symptoms.

Endocrine IPA

94. The Endocrine IPA advised that there was no record of endocrine follow up immediately following surgery. He advised *'In my opinion it would have been reasonable to have had endocrine review after the operation when there were concerns about thyroid hormone replacement'*. He also advised: *'In this case it appears that the endocrine review was not arranged and advice regarding thyroxine dose adjustment made to the GP. I think the suggestion to increase the dose and for GP to manage this was not inappropriate as often adequately managed in that setting.'*
95. The Investigating Officer asked the Endocrine IPA if an endocrine cause for the symptoms the complainant experienced after thyroidectomy should have been explored. He advised: *'The most important consideration which was explored was any change in calcium balance if the parathyroid glands near the thyroid were damaged inadvertently or removed during surgery. In fact, there is clear documentation this was NOT the case and the levels were normal reflecting effective surgery. There was mention that another endocrine disorder with low steroid levels was being considered (this is called Addison's disease) and due to auto immune damage to the adrenal glands that normally make steroids. A short synacthen test was suggested and is a useful screening test for adrenal insufficiency but I should stress this was not a valid consideration at the time of the thyroid surgery where there is no basis to expect that the surgery would somehow be linked with adrenal disease. In addition, the symptoms described after surgery are not at all typical of steroid deficiency.'*
96. The Endocrine IPA concluded *'My opinion is that on balance the definitive treatment offered was not necessarily the only option in 2016. In addition this was clearly a challenging case and it might have been prudent to ensure endocrine input formally*

after the thyroidectomy and ongoing review after May 2017 when the thyroid biochemistry was quite abnormal.'

Analysis and Findings

97. The Trust stated and the ENT IPA confirmed that the clinic letters from The consultant ENT surgeon CAH indicate there were no complications from surgery on 15 June 2016 and '*her vocal cords were mobile bilaterally and her parathormone level and calcium levels were normal*'. The Endocrine IPA advised that these normal levels evidenced that the parathyroid glands near the thyroid were not damaged or inadvertently or removed during surgery.
98. Her thyroid levels were checked appropriately by oral consultant B and her medication was altered on 4 July 2016. However, the complainant noticed an increase in her distressing symptoms and sought help from her GP who made referrals and also advised her to attend ED on several occasions.
99. Further ENT investigations included MRI and biopsy of the tongue base. The complainant's symptoms became more pronounced at this time. I accept the advice of the ENT IPA that clinicians found no explanation for the exacerbation of her symptoms despite extensive investigation and discharge from ENT with referrals to neurology and psychology colleagues was appropriate.
100. I consider that referrals to ENT, dermatology and neurology appropriately addressed the complainant's symptoms following the thyroidectomy in June 2016.
101. However, I accept the advice of the Endocrine IPA that further endocrine input following surgery and '*ongoing review after May 2017 when the thyroid biochemistry was quite abnormal*' would have been advisable. Bearing in mind the known risk of non-compliance with the medication prescribed, I question if it was sufficient to expect the complainant and her GP to manage this effectively. There is no evidence of a further consultation with the endocrinologist. This is a failing in care and treatment leading to the injustice of loss of opportunity for effective endocrine follow-up.

Issue three: Whether Neurological investigations and subsequent actions were carried out appropriately? This will include consideration of:

- i. Whether the care and treatment provided by the consultant neurologist at CAH was appropriate?**
- ii. Whether it was appropriate to refer the complainant to the London Hospital for Neurology and Neurosurgery which she attended for consultation on 22 October 2018?**
- iii. Whether follow up treatment following the consultation in London was appropriate?**

Background/detail of the complaint (please refer to appendix five for further details)

102. The clinic record of 3 September 2016 indicates that the consultant neurologist CAH diagnosed sensory neuropathy and chronic folic acid deficiency. He prescribed infusions of Pabrinex which she received on 3, 10, 17, and 31 October 2016 for vitamin B and C deficiency. On 24 November 2016 he prescribed folic acid. He deferred further management to the consultant ENT surgeon CAH at CAH.
103. The consultant neurologist CAH reviewed the complainant in April 2017 and arranged for a number of investigations which are detailed in the chronology at appendix five. He also referred the complainant to Neurology at the RVH for a second opinion. She attended the ED of the RVH on 17 May 2017 and was admitted for a three-week period.
104. The consultant neurologist CAH was unable to identify an underlying cause for the complainant's symptoms and referred the complainant to the UCLH National Hospital for Neurology and Neurosurgery in London for an independent assessment. She was admitted on 22 October 2018 and discharged on 9 November 2018. I attach an extract from the clinic letter dated 19 November 2018 to the complainant's GP following discharge.

