HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Radiotherapy delayed for man with pituitary tumour

1. On 15 August 2022, the Health and Disability Commissioner (HDC) received a complaint from Mr A about care he received from Health New Zealand | Te Whatu Ora Southern (Health NZ Southern). Mr A required radiotherapy for a tumour on his pituitary gland.[1] The radiotherapy was delayed, which resulted in the need for further surgery and possibly increased damage to his vision.

Information gathered

2. Mr A (aged 22 years at the time of his first presentation) had a one-year history of headaches and more recent visual disturbance. In August 2019, he was seen by the Health NZ Southern ophthalmology service and found to have left- and right-sided quadrantanopia (loss of vision in a quarter of his visual field).

3. On 20 August 2019, Mr A had a magnetic resonance imaging (MRI) scan, which revealed a lesion in his pituitary gland that was approximately 2–3cm in size. It was radiologically consistent with a craniopharyngioma, a rare benign tumour that forms near the pituitary gland.[2] Mr A was reviewed by endocrinologist Dr B and neurosurgeon Dr C and listed for surgery, specifically a 'right frontal craniotomy[3] and debulking[4]/excision' of the tumour.

September 2019 surgery and follow-up care

4. On 16 September 2019, Mr A underwent surgery at Hospital A performed by Dr C. Dr C did not make any record of the procedure, but the handwritten operative documentation by neurosurgical registrar Dr D describes the operation as a 'right pterional[5]/subfrontal[6] approach for craniopharyngioma'. The note does not state whether a sample of the tumour was taken for histological analysis, and there is no histology report from the surgery (that is, pathological analysis of the tumour). The operative note indicates that fluid was drained when the tumour cyst wall was opened, but there is no description of having visualised any solid component of the tumour or whether any debulking of the tumour was able to be undertaken.

5. In response to my provisional decision and in relation to the operation, Dr C clarified to HDC that he drained the cyst and established a macroscopic diagnosis (that is, he made a diagnosis through observation). Dr C stated that, as the lesion was 'mostly cystic'[7] and the cyst had completely collapsed when the fluid inside went through the suction, there was no

[1] Located in the base of the brain and responsible for excreting hormones into the bloodstream.
[2] It causes both hormonal abnormalities and visual disturbances by pressing on parts of the optic nerve.
[3] A surgical operation in which a bone flap is temporarily removed from the skull to access the brain.
[4] Reduction of as much of the bulk of a tumour as possible, without the intention of complete eradication.
[5] The area on the side of the skull where the frontal, parietal, temporal, and sphenoid bones join.
[6] The area below the frontal bone.
[7] Meaning that it was filled with fluid as opposed to solid tissue.

obvious cyst wall to biopsy. Further, he made a clinical decision that the safest option was to not take a biopsy, noting that the available tissues were stuck to important structures that would have been at risk if he had tried to obtain biopsy tissue. A postoperative CT scan taken on 17 September 2019 reported a reduction in the size of the tumour. A neuro-oncology multidisciplinary meeting (MDM) held on 24 September 2019 proposed an MRI in three months' time, with consideration for radiation oncology referral after that.

6. On 25 October 2019, an endocrinology review indicated that Mr A had postoperative diabetes insipidus[8] that could be permanent. An ophthalmology review on 29 October 2019 indicated an improvement in Mr A's visual fields following the surgery.

Presentation to Emergency Department

7. On 13 January 2020, Mr A presented to Hospital A's Emergency Department (ED) with headaches and visual deterioration. An MRI scan showed that the tumour was similar in size to that prior to the September 2019 surgery.

8. Mr A was transferred to a major tertiary hospital (Hospital B's) neurosurgical unit, where neurosurgeon Dr E inserted an Ommaya reservoir[9] into the tumour. Mr A was then transferred back to Hospital A for ongoing care.

Referral for MRI and radiation oncology

9. Health NZ Southern stated that its patient management system shows that a referral for Mr A to radiation oncology[10] (for consideration of radiation therapy) was created on 27 January 2020 and appears to have come from Hospital B. The referral was accepted on 3 February 2020 but then closed on 5 February 2020. Health NZ Southern stated that the referral was made in error and closed two days later (pending a neuro-oncology MDM in the first instance, which would result in a re-referral for radiation oncology if required).

10. Mr A's case was discussed at the Southern neuro-oncology MDM on 11 February 2020. It was noted that no histology could be found from a specimen taken on 16 September 2019. The plan from the MDM was for an MRI scan followed by a referral to radiation oncology.

