Canterbury District Health Board

General Practitioner, Dr B

Medical Centre

A Report by the

Deputy Health and Disability Commissioner

(Case 19HDC01327)

Health and Disability Commissioner

Te Toihau Hauora, Hauātanga

Contents

Executive summary 1
Complaint and investigation 2
Information gathered during investigation 3
Opinion: CDHB — breach 12
Opinion: Dr B — breach 15
Opinion: RN E — adverse comment 16
Opinion: Medical Centre 4 — no breach 17
Changes made by CDHB 17
Recommendations 18
Follow-up actions 19
Appendix A: Clinical advice to Commissioner 20
Appendix B: Independent clinical advice to Commissioner 33

Executive summary

1. This report concerns the care provided to a woman at different points between 2010 and 2018, and the delay in her diagnosis of multiple sclerosis (MS).

2. In 2010, the woman was referred by her GP to the ophthalmology service at the public hospital with sudden and unexplained vision loss. The woman was diagnosed with demyelinating optic neuritis (inflammation of the optic nerve, which is often associated with MS).

3. The woman had an MRI, which confirmed the optic neuritis and also noted several areas of abnormal white matter lesions in the brain, raising the possibility of primary demyelination.

4. In 2011, the woman was referred to the neurology service for further clinical assessment, and was prioritised as "semi-urgent". However, due to limitations on resources, the referral was declined and the woman was not seen by the neurology service.

5. In 2015, the woman presented to Dr B with tingling in her left arm and leg, which had caused her to fall over on a number of occasions. The provisional diagnosis was a mini-stroke, or possibly an inflammatory disorder. He ordered a number of screening tests, but did not refer the woman for specialist assessment by a neurologist, or put in place a management plan to provide her with any follow-up advice or structured review following receipt of the results.

6. In 2018, the woman presented to her medical centre. She vomited and collapsed at the front door of the medical practice, and was seen by a GP. The GP's impression was that the woman had a migraine and an inner-ear disorder, which is the most common cause of vertigo.

7. A few days later, the woman called the medical centre as she had been experiencing double vision and was unable to focus, which had resulted in a headache. She spoke to a nurse, but the clinical records do not indicate whether the nurse discussed the telephone call with the GP, or what actions she took after her telephone call with the woman.

8. In 2019, the woman presented to the medical centre again with worsening vision in her right eye, a tingling sensation in her legs and arms, and numbness in her left arm. On this occasion, she was seen by a GP, who found clinical documentation from 2011 noting that the woman's MRI had shown features consistent with demyelination. The woman was then urgently referred to the neurology service and was diagnosed with MS.

Findings

9. The Deputy Commissioner found that by failing to review the woman in the context of the information available to Canterbury District Health Board at the time, and by triaging the woman as "semi-urgent" but effectively declining her referral without adequate safety-netting advice to the woman (and her GP), or informing the referrer, CDHB did not provide the woman services with reasonable care and skill, in breach of Right 4(1) of the Code. While

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

acknowledging the extraordinary circumstances that faced CDHB following the earthquake in 2011 and the resource constraints that followed, the Deputy Commissioner considered that it was not reasonable for the woman's neurology referral to have been declined without any further advice being offered.

10. The Deputy Commissioner also considered that CDHB did not provide the woman with adequate information about her condition and the possibility that she might have MS, and found CDHB in breach of Right 6(1) of the Code.

11. The Deputy Commissioner considered that Dr B ought to have referred the woman for specialist assessment by a neurologist, and should have had in place a follow-up action plan. The Deputy Commissioner found the GP in breach of Right 4(1) of the Code.

12. The Deputy Commissioner found that the medical centre did not breach the Code, but she made adverse comment about the nurse's lack of documentation of discussions and actions taken following her telephone call with the woman on 3 April 2018.

Recommendations

13. The Deputy Commissioner recommended that CDHB provide a formal written apology to the woman for the deficiencies in care outlined in this report, and use the report as a basis for staff learning at CDHB.

14. As Dr B has retired from practice, the Deputy Commissioner recommended that he provide a formal written apology to the woman for the deficiencies in care outlined in this report.

15. The Deputy Commissioner recommended that the nurse undertake training on documentation.

Complaint and investigation

16. The Health and Disability Commissioner (HDC) received a complaint from Ms A about the services provided by Canterbury District Health Board (CDHB), Dr B, and Medical Centre 4.

17. Other providers were involved in the preliminary assessment of this complaint, but the concerns relating to them were resolved by other resolution pathways. These matters are not discussed in the report.

18. The following issues were identified for investigation:

- *Whether Canterbury District Health Board provided Ms A with an appropriate standard of care in 2010 and 2011.*
- *Whether Dr B provided Ms A with an appropriate standard of care in June 2015.*

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

- *Whether Medical Centre 4 provided Ms A with an appropriate standard of care in June 2015, and during March 2018 and April 2018.*

19. This report is the opinion of Deputy Commissioner Vanessa Caldwell, and is made in accordance with the power delegated to her by the Commissioner.

20. The parties directly involved in the investigation were:

Ms A	Consumer
CDHB	Provider
Dr B	Provider/general practitioner (GP)
Medical Centre 4	Provider/general practice

21. Further information was received from:

Dr D	Provider/GP
Medical Centre 1	Provider/general practice
Dr C	Provider/GP
RN E	Provider/registered nurse
Accident Compensation Corporation (ACC)	

22. Also mentioned in this report:

Dr F	General practitioner
Dr G	Ophthalmologist

23. In-house expert advice was obtained from GP Dr David Maplesden (Appendix A), and independent expert advice was obtained from a neurologist, Dr David Hutchinson (Appendix B).

Information gathered during investigation

Introduction

24. This report discusses the care provided to Ms A at different points from 2010 to 2018 by CDHB, Dr B, and Medical Centre 4. The concerns relate to a delayed diagnosis of multiple sclerosis (MS).[1]

25. The care provided to Ms A from 2012 to 2015, and from 2016 to 2017 is not discussed in this report as no concerns were identified during these intervening years.

[1] A chronic autoimmune disorder that affects movement, sensation, and bodily functions. It is caused by destruction of the myelin insulation that covers the nerve fibres (neurons) in the central nervous system (brain and spinal cord).

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Care provided during 2010 and 2011

26. On 30 September 2010, Ms A presented to her GP, Dr D of Medical Centre 1,[2] with a complaint of sudden and unexplained vision loss. Ms A was in her early twenties at that time. Dr D referred Ms A to the ophthalmology service (CDHB) on the same day.

Reviews by ophthalmology service — September 2010–February 2011

27. Ms A was seen by the ophthalmology service on the same day (30 September 2010), and was diagnosed with demyelinating[3] optic neuritis (inflammation of the optic nerve, which is often associated with MS) in her right eye. Steroid treatment was provided, and an MRI[4] was scheduled. Ms A was to be reviewed by the ophthalmology service again one week later.

28. On 5 October 2010, Ms A saw an ophthalmologist, Dr G. After the appointment, Dr G wrote to Dr D to advise of Ms A's diagnosis. He also advised Dr D that there was a connection between optic neuritis and MS, and that Ms A was having an MRI that evening. Ms A was to be reviewed by the ophthalmology service two weeks later.

29. The MRI confirmed Ms A's diagnosis of optic neuritis, and also noted several areas of abnormal myelination in the brain (white matter lesions), raising the possibility of primary demyelination.[5] The reporting radiologist suggested further clinical assessment by a neurologist.

30. CDHB said that an appointment was made for Ms A on 2 November 2010, but she did not attend. Ms A has no recollection of this appointment having been made for her, and said that she would not have dismissed the appointment after having undergone an MRI.