105. The UCLH discharge summary states *'complex pain and neuropsychiatry reviews suggested that her multiple symptoms were consistent with central sensitisation – a higher level sensory interpretation disorder at the level of the thalamus or above.'* The plan was *'follow up by her local team for further neuropsychological assessment and management'*. The complainant did not accept the findings as independent.
106. The record shows that the consultant neurologist CAH also referred her to a Consultant in anaesthesia and Pain Management CAH in February 2019. The record shows that he saw her on 22 May 2019. He stated *'I have nothing to offer this lady. I am not convinced that her neck or back pains are neuropathic at all.'*
107. The complainant's final appointment with Dr Forbes was 30 August 2019. He stated *'In summary she has chronic severe pain which is refractory to intervention and having attended the pain clinic they feel they do not have anything more to offer her.'* He referred her to CAH mental health team.
108. She complained that CAH blocked her from seeing a spinal consultant because, in her opinion, the surgeons had something to hide. She believes she has spinal damage. Her GP referred her to ICATS with a request for referral to a spinal surgeon. She was seen in ICATS on 1 July 2019 and discharged. Following further GP referrals to ICATs, she received an appointment to see a spinal consultant at Musgrave Park Hospital, Belfast and the consultation took place in September 2021.

The Trust's response to investigation enquiries

109. The Trust responded to the complainant directly on 26 July 2019 and referred her to this Office. The Trust informed her that the consultant neurologist at CAH *'has agreed to reviewing you personally in August 2019 where he will discuss any further issues you may have directly.'* I attach, as appendix seven, the summary forwarded by the consultant neurologist CAH to the Trust Governance department on 13 September 2019, following this appointment with the complainant on 30 August 2019.

Issue three

- i. Whether the care and treatment provided by the consultant neurologist at CAH was appropriate?**

Evidence Considered

Legislation/Policies/Guidance

110. I considered the following

- GMC Guidance

Relevant Trust records

111. I reviewed the complainant's medical records and referred these to a number of Independent professional advisors (IPA). I enclose the complete IPA advice at appendix three and relevant extracts below.

112. I attach examples of clinic records from the consultant neurologist at CAH at appendix eight.

Relevant Independent Professional Advice

Neurology IPA (N IPA)

113. In September 2016, the consultant neurologist at CAH diagnosed sensory neuropathy and chronic folic acid deficiency. The N IPA explained that:
'A sensory neuropathy is a disorder of sensory nerves, which can be caused by several different disease processes including inflammatory disorders, endocrine disorders and genetic predispositions. It usually causes symptoms of numbness or altered sensations. Physical examination is characterised by loss of deep tendon reflexes and sensation in the distribution of the sensory nerve involved. A 'small fibre' neuropathy is the term used to describe a neuropathy confined to small nerve fibres, such as those that conduct pain sensation. This is rare, and can be difficult to diagnose as it is occasionally found in patients with normal neurological examination.'

114. The Investigating Officer asked the N IPA if treatment by Pabrinex and folate injections was appropriate. He advised:

'Pabrinex is a proprietary preparation of vitamins B and C. There are a few patients who develop neuropathy associated with vitamin deficiency, and such patients may benefit from such supplements. ... Since treatment with Pabrinex is generally safe, however, it would be reasonable to offer this in the absence of any other available therapy for C's symptoms.'

He also advised:

'Parenteral vitamin treatment is generally very safe and would be expected to treat any folic acid deficiency promptly and reliably. Such treatment would therefore help indicate whether folic acid deficiency was responsible for any of C's symptoms. The approach was therefore appropriate.'