11. However, neither the MRI scan nor the referral were undertaken at this time. Health NZ Southern told HDC that this was due to a misunderstanding between the neurosurgery and radiation oncology services. Specifically, neurosurgery believed that a referral had already been made, whereas radiation oncology was under the impression that an MDM would occur first, with a possibility of re-referral if required. However, because the referral had been closed on the patient management system, radiation oncology was unaware that Mr A was on its wait list. On 12 February 2020, Dr B again reviewed Mr A and contacted Dr C about the need for further imaging and consideration of whether radiotherapy would be appropriate.

12. On 7 April 2020 (during the first COVID-19 lockdown), Dr D from neurosurgery called Mr A. As Mr A was based in the North Island at this time, he was advised to contact Hospital C if

[8] Production of large amounts of diluted urine, which is a common complication after pituitary tumour surgery.
[9] A small device used to deliver medication directly into the fluid surrounding the brain and spinal cord.
[10] A service that involves the use of radiotherapy on the tumour (which is the standard treatment pathway for craniopharyngiomas that cannot be removed completely by surgery).

he had concerns. No arrangements for imaging or referral to radiation oncology were made, and it is not clear from Dr D's reporting letter whether any neurosurgical follow-up was planned.

13. On 16 April 2020, Dr B re-reviewed Mr A via telephone and documented that he was doing 'very well' from an endocrine point of view. On 17 April 2020, Dr B contacted Dr C, noting that consideration of ongoing imaging remained with Dr C.

Further admissions to Hospital A

14. On 20 July 2020, Mr A (who by this time had returned to live in the South Island) presented to Hospital A with headaches and was admitted to Hospital A under the neurosurgery service. Dr C performed an aspiration of the Ommaya reservoir as a day case. There is no record of any imaging to assess the size of the tumour at that time. In response to the provisional decision, Dr C submitted that further imaging was not required (on 20 July 2020) as Mr A's 'cyst was not increasing rapidly',[11] and a permanent shunt of the cyst[12] was not required.[13]

15. In addition, Dr C stated that 4mL of cystic fluid was aspirated and Mr A's symptoms resolved. The follow-up arrangements included an outpatient appointment with neurosurgery in three months' time and twice-yearly optometry appointments. However, there is no mention of a referral for consideration of radiotherapy. On 22 July 2020, Dr B contacted Dr C again, requesting follow-up by neurosurgery. On 15 January 2021, Mr A was re-admitted to Hospital A with deterioration of his vision. An MRI revealed possible progression of the tumour, and he was transferred directly to the Hospital B neurosurgery service. On 22 January 2021, Dr E performed a craniotomy and debulked the tumour (noting that cystic and solid components were found). Total resection was not possible, and subsequent histological analysis confirmed a craniopharyngioma.

16. Mr A's case was discussed at neuro-oncology MDMs in Hospital A on 9 February 2021 and in Hospital B on 11 February 2021. He was referred for radiation therapy and underwent treatment between 16 June and 27 July 2021.

17. Follow-up with the ophthalmology service on 20 May 2022 indicated that Mr A had been left with optic atrophy (wasting of the optic nerves) and hemianopia (loss of half of the field of vision).

ACC expert advice

18. In August 2022, ACC approved a treatment injury claim for '[c]ompression of the optic nerve secondary to tumour growth, leading to visual disturbance'.[14] In making this decision, ACC obtained external advice from neurosurgeon Dr F, who stated that the standard treatment pathway for craniopharyngiomas that are not fully resectable is surgical debulking and a

[11] Dr C submitted that, as Mr A had only two aspirations over the year preceding the insertion on 16 January 2020, this demonstrated that the cyst was not increasing rapidly.
[12] A surgical procedure to implant a drainage system to relieve pressure by rerouting fluid.
[13] Dr C stated that, even with patients who have had radiotherapy for craniopharyngiomas, the cystic parts grow as the solid components of the tumour become cystic, and aspiration is still needed for long-term control of the cyst. Dr C submitted that, at this time, aspiration had not become more frequent for Mr A.
[14] ACC determined that the date of the treatment injury was 21 December 2020.

biopsy, followed by radiotherapy. Dr F said that observation is generally 'only an option reserved for lesions where a complete resection has been achieved, and so it is unusual not to irradiate post-operatively'.

19. Dr F expressed concern that although the first operation in September 2019 was successful in improving Mr A's visual function and deflating the tumour cyst, it failed to achieve the other objective of obtaining a tissue diagnosis. He also noted that if there was no contemporaneous operation note from Dr C, then that would be below the accepted standard of neurosurgical care.