31. Ms A then attended an appointment with Dr G on 8 February 2011. The clinical records do not indicate what was discussed during the appointment. Ms A and CDHB have different accounts of what was discussed. The Clinical Director of Ophthalmology at CDHB said:

> "The letters written by the Ophthalmology Consultant [Dr G] both after the initial presentation in October and after [Ms A's] review appointment in February mention the association between MS and optic neuritis. It is almost certain this association was communicated to the patient by the consultant, as well as an explanation that the MRI scan was being requested to look for causes of the optic neuritis such as MS. I would also expect that during the February 2011 appointment the consultant would have explained to the patient that the MRI scan had some abnormalities, which could fit with MS, but that the neurology team would review the scan and contact the patient for review. She would also have been told that optic neuritis can recur and [a]ffect the

---

[2] The Deputy Commissioner has concluded her assessment of the complaint as it relates to Dr D and Medical Centre 1.

[3] Demyelination is a degenerative process that erodes the covering of nerve fibres. Demyelination is seen in a number of diseases, particularly MS.

[4] Magnetic Resonance Imaging (a procedure used to create pictures of areas inside the body).

[5] Demyelination can result from various medical conditions, including MS. MS is the most common demyelinating condition. Dr Hutchinson advised that the use of the word "demyelination" in the MRI report has a similar meaning to the term "multiple sclerosis".

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

other eye and if there was a further change in vision she should present to her GP for a new referral to the Eye Department."

32. Ms A said that the seriousness of the optic neuritis and its connection to possible MS was never fully explained to her at the appointment on 8 February 2011, and as far as she was aware, this was a follow-up appointment in relation to her optic neuritis.

Referral to neurology service — February 2011

33. On 9 February 2011, Dr G referred Ms A to the CDHB neurology service. In the referral, Dr G advised the neurology service of Ms A's family history of MS. Dr G also noted Ms A's diagnosis with demyelinating optic neuritis, and enclosed a copy of the MRI report. The referral noted that Ms A's vision in her right eye had improved, and stated: "I think [Ms A] would benefit from your review and discussion about her situation and possible treatment options with further events." Dr G also advised the neurology service that he had not arranged for Ms A to have any further follow-up appointments with the ophthalmology service.

34. The letter of 9 February 2011 was copied to Ms A's GP, Dr D. Dr D recorded Ms A's diagnosis of "Optic Neuritis" in the clinical records on 17 February 2011, and noted: "[R]ight sided, resolved. Referred Neurology."

35. On 22 February 2011, Christchurch was struck by a severe earthquake, which CDHB said resulted in a "shut-down" of all outpatient services. CDHB explained that at that time, there were only two neurology registrars, and the acute and inpatient demands meant that the registrars were unable to contribute significantly to non-acute outpatient activity.

Referral to neurology service declined — March 2011

36. On 3 March 2011, CDHB wrote a letter to Ms A, copied to Medical Centre 1, acknowledging the referral. The letter stated:

> "Based on the information provided in the referral letter, you have been prioritised to a Semi Urgent category. This means that we are not able to offer you an appointment with the specialist at this time. While the preference of your family doctor and the department is to see you now, limitations on our resources mean that it is not possible to do so.
>
> Therefore, we are advising that you remain under the care of your family doctor. Your name will not appear on the active list for an appointment, however your referral details will be held on hospital records.
>
> If your condition changes or you wish to discuss your options for management of your condition, please contact your family doctor. Your family doctor may ask you to make an appointment for a consultation with them.
>
> Your doctor will contact us if a review of your priority is required."

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

37. CDHB explained that in 2011, neurology referrals were triaged in accordance with clinical priority, under the categories "acute", "urgent", "semi-urgent", and "routine". CDHB said that "urgent" patients could not be managed in primary care without timely specialist services, and they were always offered a first specialist assessment.

38. CDHB advised that the outcome for "semi-urgent" patients depended on the waiting list status at the time, which meant that the triaging neurologist could not be certain whether these patients would be offered an appointment. CDHB said that the category for "semi-urgent" patients (such as Ms A) became a category that was considered "nice to have" an appointment, rather than "absolutely essential".

39. The letter sent to Ms A (and copied to her GP) did not outline safety-netting advice such as symptoms to be alert to, or advice for the GP on when to re-refer. CDHB said that in 2011, the Neurology Department did not provide routine written advice to GPs, and "this was not explicitly considered to be part of the neurologists' job description". CDHB stated that the "focus was on maximising the time that neurologists were available to provide face-to-face clinical consultations only".

Transfer of medical records

40. Ms A's file was transferred from Medical Centre 1 to Medical Centre 2 on 19 January 2012. On 26 June 2013, Ms A's medical records were transferred to Medical Centre 3, which subsequently was sold to Medical Centre 4.

Care provided during 2015

Dr B

41. Dr B was not Ms A's regular doctor, and saw Ms A on only two occasions. Ms A first saw Dr B at Medical Centre 3 on 12 September 2013 for a repeat prescription.

42. On 17 June 2015, Ms A presented to Dr B with tingling in her left arm and leg, which had caused her to fall over on five different occasions.

43. Dr B recorded no abnormal findings and noted that Ms A's blood pressure and pulse were normal. Dr B cannot recall any discussion with Ms A about her clinical history of optic neuritis, or an abnormal MRI, and cannot recall seeing any reference to this in Ms A's clinical notes.

44. Dr B said that his provisional diagnosis was that Ms A had a condition that may have triggered temporary symptoms, such as a mini-stroke (TIA),[6] or possibly an inflammatory disorder. Dr B stated that as Ms A's examination had been normal, he considered it prudent to order a number of screening tests to provide further evidence, or not, of the provisional diagnosis. Dr B ordered blood tests, the results of which were normal.

45. Dr B said that although there are no records to support this, his normal practice would have been to advise Ms A either to call the medical centre for the test results, or to make an

[6] Transient Ischaemic Attack is a brief, stroke-like attack that, despite resolving within minutes to hours, still requires immediate medical attention to distinguish it from an actual stroke.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

appointment for further review by her regular doctor. Dr B stated that he would also have advised Ms A to return to the medical centre if she had any further symptoms or concerns.

46. Dr B did not refer Ms A for specialist assessment by a neurologist, or put in place a management plan to provide Ms A with any follow-up advice or structured review following receipt of the results.

47. There is no record to suggest that Dr B advised Ms A to stop the oral contraceptives she was taking at that time.

48. Dr B has retired from practice.

Care provided during 2018

Dr C

49. On 31 March 2018, Ms A presented to Medical Centre 4 (formerly Medical Centre 3) and collapsed and vomited at the front door. She was seen by Dr C, who was not her regular GP and who saw her only on this one occasion.

50. Dr C documented in the clinical records that Ms A had started to experience severe headaches the previous day, and that she had associated sensitivity to light and nausea. He noted that Ms A had ongoing vomiting and felt a "room spinning sensation". Dr C also noted that Ms A had significant involuntary eye movement (lateral nystagmus), but her vital observations were within the normal range.[7]

51. Dr C's impression was that Ms A was suffering from a vestibular migraine, which is a nervous system problem in which patients experience a prolonged (up to 72 hours) positional vertigo.[8]

52. Medications were administered to Ms A to treat her nausea and vomiting (Stemetil), pain (diclofenac), and headaches/migraines (Rizamelt).

53. Dr C reviewed Ms A 45 minutes later and noted that she had ongoing vomiting and still had a "room spinning sensation". Ms A also still had involuntary eye movement, but her headache was slightly better. Dr C's impression was that Ms A had a migraine and BPPV (benign paroxysmal positional vertigo) — an inner-ear disorder that is the most common cause of vertigo.

54. Dr C performed the Epley manoeuvre (an exercise that helps to treat the symptoms of vertigo), and advised Ms A to rest for another hour. After an hour, Dr C reviewed Ms A again and noted that she was feeling a lot better and she had had some sleep. Dr C provided Ms A with instructions on how to perform the Epley manoeuvre at home, and prescribed Rizamelt and Stemetil.