115. The Investigating Officer asked the N IPA if the diagnosis was appropriate. He advised:

'In this case the diagnosis of a sensory neuropathy was not particularly plausible. It would account for only a few of C's symptoms, i.e. possibly some of her pain and feeling of numbness. However, it would not account for the variability of her symptoms during the day and from day to day, the feeling of a foreign body in her mouth, her slowness of movement and strange feelings which she describes in her arms, head and within her body. I note that nerve conduction studies in March 2016 and again in May 2017 also showed no evidence of neuropathy. I conclude that this diagnosis was not particularly appropriate nor particularly plausible, and that C's symptoms were much more consistent with a diagnosis of functional neurological disorder.'

116. The consultant neurologist CAH saw C on 12 and 19 January 2017 and reported to C's GP:

'I am arranging for a CT chest, abdomen and pelvis, am repeating her imaging of brain and spine on the outside chance that this is demyelination⁷ and have checked further bloods from a systemic viewpoint.' The N IPA advised:

'He appeared to consider that C's symptoms still might have an underlying physical basis in January 2017. It can be difficult to conclude that a patient's symptoms are functional without careful exclusion of any possibility of physical disease, no matter

⁷ A disease of the nervous system in which the myelin sheath of neurons is damaged. This damage impairs the conduction of signals in the affected nerves. In turn, the reduction in conduction ability causes deficiency in sensation, movement, cognition, or other functions depending on which nerves are involved.

how remote that possibility may be...I conclude that the investigations requested by him were broadly consistent with good clinical care.'

117. He also advised that *'the CT of C's chest abdomen and pelvis was reported by [the consultant neurologist CAH] to be normal in the clinic letter of April 2017. Neuroimaging was within normal limits, demonstrating only mild degenerative changes in the spine that would be expected in someone of C's age'*.
118. The records show that cerebral spinal fluid was collected on 23 March 2017. The pathology report on 28 March 2017 reported no malignancy. The N IPA advised *'cerebrospinal fluid analysis demonstrating normal constituents needs no particular action'* so management was appropriate. The records show that a MRI of the head was performed on 4 June 2017.
119. The Investigating Officer asked the N IPA to comment on the justification for further referrals and tests instigated by the neurology consultant CAH. He said that referrals to an oral surgeon and a consultant neuropsychiatrist were appropriate. The N IPA advised that a lumbar puncture tested negative for malignancy. The consultant neurologist reviewed the complainant on 8 September 2017 and ordered a PET scan (performed on 21 October 2017) and synacthen⁸ test. Both returned normal results. The N IPA advised:
- 'By this time it appears to have been very obvious that the patient's symptoms were not those of an organic neurological disorder, and it would seem that continuing search for an underlying physical cause was prompted more by the patient's continuing expressions of dissatisfaction than any doubt about the diagnosis. Whilst I can see little justification for further investigation from a clinical perspective, the investigations requested were by and large appropriate to exclude any persisting remote suspicion of underlying physical disease.'*
120. The Investigating Officer asked the N IPA if the referrals to the RVH neurologists, neuropsychiatrist and neurophysiologist in May 2017 were followed up on appropriately. He advised:

⁸ A synacthen test involves injection of a drug (synacthen) to stimulate the adrenal gland, and is used to investigate whether the adrenal gland is producing sufficient steroid hormone (cortisol).

'The psychiatric evaluation stated that C might benefit from a clear plan and rationale for further referrals and to have a lead clinician. This was appropriately followed through as far as possible by the Neurologists involved in her care.'

121. On 22 November 2017 the consultant neurologist referred the complainant to a consultant physician CAH with recommendation for referral to the Mental Health (MH) team. The N IPA advised:

'Management of non-organic symptoms is particularly difficult, especially in patients who do not accept the diagnosis. Referral to a mental health team is sometimes helpful in persuading a patient to engage in treatment of emotionally-generated symptoms, so in this case these referrals were appropriate.'