20. Dr F's opinion was that, had Mr A undergone radiation after his 2019 surgery, it is highly likely he would have avoided the need for a further craniotomy in 2021. Dr F considered it likely that the prolonged period of ongoing compression of Mr A's optic nerves during 2020 negatively impacted on the prognosis of his long-term visual function.

21. Dr F advised that there was a failure to refer Mr A for consideration of radiotherapy following the Hospital A neuro-oncology MDM on 11 February 2020. Dr F stated:

> 'The failure to refer for consideration of further treatment at that time is an omission in the treatment pathway that has resulted in a treatment injury and is below the standard of care.'

22. Dr F said there were further opportunities for referral to radiotherapy when Mr A was in direct contact with the Neurosurgery Department in Hospital A. One was the neurosurgical follow-up on 7 April 2020, and another was when Mr A was admitted to the neurosurgical ward under Dr C on 20 July 2020 for aspiration of the Ommaya reservoir to relieve Mr A's headaches. Dr F said it is unclear whether any imaging was undertaken to assess the size of the cyst at that time. However, his opinion was that the presentation with headaches and the need for cyst aspiration should have raised suspicion that the cyst was re-collecting and that the tumour was not under control, and that should have prompted re-imaging and most likely a referral to radiation oncology.

23. Dr F identified six opportunities for Mr A to be referred for radiotherapy, but the opportunity to consider radiotherapy earlier in his treatment pathway was not provided to him, and therefore he was unable to make an informed choice about his treatment options.

Adverse event review

24. In October 2022, Health NZ Southern completed an Adverse Event Review (AER). Health NZ Southern identified that it was 20 months from the time of the initial MDM discussion that mentioned radiotherapy until that treatment commenced. Health NZ Southern acknowledged that Mr A's tumour regrew as a consequence of the delay in receiving the recommended treatment, resulting in the need for further surgery.

25. In addition, the AER found that the MDM plans of 24 September 2019 and 11 February 2020 for a follow-up MRI scan followed by referral for radiation therapy were not implemented. Health NZ Southern stated that the Hospital A Neurosurgery Department was not involved in each episode of care, and there was a misunderstanding as to who would enact the MDM recommendations.

26. Mr A was treated by neurosurgical services in two different centres across Health NZ, which the AER stated would have contributed to a breakdown in communication. The AER noted that, to ensure continuity of care, it is critical that the same information exists in the physical records of both units.

27. The AER also noted that, although the MDM meeting notes included actions and responsibilities, there is no record of whether those actions were carried out. The AER concluded that, as the MDM notes were electronic, the omissions that occurred may not have been noticed and corrected at subsequent follow-up clinic assessments as they were not included in Mr A's physical clinical records. There was no documentation of radiation therapy having been planned or arranged by any of the services involved in Mr A's care, and, as a result, he did not receive the planned radiation treatment at the optimal time.

28. Health NZ Southern made the following recommendations in the AER report:

a) That the MDM process be reviewed with the aim to ensure that the decisions made are actioned.

b) That the appointment of a neurosurgical clinical nurse specialist be investigated with urgency.

c) That MDM participants are reminded that the overall responsibility to ensure that agreed actions are carried out remain with the named lead clinician (noting that tasks can be delegated but not overall responsibility).

d) That the process to inform patients of their plan of care is reviewed to ensure that they can participate in their care. This is to include giving them relevant written information.

Agreed breach

29. Health NZ Southern accepted that it breached Right 4(1) of the Code of Health and Disability Services Consumers' Rights (the Code),[15] in that the systemic failures outlined above caused a delay in care being delivered to Mr A.

Responses to provisional opinion

Mr A

30. Mr A was provided with an opportunity to comment on relevant sections of the provisional decision and stated that he had no comments to make.

Health NZ Southern

31. Health NZ Southern was provided with an opportunity to comment on the provisional decision and stated that it accepted all my recommendations.

Dr C

32. Dr C was provided with an opportunity to comment on relevant sections of the provisional decision, and those comments have been incorporated into this report where appropriate.

[15] Right 4(1) of the Code states: 'Every consumer has the right to have services provided with reasonable care and skill.'

Opinion: Health NZ Southern — breach

33. As the above chronology and background outlines, it was anticipated at the Southern neuro-oncology MDM on 11 February 2020 that following an MRI, Mr A would be referred to radiation oncology for consideration of radiotherapy. However, neither the MRI nor the referral occurred at that time, and, despite multiple opportunities to action referral to radiation oncology, this occurred only in February 2021, with treatment commencing in June 2021 — a referral delay of 12 months.