[7] Temperature 36.6°C, blood pressure 110/80mmHg, heart rate 59 beats per minute.
[8] A sudden internal or external spinning sensation.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

55. Dr C said that Ms A's symptoms were not typical "MS relapse" symptoms. He stated that MS was not considered, and would be an extremely rare initial diagnosis, unless he had been aware of Ms A's MS history or optic neuritis history.

56. Dr C said that at that time, Ms A had no diagnosis of MS, and her clinical records went back only as far as 2012, when they were transferred to Medical Centre 4 by Ms A's former medical practice. Dr C stated that Ms A's optic neuritis occurred during 2010 and 2011 and, although this was deemed to be a significant event, there was no "classification" from her previous medical centre. Dr C said that he could access all of Ms A's medical records via an online portal, but this was not his routine practice unless the presentation was "very complex".

Call with practice nurse, RN E

57. On 3 April 2018, Ms A called Medical Centre 4 and spoke to the practice nurse, RN E. Ms A wanted to speak with Dr C to find out when she could expect her vision to improve, as she was experiencing double vision and was unable to focus, which resulted in a headache. Ms A said that she was still experiencing nausea, but no vomiting, and she had abdominal pain.

58. While there is a record of this telephone conversation in Ms A's clinical notes, there are no notes to indicate whether RN E discussed the telephone call with Dr C, or what actions RN E took after her telephone call with Ms A.

59. RN E said that as she did not document what actions she took, she can only assume what she may have done based on her usual practice. RN E stated that it is possible that she had a conversation with Dr C at the time of the telephone call, and that she immediately provided Ms A with advice, but then failed to record this. RN E said that alternatively, she may have printed the note of her telephone call with Ms A and handed it to Dr C, who could have advised that he would give Ms A a call.

60. RN E said that based on her prior work experience in an after-hours clinic, she believes that she would have advised Ms A to seek GP review and further follow-up care.

61. Dr C said that he does not have a clear recollection of events, but he vaguely recalls RN E speaking to him about Ms A's telephone call. He recalls informing RN E that it is not typical for a migraine to last so long, and that as Ms A had "new neurology", she would need to be seen. He said that given the time of day, RN E would likely have offered a next available appointment, or advised Ms A to go to the ED. There is no documentation to confirm this, but Dr C said that this was their usual practice.

62. Ms A told HDC that she was "never told to come back", otherwise she would have done so. Ms A stated: "I remember specifically being told vertigo is one of those things that can't be treated and was told to google exercises that can help ..." In response to the provisional opinion, Ms A maintained that during the telephone call there was no mention that it was not typical for a migraine to last so long, and that she had "new neurology" and would need to be seen. Ms A stated that she clearly recalls being advised that vertigo cannot be treated, and that she was to continue with the exercises.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

63. On 7 April 2018, the duty doctor at Medical Centre 4 noted in the clinical records: "[Ms A] needs review if limited improvement next 48 hours or sooner if ongoing concerns. BPPV as below …"

Diagnosis

64. On 28 June 2019, Ms A presented to Medical Centre 4 with worsening vision in her right eye, a tingling sensation in her legs and arms, and numbness in her left arm for the past 24 hours.

65. Ms A was reviewed by Dr F. During the consultation, Dr F asked Ms A about any previous "unusual" symptoms. Dr F said that Ms A reported several episodes of dizziness and headache symptoms. She also had a vague recollection of having lost her vision, but she could not recall this clearly as it had been such a long time ago (referring to Ms A's diagnosis with optic neuritis in 2010).

66. Dr F said that he "scanned back" through Ms A's recent medical records and, as the reported loss of vision "intrigued" him, he also reviewed Ms A's earlier medical records (i.e., records older than 2012). Dr F stated that this was when he came across the letter of 9 February 2011 from Dr G to the neurology service, which noted that Ms A's MRI had shown features consistent with demyelination.

67. Dr F said that based on this information, he concluded that a diagnosis of MS was a significant possibility, and he referred Ms A urgently to the neurology service at CDHB.

68. Ms A was diagnosed with MS on 12 July 2019.

Further information

Ms A

69. Ms A said that the emotional and physical symptoms from the delayed diagnosis with MS have had a great impact on her and her family. She stated that her MS has progressed as a result of not having received the necessary treatment, and she has lost "a lot of use" in her left hand. Ms A said that she cannot perform normal daily tasks, and her work has also suffered. Ms A stated that this has changed her life "completely" and has "affected [her] life greatly".

ACC

70. ACC obtained external clinical advice from a GP on Ms A's treatment injury claim.

71. The GP advised that the clinical management of Ms A in June 2015 by Dr B was inadequate. The GP stated:

> "If TIAs were confirmed [Ms A] should not have been given the oral contraceptive. Having an unexplained neurological disorder warrants further investigation … At least an urgent phone call to Neurology would have allowed discussion and a management plan could have been organised. Consideration of epilepsy, or multiple sclerosis would have been my differential diagnoses."

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

72. The GP also advised that "if TIA was considered a possibility, urgent discussion with neurology and referral should have taken place".

Dr B

73. Dr B said that he has reflected on this case and concluded that his assessment and management of Ms A was not up to the standard he expected of himself.

74. Dr B stated that at that time, he was overly committed with a number of governance positions, and there were periods of a heavy clinical workload. Dr B said that while these additional commitments had largely ceased by 2014, they had taken their toll on him personally. Dr B explained that around the time of Ms A's consultation with him, consultations for the medical practice to be sold were under way and subsequent arrangements were made for the staff to be moved to new premises.

75. Dr B told HDC that at the time of his consultation with Ms A, he was having difficulty dealing with the "change in philosophy" of how the new practice owners wished the practice to be managed. He recalls that it was an "extremely stressful" period in his life. He said that he also had increasing health issues, which eventually led to his decision to retire from medical practice.

76. Dr B stated that he does not offer this information as an excuse, and passed on his sincere regrets and apologies to Ms A.

Dr C

77. Dr C told HDC that in light of this case, he has taken the opportunity to revise his knowledge of vertigo and migraines. He said that he has also been reminded of how important it is to keep more detailed notes and to document safety-netting advice, and has changed his practice to document negative findings.

CDHB

78. CDHB accepted that in 2011, no follow-up from the neurology service was initiated. CDHB acknowledged that the lack of referral had an impact on Ms A and the care she received, and apologised to Ms A for the breakdown in communication that occurred.

79. CDHB also said that it considers that the letter dated 3 March 2011 that was sent to Ms A and her GP was appropriate safety-netting. It considers that it would have increased the burden on resources to keep Ms A within the ophthalmology system, especially as there were no further services or investigations that ophthalmology could provide to Ms A.

80. CDHB said that it was only because of resource availability that Ms A was not seen by the neurology service. CDHB stated that if the neurology service had seen Ms A, it would have advised her to see her GP if any new problems arose, which effectively was the same advice that was provided in the letter to Ms A on 3 March 2011. CDHB said that in order for detailed information and advice to have been included in the letter of 3 March 2011, Ms A's clinical information and the investigations undertaken would have had to be reviewed. CDHB stated: "[T]his is more than triage, and resources at the time within the neurology department did not permit this level of detail." CDHB said that Ms A's GP was included in

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

the management plan from the ophthalmology service regarding the finding of optic neuritis, its association with MS, and the intention for Ms A to have an MRI.

CDHB — status in 2011

81. CDHB said that in 2011, waiting list management was a resource limitation issue. Appointments with the neurology service were booked based on capacity, and each appointment had a maximum waiting time of six months. CDHB stated that this was a management policy across CDHB at that time, rather than allowing "open-ended" waiting lists that could continue to expand without any time limit at all.

82. CDHB advised that the resource-constrained environment in which it (and other health services) operates must be acknowledged and given due consideration when assessing decisions around triaging and looking generally at the provision of services. It considers that in 2011 Ms A was triaged appropriately as semi-urgent, and it was unfortunate that resource constraints and the demand on the service meant that she could not be seen by one of its specialists.