122. The complainant was admitted to CAH via ED on 12 Dec 2017 until 19 December 2017 and was seen by the consultant neurologist on 13 December 2017. The N IPA advised:

'[The consultant neurologist CAH's] clinic letter states that the complainant was seen and examined. He suggested that the complainant try the drug nabilone⁹ to help with her symptoms (which he attributed to a neuropathy).'

He also suggested further referral to Gynaecology and Urology for 'changing pelvic type symptoms' and haematuria, respectively. A further review took place on 19 December 2017.

The N IPA advised:

'This review appears largely to have been to assess the effect of nabilone treatment, which was reported in the clinic letter to be helping her symptoms slightly. This review was appropriate.'

Issue three

- ii. Whether it was appropriate to refer the complainant to the London Hospital for Neurology and Neurosurgery (UCLH) which she attended for consultation on 22 October 2018?**

Evidence Considered

⁹ Man-made form of cannabis that can be used as an analgesic to treat neuropathic pain

Legislation/Policies/Guidance

123. I considered the following [legislation/policies/guidance]:

- GMC Guidance

Relevant Trust's records

The consultant neurologist's referral letter to UCLH 13 July 2018

124. This letter states: *'I have sought a second opinion from my colleagues in the Royal Victoria Hospital on her case as she was becoming exasperated at my inability to identify an underlying cause. I have proceeded to do CT PET scanning which has not identified underlying cancer and in the end of the day I think she has a painful predominantly small fibre sensory neuropathy with neuropathic pain with the presence of refractory Folic Acid deficiency.*

My reason for writing is that I am seeking confirmation both of diagnosis but also to see whether you might refine this further in case she is in some way either syndromic or an autosomal recessive neuropathy. She is keen for a referral to a Specialist Clinic and as she has already been through our Regional Service my only option would be your own clinic.'

125. **Discharge letter typed 18 December 2018 from UCLH.**

The discharge summary states:

'Complex pain and neuropsychiatry reviews suggested that her multiple symptoms were consistent with central sensitisation – a higher level sensory interpretation disorder at the level of the thalamus or above.' The plan was *'follow up by her local team for further neuropsychological assessment and management'*.

Relevant Independent Professional Advice

N IPA

126. The Investigating Officer asked the N IPA if the referral to the UCLH Queens College Hospital in London neurology and neurosurgery department was appropriate. He advised:

'The clinicians involved in C's care were struggling to help a patient with multiple medically unexplained symptoms, and one who did not accept the diagnosis of

functional disorder. A diagnosis of a neuropathy had also been made with very limited clinical support. In these circumstances referral for a definitive opinion from the national centre of excellence was entirely appropriate.'

127. The Investigating Officer asked the N IPA to explain the diagnosis of 'profound central sensitisation'. He advised:

'The choice of words used in the discharge summary from the National Hospital for Neurology was unclear as it uses non-standard terminology. The words imply that [the complainant's] symptoms are generated by abnormal processing of sensations coming from sense organs in her body, which is a widely accepted mechanism for the production of sensory functional neurological symptoms. In my opinion, therefore, the discharge summary confirmed the diagnosis of functional neurological disorder. No evidence of an organic sensory neuropathy was found.'

Issue three

iii. Whether follow up treatment following the consultation in London was appropriate?

Relevant Independent Professional Advice

N IPA

128. The UCLH recommendation was for '*follow up by her local team for further neuropsychological assessment and management*'.

The record states that the consultant neurologist CAH saw the complainant on 7 February 2019 for review. He explained the nature of chronic pain and the process of central sensitisation. He discharged her and referred her to a Consultant in Pain Management at CAH. The Investigating Officer asked the N IPA if the consultant neurologist CAH carried out appropriate follow up on the complainant's return from London. He advised:

'The discharge letter recommended a 'holistic multidisciplinary approach focussed on self-management and referral back to the pain management service.'

He also advised:

'As there were no other options available to help C other than symptomatic treatment, this was reasonable...C complained of pain as a dominant symptom. The term 'chronic pain disorder' is descriptive rather than diagnostic. Use of the term is therefore reasonable...He appears to have exhausted all available management options for C. The approach was therefore appropriate.'