34. Dr F advised ACC that the standard treatment pathway for craniopharyngiomas that are not fully resectable is surgical debulking and biopsy, followed by radiotherapy, and it is unusual not to irradiate postoperatively. He stated:

> 'The failure to refer for consideration of further treatment at that time is an omission in the treatment pathway that has resulted in a treatment injury and is below the standard of care.'

35. I consider that Dr F's advice is consistent with the findings of Health NZ Southern's AER. I also consider that, in this instance, predominantly it was systems issues that led to the failure to refer, specifically, a failure of the referral process (miscommunications across services as to who had responsibility for follow-up, and inadequate systems to monitor whether actions arising out of MDMs were completed), and lost opportunities to correct the errors.

36. I am satisfied that several opportunities existed for recognition that the referral to radiation oncology had not occurred, including contact with the neurosurgical team on 7 April and 20 July 2020, although a critical communication error also occurred after the first MDM.

37. In my view, failures at a systems level led to the breakdown in communication between services regarding Mr A's need for radiotherapy, which ultimately led to a delay in referral and treatment. Under Right 4(1), every consumer has the right to have services provided with reasonable care and skill, and the delays in this matter fell below the expected standard of care. Therefore, I find that Health NZ Southern failed to provide services to Mr A with reasonable care and skill and breached Right 4(1) of the Code.

Changes made

38. Health NZ Southern told HDC that it 'sincerely apologise[s]' to Mr A for the 'significant system failure' in this case. Health NZ Southern acknowledged that the delay in accessing radiation therapy 'added significant stress' to Mr A and his family. Health NZ Southern stated that, since these events, it has made the following changes:

a) Introduced MDM coordinators,[16] whose role includes the taking of the meeting minutes and then uploading decisions to a patient's file. This process has also been adopted for all other services. In addition, Health NZ stated that the terms of reference for the Oncology MDM are well defined and clear in their expectations of all participants in the meeting, as are referral guidelines that are documented for the MDM;

[16] Health NZ Southern stated that they are not clinical personnel but provide administrative support to frontline clinical staff.

b) Created a position in the oncology service for a nurse navigator who manages patients on the wait list who have yet to be seen at a first specialist appointment for the oncology service. However, Health NZ Southern stated that there is no nurse navigator role at Hospital A;

c) Trialled the position of a neurosurgical clinical nurse specialist, but ongoing funding is not currently available;[17]

d) All postoperative notes from neurosurgery are now recorded electronically, including postoperative instructions. Health NZ Southern stated that this process was audited in July 2024, and 19 of 19 patients had postoperative notes and instructions available electronically;[18]

e) The findings of the AER report were shared with the participants of the MDMs at the time and have been shared subsequently; and

f) There is now a combined patient management system (SI PICS) for two Health NZ Southern sites, and there is a plan for a third Health NZ site to be added. This means that all referrals and waitlists are kept in one system. Referrals can be seen in both SI PICS and the clinical intranet (HCS), which will enhance patient safety.

Recommendations and follow-up actions

39. I recommend that Health NZ Southern:

a) Provide a written apology to Mr A for the breach of Right 4(1) of the Code. The apology is to be sent to HDC within three weeks of the date of this report, for forwarding to Mr A;

b) Review the referral process not just to the MDMs but following the MDMs to ensure that clinicians understand which service has responsibility for making the referral, and that appropriate systems are in place to ensure follow-up of such referrals. This recommendation is intended to mitigate the possibility that referrals proposed within the MDM process are not actioned or otherwise fall through the cracks. Health NZ Southern is to report to HDC on the findings of its review and the steps undertaken within three months of the date of this report;

c) Further consider the appointment of a neurosurgical clinical nurse specialist, and, in the event that funding barriers remain, Health NZ Southern is to report to HDC on likely timeframes for when this position may be feasible, within three months of the date of this report; and

d) Further consider how patients in the neurosurgical service can be better informed of their plan of care so that they can be partners in their care (and therefore enabled to be their own advocates). Health NZ is to report back to HDC on the findings of its consideration and the steps undertaken, within three months of the date of this report.

[17] Health NZ Southern stated that this position would be of 'considerable value' to the neurosurgical service, and it will request funding for this position when the budget is available.

[18] I note that the operation note in this case was the subject of criticism by Dr F. I am satisfied that this improvement will reasonably address the concerns raised.

40. A copy of this report with details identifying the parties removed, except Health NZ Southern, will be sent to the Health Quality & Safety Commission Te Tāhū Hauora, the Neurological Association of New Zealand, and the Royal Australasian College of Surgeons and will be placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Morag McDowell
Health and Disability Commissioner