83. CDHB said that in 2011, following the Christchurch earthquake, there were only two neurology registrars and four full-time senior consultant neurologists, who had relatively little support from junior staff or from specialist nursing. CDHB said that this was because of staff resourcing, and at that time there were insufficient neurologists nationwide.

84. CDHB also advised that the Christchurch earthquakes had a considerable impact on CDHB's ability to provide care in general (other than acute care), and on clinic capacity.

85. CDHB said that in 2021, it had a full-time Parkinson's disease nurse, a half-time MS nurse, and a full-time MS nurse position. It stated that when its neurology service was credentialled in July 2011, the executive summary included the following comment:

> "The provision of neurology services within the CDHB is currently impacted on by two major factors. Firstly, a currently vacant post for a [senior consultant neurologist] and secondly the effect of the Christchurch earthquakes in disrupting services to stroke patients and increasing workload in [the ward]."

86. CDHB said that it is confident that the processes the neurology service now has in place provide clear expectations for both the patient and their GP.

Responses to provisional opinion

87. CDHB was given an opportunity to respond to the sections of the provisional opinion that relate to CDHB. CDHB accepted the provisional findings.

88. Dr B was given an opportunity to respond to the sections of the provisional opinion that relate to him. He advised that he accepts that the care he provided was not up to the standard he expects of himself, and asked for his sincere regrets and apologies to be passed on to Ms A.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

89. Medical Centre 4 was given an opportunity to respond to the sections of the provisional opinion that relate to the care it provided. Medical Centre 4 advised that it accepted the findings and had no further comment to make.

90. RN E was given an opportunity to respond to the sections of the provisional opinion that relate to her. She advised that she accepts that her notes were inadequate and not up to the Nursing Council of New Zealand's standards. She stated that in future, she will endeavor to document all necessary information in an accurate and timely manner, and that she will continue to discuss new and ongoing symptoms with a GP to ensure that "no new or [unresolved] disease processes" are missed.

91. Ms A was given an opportunity to respond to the "information gathered" section of the provisional opinion, and her comments have been incorporated where relevant. She stated that there was a clear breakdown in communication and failure between the GPs and CDHB, leaving her with permanent health issues, both mentally and physically, which could have been avoided.

Opinion: CDHB — breach

92. First, I acknowledge the distress suffered by Ms A as a result of the services she received from CDHB. The possibility of MS had been raised in 2010, but the diagnosis was confirmed only nine years later in 2019. This delayed diagnosis resulted in missed opportunities for Ms A to obtain earlier treatment for her condition.

Referral management

93. In assessing whether or not the referral to the neurology service was managed adequately, I have relied on the independent clinical advice provided by neurologist Dr David Hutchinson.

94. Dr Hutchinson identified departures from the standard of care on the part of the neurology service. I have considered whether any individuals should be held to account, but conclude that because the failure was a service delivery failure, responsibility rests more appropriately with CDHB.

95. The results of the MRI on 5 October 2010 confirmed Ms A's diagnosis of optic neuritis, and also raised the possibility of primary demyelination. Dr Hutchinson advised that the use of the word "demyelination" in the MRI report has a similar meaning to the term "multiple sclerosis".

96. In Dr Hutchinson's view, the information contained in Dr G's referral letter to the neurology service dated 9 February 2011 (Ms A's age, her diagnosis with optic neuritis, her family history of MS, and the MRI result) "would lead any neurologist to be suspicious the patient had MS". Dr Hutchinson advised:

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

> "The information contained in the referral from the Ophthalmology department made it clear that [Ms A] almost certainly had either Clinically Isolated Syndrome (CIS)[9] or multiple sclerosis."

97. On 3 March 2011, CDHB wrote a letter to Ms A advising that she had been prioritised to a semi-urgent category, and that because of limitations on its resources, it could not offer her an appointment with a specialist neurologist at that time.

98. Dr Hutchinson advised:

> "In any neurology department, a substantial fraction of patients triaged as semi-urgent will have serious neurological conditions. They should be seen, or at least specific communication made with the referring doctor/general practitioner."

99. Dr Hutchinson concluded that the neurology service should have reviewed Ms A, and he considers the failure to do so to be a moderate departure from the accepted standard of care.

100. I accept Dr Hutchinson's advice, and agree that in light of the MRI result and the clinical information available at that time, Ms A should have been reviewed by the neurology service.

101. I acknowledge that due to the Christchurch earthquake, CDHB was operating in a challenging environment. However, I do not consider that it was reasonable for Ms A's neurology referral to have been declined without any further advice being offered. In my view, this was a service failure, for which ultimately CDHB was responsible.

Provision of information

102. The neurology service advised Ms A by letter dated 3 March 2011 (copied to her GP, Dr D) that it was unable to offer her an appointment. The letter contained no safety-netting advice, such as symptoms to be alert to, or advice for Ms A's GP on when Ms A should be referred back to the neurology service. The neurology service also did not inform the referrer, Dr G, that Ms A's referral had been declined.

103. Dr Hutchinson advised that "a distant second-best option" would have been for CDHB to outline Ms A's situation in its letter of 3 March 2011. Dr Hutchinson said that CDHB should have asked Ms A's GP to distinguish CIS from MS, to document the neurological examination, and to suggest that Ms A be referred back to the neurology service if, or when, MS was confirmed.

104. I accept Dr Hutchinson's advice and consider that CDHB did not take sufficient action to alert Ms A and her GP to the seriousness of her condition. I reject CDHB's submissions that the letter dated 3 March 2011 contained appropriate safety-netting advice.

[9] "CIS" refers to a first episode of neurological symptoms that lasts at least 24 hours and is caused by inflammation or demyelination (loss of the myelin that covers the nerve cells) in the central nervous system. Individuals who experience CIS may or may not go on to develop MS.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

105. If CDHB could not offer Ms A an appointment due to its resource constraints, it should have provided both Ms A and her GP with further information about Ms A's condition, and the possibility that Ms A could have MS. In my view, CDHB did not make the seriousness of Ms A's condition adequately clear in its letter to Ms A and her GP. I consider that it was reasonable for Ms A's GP to conclude that the neurology service would not have declined to see Ms A if there had been a serious issue. The letter of 3 March 2011 does not contain any specific reference to MS, or the possibility that Ms A could have MS. There was no confirmation of the diagnosis of MS, or suspected diagnosis of MS, and no management advice was provided. The possibility that Ms A could have MS was information that Ms A reasonably would have expected to receive, and this was not provided to her.

106. Further, I reject CDHB's submission that if the neurology service had seen Ms A, effectively the outcome would have been the same, as the advice provided in the letter to Ms A on 3 March 2011 was to see her GP if any new problems arose. Ms A was diagnosed with MS in 2019 following her eventual appointment with the neurology service. It therefore follows that if Ms A had had an appointment with the neurology service earlier, it is possible that she would have been diagnosed with MS at that point. An earlier diagnosis would have enabled Ms A to obtain earlier treatment for her condition.

Conclusion

107. I acknowledge the extraordinary circumstances that faced CDHB following the earthquake in 2011 and the resource constraints that resulted. That said, I do not consider that it was reasonable for Ms A's neurology referral to have been declined without any further advice being offered, and consider that the service failure on the part of CDHB was a contributing factor to the delay in Ms A receiving the neurological review and treatment she required. I find that by failing to review Ms A in the context of the information available to CDHB at the time, and by triaging Ms A as "semi-urgent" but effectively declining her referral without adequate safety-netting advice to Ms A (and her GP), or informing the referrer, CDHB breached Right 4(1)[10] of the Code of Health and Disability Services Consumers' Rights (the Code).