129. In April 2019 the consultant neurologist CAH wrote to the complainant's GP, advising:

'This lady's nerve conduction study did not show any evidence of large fibre neuropathy and supports the case that she has a central sensory sensitisation syndrome.'

130. The consultant neurologist CAH also wrote to the complainant on 3 April 2019 to advise her that he did not believe that she had low CSF pressure. He diagnosed central pain sensitisation and referred her to the pain clinic. In August 2019 he referred the complainant to the mental health team at CAH

131. The Investigating Officer asked the N IPA if there was adequate follow up of these investigations. He advised:

'Since investigations were all normal, no further investigation or follow up of such investigations [by the consultant neurologist CAH] was necessary or appropriate.'

132. He also advised:

'Ideally, C would have been offered a consistent and concerted approach to her diagnosis from clinicians expert in assessing and treating patients with medically unexplained symptoms...

The letters from the neurologists involved in C's care make reference to a neuropathy as a possible cause for her symptoms, a diagnosis that had scant clinical and no neurophysiological support. I suspect this had the effect of undermining the message that C's symptoms were emotionally-generated and confusing the issue.'

133. The N IPA concluded:

'Overall, the standard of care offered to C was good and consistent with GMC Good Medical Practice. Investigations were undertaken promptly, though many clinicians

would have considered that many of the investigations were unnecessary given the clinical picture characteristic of non-organic symptomatology.'

Pain Management IPA (PM IPA)

134. The Investigating Officer asked the PM IPA to comment on the consultation with Orthopaedic ICATs on 1 July 2019. He advised:

'The annotated examination is appropriate and sufficient. It is recorded in extensive detail. I note the patient was unable to perform movements during examination which had been observed when climbing onto the couch.

In such a complex case it would have been inappropriate not to have raised the possibility of Psychiatric elements. Perhaps this could have been raised as an additional coping mechanism rather than use the word Psychiatric.

As examination did not reveal any signs suggestive of a physical lesion MRI would probably have been declined by the reviewing Radiologist. All other reasonable investigations had already been done.

As triage services are in place to prevent non-productive use of Specialist consultations with associated adverse effect on already long waiting times and no further investigations had been performed, discharge was appropriate.'

135. In September 2019, the GP made direct referrals to Musgrave Park Hospital requesting review by a spinal surgeon. The Investigating Officer asked the PM IPA if there was evidence ICATS doctor gave sufficient consideration to the GP's requests. He advised:

'The local policy was that GPs could not refer directly to Spinal Surgeons, hence the referral back to ICATs. Due consideration of the case has been undertaken before declining referral.

The triaging doctor has acted within their remit having considered the dialogue. It is difficult to envisage any further advice that the triage doctor could have offered to the GP. The decision to turn down the GP's repeated request for a referral for spinal surgery was appropriate.

There were no obvious other steps that the Dr could have taken to provide direction to the GP.'

136. The complainant's GP made a further referral on 18 June 2020 directly to Musgrave Park hospital. The ICATS Dr discussed this with a consultant spinal surgeon who suggested MRI of whole spine. The ICATS Dr contacted the complainant to tell her she was on a one year waiting list for MRI. However, MRI was performed on 6 October 2020 and showed no *'orthopaedic cause that would explain her symptoms'*. The consultant spinal surgeon suggested referral to a spinal surgeon at Musgrave Park hospital. She was referred by letter 27 October 2020 and was put on his waiting list. She was not expected to get an appointment until May 2023 due to waiting lists however she received an appointment in September 2021.

137. The Investigating Officer asked if it was appropriate for the ICATS doctor to make this referral at this time. He advised:

'It is appropriate for either GP or ICATS doctor to make this referral as it is effectively consultant to consultant. It is appropriate for triage doctors to follow guidelines. When looking at how things have progressed, discussion with the Spinal Surgeons might have been appropriate at an earlier stage, however this is heavily influenced by hindsight. This is a long-term ongoing problem. As such routine referral is appropriate. There was no indication that the referral should have been made other than routine. I cannot think of any further investigations that may be helpful.'