108. In addition, the failure to provide Ms A with information about her condition and the possibility that she could have MS resulted in a missed opportunity for her to seek further advice and treatment. I consider that CDHB failed to provide Ms A with information that a reasonable consumer in her circumstances would expect to receive and, as such, I find that CDHB breached Right 6(1)[11] of the Code.

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

[11] Right 6(1) of the Code states: "Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive."

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Opinion: Dr B — breach

109. Ms A presented to Dr B with neurological symptoms (tingling in her left arm and leg) on 17 June 2015. Dr B said that his provisional diagnosis was that Ms A had had a mini-stroke (TIA), or possibly had an inflammatory disorder. Dr B ordered a number of screening tests, but did not refer Ms A for specialist assessment by a neurologist. Dr B also did not put in place a management plan to provide Ms A with any follow-up advice or structured review following receipt of the test results, which were all normal.

110. I obtained in-house clinical advice from GP Dr David Maplesden on whether the care provided by Dr B to Ms A was reasonable.

111. Dr Maplesden advised:

> "In summary, I am mildly to moderately critical of the standard of documented assessment and the management plan, including absence of follow-up or safety-netting advice. If TIA was considered a likely diagnosis, I would be moderately critical of the failure to refer a young person with possible TIA for further specialist assessment. I would be moderately critical if [Ms A] was not advised to stop the [combined oral contraceptive] if the diagnosis of TIA was considered a possibility.[12] In the circumstances described, and without the benefit of hindsight, I am not critical that [Dr B] failed to consider a diagnosis of MS but acknowledge this was a missed opportunity to do so."

112. I accept Dr Maplesden's advice and agree that the lack of referral by Dr B was a missed opportunity for Ms A to receive specialist assessment by a neurologist. As Dr B was not aware of Ms A's history of optic neuritis at that time, I am not critical that he did not consider a diagnosis of MS. There is nothing in the clinical records to suggest that Ms A had mentioned her earlier vision loss or history of optic neuritis to Dr B. As Dr B was not aware of any of Ms A's previous neurological symptoms, there was no reason for him to review Ms A's earlier clinical records. I therefore consider that it was reasonable for Dr B not to have investigated Ms A's earlier records.

113. Dr B did, however, consider TIA as a provisional diagnosis, which required a referral for further assessment or medical review.

114. Further, Dr B should have provided Ms A with safety-netting advice and a clear management plan following receipt of the test results, which he failed to do.

115. In my view, the lack of a referral for specialist assessment by a neurologist, and the lack of a follow-up action plan, contributed to the delay in Ms A receiving the neurological review and treatment she required, and did not meet the required standard of care. Accordingly, I

[12] Prescribing a combined oral contraceptive pill is not consistent with guidelines recommending review of the use of combined oral contraceptive pills in the presence of stroke/TIA, as it is considered a condition where the theoretical or proven risks usually outweigh the advantages of using the combined oral contraceptive pill.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

consider that Dr B failed to provide services to Ms A with reasonable care and skill, in breach of Right 4(1) of the Code.

Opinion: RN E — adverse comment

116. On 3 April 2018, Ms A called Medical Centre 4 as she had been experiencing double vision and was unable to focus, which had resulted in headaches. Ms A spoke to RN E, but the clinical records do not indicate whether RN E discussed the telephone call with Dr C, or what actions RN E took after her telephone call with Ms A.

117. The Nursing Council of New Zealand's Code of Conduct for Nurses dated June 2012 provides guidance on documentation. It provides that registered nurses should:

> "• Keep clear and accurate records of the discussions you have, the assessments you make, the care and medicines you give, and how effective these have been.
> • Complete records as soon as possible after an event has occurred."

118. RN E did not record the outcome following her telephone discussion with Ms A on 3 April 2018, which was inadequate. I note Dr C's comment that RN E would normally document plans very clearly, and that this was one of the "very rare times" where she did not do so.

119. A full and accurate clinical record is vitally important, and in previous reports HDC has made numerous comments stressing the importance of good record-keeping and the accuracy of clinical records.[13]

120. My in-house clinical advisor, Dr Maplesden, advised that the symptoms Ms A reported to RN E on 3 April 2018 raised the possibility of an alternative diagnosis not consistent with BPPV (benign paroxysmal positional vertigo). Dr Maplesden said that this should have resulted in a prompt review of Ms A and further neurological assessment by a GP.

121. I encourage RN E to reflect on Dr Maplesden's advice and to ensure that she maintains accurate record-keeping in the future.

[13] For example: Case numbers 19HDC01547, 12HDC00437, and 11HDC01103.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Opinion: Medical Centre 4 — no breach

122. Ms A presented to Medical Centre 4 on 31 March 2018, when she collapsed and vomited at the front door. Ms A was seen by Dr C, whose impression was that Ms A had a vestibular migraine.

123. Dr C said that Ms A's symptoms were not typical "MS relapse" symptoms. He stated that MS was not considered at that time, and it would be an extremely rare initial diagnosis, unless he had been aware of Ms A's history of MS or optic neuritis.

124. Dr C said that the clinical records went back only as far as 2012, which was when the clinical records were transferred to Medical Centre 4 by Ms A's former medical practice. As Ms A's diagnosis with optic neuritis was prior to 2012, Dr C was not aware of this.

125. In determining whether the care provided to Ms A by Dr C and Medical Centre 4 was reasonable, I obtained in-house clinical advice from Dr Maplesden.

126. Dr Maplesden advised:

> "[I]n the apparent absence of any report from [Ms A] of previous neurological symptoms or investigations, and the history of optic neuritis or suspected MS not readily apparent in the accessible clinical notes, I am not critical of [Dr C's] failure to diagnose MS …"

127. I accept Dr Maplesden's advice. Dr C was not aware of Ms A's history of optic neuritis, and this information was not readily accessible in the clinical records. In my view, the care provided to Ms A by Dr C and Medical Centre 4 was appropriate and, accordingly, there was no breach of the Code on the part of either Dr C or Medical Centre 4.

Changes made by CDHB

128. CDHB said that its policies are now significantly different compared to 2011. Currently it does not have a specific neurology referral pathway, and it follows the Ministry of Health derived policy or guidelines for triage. CDHB said that the triage process now explicitly has a first step of "accept vs decline". There are four triage categories for accepted patients: "<7 days", "<28 days", "<100 days", or the option of a "virtual clinic", whereby an advice letter is provided instead of a face-to-face clinical appointment. CDHB advised that the virtual clinic option is used frequently. In addition, CDHB said that a patient can now be triaged to a nurse clinic.

129. CDHB stated that if a referral is declined, a reason is specified, and the neurology service may add a brief additional document, but this advice would be less detailed than a "virtual clinic" letter. CDHB advised that referrals are declined only when there is nothing of use the

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

neurology service can add without seeing the patient, but the patient does not meet the threshold to be seen.

130. CDHB said that the neurology service has since activated an e-triage system, which allows the hospital services to communicate electronically with the referrer, questioning and seeking more information as required. In addition, immediate management advice and strategies can be offered to the referrer for possible implementation prior to the neurology clinic appointment.

131. CDHB stated that it recognises that an electronic referral system would be desirable as part of future planning. It said that three other departments at the public hospital have developed an interim solution between themselves to manage frequent traffic between the departments, but this does not include the neurology and ophthalmology services. CDHB stated that once funding allows, this "small-scale design may serve as a wider and truly robust model for all areas".

132. CDHB told HDC that at the time of events, there was no routine mechanism for departments such as neurology to respond to an internal referral (i.e., it did not advise the ophthalmology service that effectively the referral had been declined), but there was such a procedure for an external referral. CDHB said that it is now normal process for departments to respond to both internal and external referrals.

133. CDHB told HDC that since 2011, it has employed a full-time clinical nurse specialist and a half-time registered nurse specifically for MS outpatient work.