138. The PM IPA concluded:

'Guidelines are helpful, however, the patient had a normal MRI and referral to a Spinal Surgeon. It is highly unlikely that there will be any surgical intervention. This illustrates the difficulties in balancing the demands of a challenging patient for an unnecessary referral and the inappropriate consumption of NHS resources, without which patient management is impracticable as witnessed by repeated requests. This is a complex case where everyone involved attempted to manage the challenges.'

Analysis and findings issue three

i. Whether the care and treatment provided by the consultant neurologist at

CAH was appropriate?

139. The Investigating Officer asked the N IPA to consider the care and treatment the consultant neurologist CAH provided to the complainant as an outpatient. The N IPA reviewed all the clinical records and commented on the tests and assessments. He advised:
- 'It can be difficult to conclude that a patient's symptoms are functional without careful exclusion of any possibility of physical disease, no matter how remote that possibility may be...I conclude that the investigations requested by the consultant neurologist CAH were broadly consistent with good clinical care.'*
140. I accept the N IPA advice that treatment by Pabrinex and folate injections was an appropriate starting point to treat vitamin B and C deficiency (diagnosed in September 2016) and to monitor whether her symptoms would improve as a result.
141. During this period (September 2016), the complainant was also being treated at ENT CAH with onward referrals, including clinical psychology, dermatology and general medicine at CAH. In May 2017, the consultant neurologist CAH referred the complainant for a second opinion to neurology at the RVH as there were no in-patient neurology facilities at CAH. This meets the GMC standard *'refer a patient to another practitioner when this serves the patient's needs'*.
142. On 17 May 2017, the complainant attended the ED of the RVH and was admitted for a period of three weeks for further tests. There were also referrals to neurophysiology, neuropsychology and neuropsychiatry. The consultant neurologist CAH saw the complainant again in August 2017 for follow up. The N IPA advised that CT scans, a lumbar puncture test, a PET scan and synacthen test requested by the consultant neurologist CAH all returned normal results.
143. I am satisfied that the consultant neurologist CAH provided care and treatment, relative to his area of competence, that was thorough and comprehensive. He also referred the complainant to colleagues from other disciplines in line with the GMC guidance *'consult colleagues where appropriate.'* These colleagues, as well as the complainant's GP also made referrals to other clinicians such as orthopaedic ICATS.

144. The chronology of care at appendix five records the referrals to other clinicians, including gynaecology, urology, respiratory, psychology, dentistry and a consultant oral and maxiofacial surgeon. I will not repeat the detail here, however, it is clear that the consultant neurologist CAH and his colleagues made a concerted effort to seek an underlying cause for the complainant's distressing symptoms.

145. I accept the N IPA advice that:

'By this time it appears to have been very obvious that the patient's symptoms were not those of an organic neurological disorder, and it would seem that continuing search for an underlying physical cause was prompted more by the patient's continuing expressions of dissatisfaction than any doubt about the diagnosis.'

146. I am satisfied that the consultant neurologist CAH upheld the standards of good medical practice and I do not uphold this issue of complaint.

ii. Whether it was appropriate to refer the complainant to the UCLH London Hospital for Neurology and Neurosurgery which she attended for consultation and investigation on 22 October 2018?

147. The London Hospital for Neurology and Neurosurgery is outside my jurisdiction therefore my consideration of this issue is limited to whether the referral by the consultant neurologist at CAH was appropriate.

148. The consultant neurologist CAH diagnosed *'small fibre sensory neuropathy with neuropathic pain with the presence of refractory Folic Acid deficiency.'* He referred the complainant to UCLH for confirmation of the diagnosis and *'to see whether you might refine this further in case she is in some way either syndromic or an autosomal recessive neuropathy'*.

149. The UCLH discharge letter dated 18 December 2018 described *'a higher level sensory interpretation disorder at the level of the thalamus or above.'* The N IPA advised that this is *'non-standard terminology'*. While the language could be more

definitive, I accept the N IPA advice that this does not support a diagnosis of sensory neuropathy but rather confirms the diagnosis of functional neurological disorder.