Recommendations

134. Having considered the changes made by CDHB since these events, I recommend that CDHB:

a) Provide a formal written apology to Ms A for the deficiencies in care outlined in this report. The apology is to be provided to HDC within three weeks of the date of this report, for forwarding to Ms A.

b) Use this report as a basis for staff learning at CDHB, and provide HDC with evidence that this has been completed within six months from the date of this report.

135. As Dr B has retired from practice, I recommend that he provide a formal written apology to Ms A for the deficiencies in care outlined in this report. The apology is to be provided to HDC within three weeks of the date of this report, for forwarding to Ms A.

136. I recommend that RN E undertake training on documentation. Evidence of this is to be provided to HDC within six months of the date of this report.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Follow-up actions

137. A copy of this report with details identifying the parties removed, except CDHB and the experts who advised on this case, will be sent to the Medical Council of New Zealand, and it will be advised of Dr B's name in covering correspondence.

138. A copy of this report with details identifying the parties removed, except CDHB and the experts who advised on this case, will be sent to the Health Quality & Safety Commission and placed on the Health and Disability Commissioner website, www.hdc.org.nz, for educational purposes.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Appendix A: Clinical advice to Commissioner

The following in-house expert advice was obtained from GP Dr David Maplesden:

"I have reviewed the information in file. [Ms A] complains about delays in the diagnosis of her multiple sclerosis (MS) which was made following hospital admission in July 2019. [Ms A] had symptoms (optic neuritis) and MRI findings consistent with a clinically isolated syndrome suspicious for MS towards the end of 2010 and was referred by the CDHB ophthalmology service for DHB neurologist review. This internal referral was never received by the neurology service and [Ms A] was never sent an appointment[1]. There were possible missed opportunities to recognise this omission when [Ms A] presented to her GPs in June 2015 and March 2018 with neurological symptoms.

On 30 September 2010 GP [Dr D] of [Medical Centre 1] referred [Ms A] to the [CDHB] ophthalmology service with a several day history of vision loss affecting her right eye. [Ms A] was seen the same day and was diagnosed with *R optic neuritis ?2° to demyelination* and treatment was commenced with IV methyl-prednisolone then oral steroids with MRI head and orbits within a week and review in a week. There is no record of a clinic letter to the referring GP at this time.

[Ms A] was reviewed again on 5 September 2010 as planned. The MRI had yet to be done and was performed following the clinic assessment. In the [CDHB] notes is a letter dated 6 October 2010 from ophthalmologist [Dr G] to [Dr D] at [Medical Centre 1]. This records [Ms A's] diagnosis of *right demyelinating optic neuritis* and treatment to date (high dose steroids) with some improvement in vision. Note includes: *There is an association between optic neuritis and MS and she is having a prognostic MRI tonight (5 October). We will review her back in two weeks' time.*

MRI head and orbits scan dated 5 October 2010 (reported 6 October 2010) notes [Dr G] as the referrer and copy to [Medical Centre 1] (no specific GP). The report conclusion is:

Focus of increased T2 signal within the right optic nerve consistent with right optic neuritis

Several white matter lesions, with at least 3 periventricular lesions raising the possibility of primary demyelination. Specialist neurologist opinion for further clinical assessment regarding this possibility is suggested.

Ophthalmology Clinic notes dated 2 November 2010 record a 'did not attend' and [Ms A] and the follow-up appointment was apparently rescheduled for February 2011 (see below). The content of any conversation held with [Ms A] related to the rescheduling

[1] This advice was on the basis of incorrect information as it was later discovered that the referral had in fact been received by the neurology service.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

of the appointment is not clear, and [Ms A] does not recall receiving an appointment for 2 November 2010.

There is an internal referral letter on file dated 9 February 2011 from [Dr G] to *Neurologist Colleague.* A copy of the letter has been sent to [Dr D] at [Medical Centre 1]. The letter notes [Ms A's] history of *demyelinating optic neuritis* and family history … of multiple sclerosis. The MRI is referred to only as *I enclose a copy of her MRI.* Review by the neurologists is requested with no follow up planned by the ophthalmology department. There is no specific reference to a provisional diagnosis of multiple sclerosis. The DHB response states it would be expected the reasons for the referral (suspicion of MS based on MRI result and symptoms) would have been discussed with [Ms A] at the time the referral was arranged. It is not apparent from the complaint what [Ms A] recalls in this regard.

GP notes have been provided from October 2012 (unsure which medical centre at this time) with old notes received from [Medical Centre 2] on 4 October 2012. [Ms A] apparently transferred from [Medical Centre 1] sometime after October 2010, or she had attended [Medical Centre 1] as a casual patient (noting it was attendance at an 'urgent clinic'). On 26 June 2013 notes were transferred to [Medical Centre 3]. It is unclear when [Ms A] joined [Medical Centre 4].

I am unable to determine from the available notes whether [Ms A's] history of optic neuritis and/or suspicion of possible MS was coded in the relevant module of the PMS. If it was not, and the DHB letters and MRI result were filed on receipt in 2010, for any subsequent provider to consider MS as a diagnosis would have required prompting by [Ms A] regarding this history unless the symptoms were highly suggestive of MS (such as optic neuritis). The only references to [Ms A] presenting subsequently with neurological symptoms were:

17 June 2015 ([Dr B], unsure which medical centre) when [Ms A] presented with vague intermittent left sided numbness in arm and leg and possible leg weakness. It is not possible to determine the differential diagnosis or management plan from the clinical notes. The symptoms apparently resolved without specific treatment.

31 March 2018 ([Dr C] — [Medical Centre 4]) when [Ms A] presented with headache, giddiness, double vision and nystagmus was noted).

28 June 2019 ([Dr F] — [Medical Centre 4]) when [Ms A] presented with further limb symptoms and was referred by [Dr F] for urgent neurological review once he established the previous neurological history.

[CDHB] discharge summary dated 14 July 2019 notes [Ms A's] recent admission with a new diagnosis of multiple sclerosis (following correlation of neurological symptoms and updated MRI findings). History provided by [Ms A] included: *Reports prior neurological symptoms* [following optic neuritis diagnosed in October 2010] *including: vertigo for around 10 days in April 2018; 3 days of 20 second episodes of L-sided sensory changes*

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

in 2013 [handwritten notes record 2015]*; few months of tingling legs bilaterally — walking feeling unstable at this point, but now resolved.*

Comments on DHB management:

There were deficiencies in the DHB internal referral processes which resulted in loss of the referral[2]. There was apparently no 'tracking' or audit system in place which might have detected the delayed referral. Such tracking is expected in primary care and I see no reason why the same expectation should not apply to internal referrals in secondary care. The GP was notified as a professional courtesy that an internal referral had been made. I think it was reasonable for the GP to determine the DHB had robust referral systems and had had appropriate communication with [Ms A] regarding the importance of the referral and what to do should there be any perceived delays. I would not expect the GP to track a referral that has been initiated in secondary care unless there were specific instructions to do so.

There may have been deficiencies in communication between DHB clinicians and [Ms A] regarding: the MRI result including its clinical significance; when neurology review might be expected; and what [Ms A] should do if there appeared to be delays in the review.

Given the length of time since the events in question, further clarification of the communication issues will be difficult although [Ms A] has stated she does not recall any discussion regarding a possible link between her optic neuritis (which had largely resolved by the time of review) and MS. Consideration could be given to seeking comment from a systems expert (or informal comment from …) regarding the standard of referral processes in place at the DHB in 2010 and adequacy of the improvements outlined in the provider response.

The provider response does accurately outline (in hindsight) the likely trajectory of [Ms A's] management within the restricted drug access imposed by Pharmac at the time, indicating she may not have been eligible for definitive treatment until her second episode of neurological symptoms which was June 2015. Nevertheless, she was denied regular neurologist monitoring and treatment commenced in 2015 may have significantly altered the trajectory or her disease. It is appropriate an ACC claim for treatment injury was initiated.

There may have been some deficiencies in GP management but further information is required.