150. I attach an extract from the UCLH clinic letter to the complainant's GP at appendix six. This states *'there was no evidence of any sensory neuropathy found'*. The letter records a discussion with the complainant about how *'chronic pain and central sensitisation mechanisms could explain her multiple symptoms'* and recommended a referral to the local pain management service.

151. I accept the N IPA's advice that *'referral for a definitive opinion from the national centre of excellence was entirely appropriate.'* I do not uphold this element of complaint.

iii. Whether follow up treatment following the consultation in London was appropriate?

152. As referred to above the London Hospital for Neurology and Neurosurgery is outside my jurisdiction therefore my consideration of this issue is limited to whether the consultant neurologist at CAH followed up the referral appropriately.

153. The records indicate that consultant neurologist CAH reviewed the complainant on 7 February 2019. The complainant does not recall this consultation. I attach the record at appendix eight. He referred her to a Consultant in Pain Management at CAH. I accept the advice of the N IPA that this approach was appropriate. The N IPA advised:

'Since investigations were all normal, no further investigation or follow up of such investigations [by the consultant neurologist CAH] was necessary or appropriate.'

154. The record shows that the consultant neurologist CAH wrote to the complainant in April 2019 to reassure her about the results of the CSF test. He also wrote to her GP to inform him that the nerve conduction study showed no evidence of large fibre neuropathy. This is evidence of good communication as required by the GMC guidance (appendix four).

155. The detailed records show that the complainant attended ICATS on 1 July 2019, however she does not recall this. I accept the advice of the PM IPA that the examination was *'appropriate and sufficient'* and do not find any failings in care and treatment at ICATS.

156. The consultant neurologist at CAH saw the complainant again on 30 August 2019. By this time, neuropsychology and neuropsychiatry has assessed her and had asked her GP to arrange a spinal review. Appendix seven recorded his opinion about how the complaint might be taken forward by the Trust Corporate Governance team.

157. I accept the N IPA's conclusion:

'Overall, the standard of care offered to C was good and consistent with GMC Good Medical Practice. Investigations were undertaken promptly, though many clinicians would have considered that many of the investigations were unnecessary given the clinical picture characteristic of non-organic symptomatology.'

158. I consider that the consultant neurologist CAH had undertaken as thorough an investigation as possible to identify a physical cause for her symptoms and it was appropriate to discharge her with a referral to the mental health team at CAH. I do not uphold this element of complaint.

159. I note that an MRI was performed on 6 October 2020 and showed no *'orthopaedic cause that would explain her symptoms'*. The consultant spinal surgeon suggested referral to a spinal surgeon at Musgrave Park hospital. She was referred by letter 27 October 2020 and was put on his waiting list. She was not expected to get an appointment until May 2023 due to waiting lists however she received an appointment in September 2021 and is receiving ongoing care. This is outside the scope of this investigation.

CONCLUSION

160. I received a complaint about the actions of the Trust. The complainant said that

surgery performed at CAH in 2014 caused her injuries which resulted in distressing symptoms which were not adequately investigated or treated. My report of this investigation covers three main issues of complaint and several sub issues.

161. Issue one of this report concerned the care and treatment provided to the complainant from March 2014 to June 2016 following diagnoses of hyperthyroidism and Grave's disease.

162. I concluded as follows:

- i. The surgery for removal of a lymph node on 1 July 2014 was performed to the required standard.
- ii. The complainant's symptoms following the surgery on 1 July 2014, including swelling, hypertension and haematuria were appropriately managed.
- iii. It was appropriate to perform a thyroidectomy in June 2016.
I did not find any failings in care and treatment in relation to issue one and I did not uphold this issue of complaint.

163. Issue two of this report investigated whether the surgery for removal of the thyroid in June 2016 was performed to the required standard. I concluded:

- i. The complainant's symptoms following the thyroidectomy in June 2016 were appropriately addressed including referrals to ENT, dermatology and neurology.
- ii. There ought to have been further input from the endocrinologist following surgery, in view of the known risk of the complainant's failing to take her medication as prescribed. I found this to be a failing in care and treatment.