(i) A response from [Medical Centre 1] and [Dr D] (with any available GP notes from [Medical Centre 1] from September 2010 onwards) clarifying:

[2] This advice was on the basis of incorrect information as it was later discovered that the referral had in fact been received by the neurology service.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Who reviewed and filed the correspondence from the [CDHB] ophthalmology service (including the MRI result) in October 2010 and February 2011) and was any particular management plan initiated in light of these results?

Was there any coding of [Ms A's] diagnoses of optic neuritis and/or suspected MS?

Was there any discussion with [Ms A] regarding the diagnosis of possible MS?

Any other comments?

A response (if possible) from [Dr B] with his recollection of [Ms A's] presentation on 17 June 2015 — in particular, was there any discussion of [Ms A's] prior history of optic neuritis and abnormal MRI scan, and what was the provisional diagnosis and management plan on this occasion.

A response from [Dr C] regarding [Ms A's] presentation in March 2018 clarifying his differential diagnosis and management plan and whether there was any discussion of [Ms A's] prior history of optic neuritis and abnormal MRI scan.

A response from [Dr F] (whose management of [Ms A] in June 2019 was conscientious and appropriate) regarding how he established [Ms A's] prior history of optic neuritis and abnormal MRI scan (eg did [Ms A] volunteer the information? Was it readily available on review of the notes).

Further advice

Dr Maplesden provided the following further expert advice:

"1. Thank you for the request that I provide clinical advice in relation to the complaint from [Ms A] about the care provided to her by various providers. In preparing the advice on this case to the best of my knowledge I have no personal or professional conflict of interest. I agree to follow the Commissioner's Guidelines for Independent Advisors. I provided an initial file steer on 22 September 2020 having reviewed response and clinical notes from Canterbury DHB and clinical notes from ([Medical Centre 4]). Since providing the preliminary advice, further information has been reviewed:

- Response from [Dr C] of [Medical Centre 4]
- Response from [Dr F] of [Medical Centre 4]
- Response from [Medical Centre 1]
- Response from [Dr D] of [Medical Centre 1]
- GP notes from October 2010 to current including those from [Medical Centre 2], [Medical Centre 3], [Medical Centre 1] and [Medical Centre 4]

2. [Ms A] complains about delays in the diagnosis of her multiple sclerosis (MS) which was made following hospital admission in July 2019. [Ms A] had symptoms (optic neuritis) and MRI findings consistent with a clinically isolated syndrome suspicious for MS towards the end of 2010 and was referred by the CDHB ophthalmology service for

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

DHB neurologist review. She never received an appointment from the neurology service. [Ms A] states she was seen by GPs subsequently with neurological symptoms (she describes as mini-strokes) and headaches/vertigo but was never re-referred to neurology until July 2019 when the clinician she saw at that time reviewed her past history and notes and made an urgent neurology referral with diagnosis of suspected MS. [Ms A] is concerned that treatment for MS has been delayed for almost 10 years because of these oversights.

3. On 30 September 2010 GP [Dr D] of [Medical Centre 1] referred [Ms A] to the [CDHB] ophthalmology service acutely with a several day history of painless vision loss affecting her right eye. The referral letter has been reviewed and is of good quality. Management by [Dr D] was clinically appropriate.

4. [Ms A] was seen on 30 September 2010 and was diagnosed with *R optic neuritis ?2° to demyelination* and treatment was commenced with IV methyl-prednisolone then oral steroids with MRI head and orbits within a week and review in a week. There is no record of a clinic letter to the referring GP at this time. [Ms A] was reviewed by the ophthalmology service ([Dr G]) again on 5 September 2010 as planned. The MRI had yet to be done and was performed following the clinic assessment. In the [CDHB] notes is a letter dated 6 October 2010 from ophthalmologist [Dr G] to [Dr D] at [Medical Centre 1]. This records [Ms A's] diagnosis of *right demyelinating optic neuritis* and treatment to date (high dose steroids) with some improvement in vision. Note includes: *There is an association between optic neuritis and MS and she is having a prognostic MRI tonight (5 October). We will review her back in two weeks' time.* The report was received and filed on 9 October 2010. In the interim, an MRI report was received at [Medical Centre 1] on 6 October 2010.

5. MRI head and orbits scan dated 5 October 2010 (reported 6 October 2010) notes [Dr G] as the referrer and copy to [Medical Centre 1] (no specific GP). The report conclusion is:

1. Focus of increased T2 signal within the right optic nerve consistent with right optic neuritis

2. Several white matter lesions, with at least 3 periventricular lesions raising the possibility of primary demyelination. Specialist neurologist opinion for further clinical assessment regarding this possibility is suggested.

The report was filed with the comment *optic neuritis.* [Dr D] is unable to confirm that he filed this letter and the report but the [Medical Centre 1] response states it is most likely he did so. There is no specific reference to MS in the MRI report.

6. Ophthalmology Clinic notes dated 2 November 2010 record a 'did not attend' and a follow-up appointment was apparently rescheduled for February 2011 (see below). The content of any conversation held with [Ms A] related to the rescheduling of the appointment is not clear from the DHB notes or response, and [Ms A] does not recall receiving an appointment for 2 November 2010.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

7. There is an internal referral letter in the CDHB notes dated 9 February 2011 from [Dr G] to *Neurologist Colleague.* A copy of the letter has been sent to [Dr D] at [Medical Centre 1]. The letter notes [Ms A's] history of *demyelinating optic neuritis* and family history … of multiple sclerosis. The MRI is referred to only as *I enclose a copy of her MRI. I think she would benefit from your review and discussion about her situation and possible treatment options with further events.* Review by the neurologists is requested with no follow up planned by the ophthalmology department. There is no specific reference to a provisional diagnosis of multiple sclerosis — in fact the only reference to possible MS diagnosis (specifically) in the correspondence between CDHB and [Medical Centre 1] by this time is the brief mention as a possible association with demyelinating optic neuritis noted in the clinic letter of 6 October 2010 as noted above. The DHB response states it would be expected the reasons for the referral (suspicion of MS based on MRI result and symptoms) would have been discussed with [Ms A] at the time the referral was arranged. It is not apparent from the complaint what [Ms A] recalls in this regard and it does not appear she ever mentioned a possible diagnosis of MS to her subsequent GP providers.

8. A copy of the internal referral letter was received at [Medical Centre 1] on 17 February 2010 and was seen and filed by [Dr D]. [Dr D] also entered a disease classification into the PMS as: *optic neuritis [F4H3.00] — right sided resolved — referred neurology.* This classification should have been visible to subsequent providers if medical history was reviewed on the PMS assuming there was no corruption of the electronic record in the subsequent electronic notes transfers between practices. However, I am unable to determine if the coding was under 'long-term conditions' or highlighted which might have made it more visible to subsequent providers.

9. The DHB response states the internal referral was never received by the neurology service and [Ms A] was never sent an appointment. The new information received since my initial steer includes a letter addressed and sent to [Ms A] from CDHB (cc [Medical Centre 1]), dated 3 March 2011 which reads as follows:

We have received a letter requesting an appointment for you at the [Neurology Clinic], [CDHB].

Based on the information provided in the referral letter, you have been prioritised to a Semi Urgent category.

This means that we are not able to offer you an appointment with the specialist at this time. While the preference of your family doctor and the department is to see you now, limitations on our resources mean that it is not possible to do so.

Therefore we are advising that you remain under the care of your family doctor. Your name will not appear on the active list for an appointment, however your referral details will be held on hospital records.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

If your condition changes or you wish to discuss your options for management of your condition, please contact your family doctor. Your family doctor may ask you to make an appointment for a consultation with them.

Your doctor will contact us if a review of your priority is required.

This letter indicates that, contrary to the DHB response, the referral from the ophthalmology department had indeed been processed and although triaged as semi-urgent [Ms A] was not to be offered an appointment.