164. Prior to thyroidectomy, both the surgeon and the endocrinologist informed the complainant that she would require lifelong medication to maintain thyroid function. I found that the failing to monitor her compliance with medication effectively following surgery led to injustice to the complainant of loss of opportunity for effective endocrine follow-up. I upheld this element of issue two of the complaint.

165. Issue three of this report considered whether neurological investigations and subsequent actions were carried out appropriately at CAH. I concluded:

- i. The care and treatment provided by the consultant neurologist at CAH was

appropriate.

- ii. It was appropriate to refer the complainant to the UCLH for investigations.
- iii. Follow up treatment by the consultant neurologist CAH following the consultation at UCLH was appropriate.

I did not find any failings in care and treatment in relation to issue three and I did not uphold this issue of complaint.

Recommendations

166. I recommend that the Trust provides the complainant with a written apology in accordance with NIPSO 'Guidance on issuing an apology' (June 2016), for the injustice caused as a result of the failure identified in relation to issue two within **one month** of the date of this report

167. The Trust has already identified that the Consultant ENT surgeon did not inform the Endocrinologist of the change of the surgery date, therefore there was no prompt to provide a new review date. This resulted in a change of process whereby the discharge letter following endocrine surgery will be copied and sent to the Endocrinology Service. I welcome this learning

168. I recommend, for service improvement and to prevent future recurrence that the Trust asks the ENT and oral surgeons and consultant endocrinologist to further reflect on this case and identify what other lessons they have learned from this investigation regarding post-operative care.

169. I recommend that the Trust implements an action plan in relation to the recommendation and provides me with an update within three months of the date of my final report. That action plan should be supported by evidence to confirm that appropriate action has been taken including, where appropriate, records of any relevant meetings, training records and/or self-declaration forms which indicate that staff have read and understood any related policies.

Margaret Kelly, Ombudsman
January 2022

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.

PRINCIPLES OF GOOD COMPLAINT HANDLING

Good complaint handling by public bodies means:

Getting it right

- Acting in accordance with the law and relevant guidance, and with regard for the rights of those concerned.
- Ensuring that those at the top of the public body provide leadership to support good complaint management and develop an organisational culture that values complaints.
- Having clear governance arrangements, which set out roles and responsibilities, and ensure lessons are learnt from complaints.
- Including complaint management as an integral part of service design.
- Ensuring that staff are equipped and empowered to act decisively to resolve complaints.
- Focusing on the outcomes for the complainant and the public body.
- Signposting to the next stage of the complaints procedure, in the right way and at the right time.

Being customer focused

- Having clear and simple procedures.
- Ensuring that complainants can easily access the service dealing with complaints, and informing them about advice and advocacy services where appropriate.
- Dealing with complainants promptly and sensitively, bearing in mind their individual circumstances.
- Listening to complainants to understand the complaint and the outcome they are seeking.
- Responding flexibly, including co-ordinating responses with any other bodies involved in the same complaint, where appropriate.

Being open and accountable

- Publishing clear, accurate and complete information about how to complain, and how and when to take complaints further.
- Publishing service standards for handling complaints.

- Providing honest, evidence-based explanations and giving reasons for decisions.
- Keeping full and accurate records.

Acting fairly and proportionately

- Treating the complainant impartially, and without unlawful discrimination or prejudice.
- Ensuring that complaints are investigated thoroughly and fairly to establish the facts of the case.
- Ensuring that decisions are proportionate, appropriate and fair.
- Ensuring that complaints are reviewed by someone not involved in the events leading to the complaint.
- Acting fairly towards staff complained about as well as towards complainants.

Putting things right

- Acknowledging mistakes and apologising where appropriate.
- Providing prompt, appropriate and proportionate remedies.
- Considering all the relevant factors of the case when offering remedies.
- Taking account of any injustice or hardship that results from pursuing the complaint as well as from the original dispute.

Seeking continuous improvement

- Using all feedback and the lessons learnt from complaints to improve service design and delivery.
- Having systems in place to record, analyse and report on the learning from complaints.
- Regularly reviewing the lessons to be learnt from complaints.
- Where appropriate, telling the complainant about the lessons learnt and changes made to services, guidance or policy.