10. [Dr D] states he did not see [Ms A] again following the September 2010 appointment (confirmed on review of notes). [Ms A] transferred to [Medical Centre 2] on 19 January 2012 and then to another medical centre (not identified) on 4 October 2012. On 26 June 2013 notes were transferred from that medical centre to [Medical Centre 3]. It is unclear when [Ms A] joined [Medical Centre 4]. There is no reference to [Ms A] presenting with neurological symptoms at any subsequent GP presentations (although many other issues were addressed at multiple consultations) apart from 17 June 2015 ([Dr B]) and 31 March 2018 (Dr C), until the presentation on 28 June 2019 ([Dr F]) at which time urgent neurology referral was made after the past history of optic neuritis was noted. These consultations are discussed further below. I note [Ms A] had hospital admissions over this period including 14–15 March 2012 (… 13–20 August 2012 … and 30 January 2013 … The discharge summary related to the 30 January 2013 assessment included past medical history of *Demyelinating optic neuritis Feb 2011 — short course steroids required* confirming the diagnosis was present in the DHB file.

Comment: I believe [Ms A's] overall management by [Dr D] was consistent with accepted practice. There is nothing in the information he received from the DHB confirming a diagnosis of MS, and only one brief mention of an association between demyelinating optic neuritis and MS. The diagnosis of optic neuritis was accurately recorded in patient classifications and, in hindsight, the classification would have been best highlighted so it remained prominent in the patient notes. [Ms A's] care was handed back to the GP by the neurology service (via copy of a letter to [Ms A]) without any reason for the declined referral, without any confirmation of the diagnosis or suspected diagnosis, and without any management advice. I think it was reasonable for [Dr D] to infer that a 'serious' diagnosis was unlikely given the neurology service response, and there was no need to proactively recall [Ms A] to discuss the letter. I believe it was also reasonable for [Dr D] to assume that, as part of gaining consent for the neurology referral, [Dr G] had explained the reason for referral including the need to exclude or confirm MS as a diagnosis, and the neurologist would be best placed to do this and to provide further management and prognostic advice.

11. Notes for the consultation of 17 June 2015 ([Dr B]) read:

c/o L hand side of body — tingling in L side-arm

Leg involved — falls over

X 5 occasions Monday — 15–20 secs

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Denies stress — works in …

No FH CVS/strokes

BP 125/80 reg

No m carotids No weaknesses

Blood tests were arranged and were normal (CBC, CRP, lipid profile, liver and renal function, thyroid function, HbA1c). [Dr B] states in his response that he retired at the end of 2018 and has no clear memory of the consultation in question. He confirms the history and examination findings as above and *I do not recall [Ms A] volunteering any past history of optic neuritis or abnormal MRI scan. Nor do I recall seeing any reference to this in her past notes and as such I do not recall any discussion around this.* Although there is no provisional diagnosis or management plan evident from the notes, [Dr B] states: *The provisional diagnosis on this occasion would have been conditions that may have triggered temporary symptoms as described eg Transient Ischaemic attack or possibly an inflammatory disorder. As her examination was normal and excluded some obvious causes eg hypertension, atrial fibrillation. I felt it would be prudent to order a number of screening tests that may provide further evidence, or not, of the provisional diagnosis … Although there are no notes to support my next comments, my normal practise would have been to advise the patient to either call the surgery to be advised re the results or make an appointment for further review and see her regular Doctor. I would have added if there were any further symptoms or concerns to return to the surgery.*

Comments:

(i) With the benefit of hindsight, this was the first opportunity I could identify where review of [Ms A's] neurological history was indicated and when there might have been opportunity to refer her for neurological assessment and likely diagnosis of MS (current symptoms combined with previous history of demyelinating optic neuritis). However, it does not appear [Ms A] was aware of the significance of her previous history (which must reflect her understanding of any advice she was provided by the DHB ophthalmology service at the time of her neurology referral) and she did not convey the history to [Dr B]. Without prompting by [Ms A] that she had had previous neurological symptoms or brain MRI, there was no particular indication to examine her clinical notes in detail, which would have been required to ascertain the MRI result and correspondence related to optic neuritis (assuming that 'optic neuritis' was not prominent in the list of previous coded diagnoses). Had [Ms A] disclosed a history of previous brain MRI or optic neuritis diagnosis, I would be critical that [Dr B] did not review the clinical notes in more detail to confirm relevant past history.

(ii) Putting aside the issue of past neurological history, I examine the consultation as a de novo presentation of transient neurological symptoms in an apparently fit young woman. The history suggests unilateral sensory and motor symptoms. This could have a broad differential diagnosis including infective or inflammatory polyneuropathy, central disorder (TIA, space occupying lesion), demyelinating disorder, focal migraine,

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

functional disorder. Recorded history might have been improved by recording of relevant positive or negative symptoms including headache, visual or speech disturbance, balance disturbance. The documented assessment is deficient in that there is no assessment of general alertness, gait, basic cranial nerve assessment, reflexes or sensation in the limbs, or coordination. Cardiovascular assessment was satisfactory to exclude overt cause for TIA (eg atrial fibrillation or carotid artery bruit suggesting stenosis) or extreme hypertension. There is no recorded differential diagnosis or diagnosis, no management plan (other than blood tests) and no record of follow up or safety netting advice provided. TIA would be unusual in [Ms A's] age group and if this was considered a likely diagnosis, emergent or urgent neurology or medical referral should be considered. While it was reasonable to order blood tests to establish any elevated cardiovascular risk (which was done) I believe there should have been at least a structured review in place following receipt of the results to assess progress of the symptoms and refine the diagnosis and management plan. Another possible issue is use of the combined oral contraceptive (COC) if TIA was considered a possible diagnosis. [Ms A] had been previously (within the past six months) prescribed the COC Ava-30, and use is contraindicated in patients with a history of stroke or TIA[3]. There is no record of prescriptions associated with the consultation of 17 June 2015 in the notes available to me.

(iii) In summary, I am mildly to moderately critical of the standard of documented assessment and the management plan, including absence of follow-up or safety-netting advice. If TIA was considered a likely diagnosis, I would be moderately critical of the failure to refer a young person with possible TIA for further specialist assessment. I would be moderately critical if [Ms A] was not advised to stop the COC if the diagnosis of TIA was considered a possibility. In the circumstances described, and without the benefit of hindsight, I am not critical that [Dr B] failed to consider a diagnosis of MS but acknowledge this was a missed opportunity to do so. The clinical notes do not indicate [Ms A] returned for review of any persistent or new neurological symptoms until 31 March 2018 (see below) and I assume the symptoms presented in the consultation of 17 June 2015 were transient and resolved fully without any specific treatment. Had the symptoms persisted, neurologist review was certainly indicated. I note [Dr B] has been retired for over two years and there are few relevant remedial actions to consider in this circumstance.

12. On 31 March 2018 [Ms A] presented to [Dr C] at [Medical Centre 4]. Nurse triage notes include: *Collapsed at front door, vomiting. Assisted into wheelchair and into obs area. [*Dr C] has recorded: *Severe headaches started yesterday. Associated with photophobia and nausea. Vomited yesterday. Since this morning getting room spinning sensation, more vomiting +++. Not keeping any fluid down.* Assessment findings include: *temp 36.6, BP 110/80, HR 59, HS dual, Chest clear, Gross neuro nad, significant lateral nystagmus. Imp: probable vestibular migraine.* [Ms A] was administered IM Stemetil and diclofenac with oral Rizamelt. At review after 45 minutes [Dr C] noted: *Ongoing vomiting, really sick, room spinning sensation. Nystagmus ++. Dix Hallpike shows*

[3] http://ukmec.pagelizard.com/2016#sectionb/cardiovascular_disease_cvd_ Accessed 22 February 2021

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

positive on right side. Large vomiting. Headache slightly better. Imp: Migraine + BPPV right side. Performed Epley maneuver x1. Vomiting ongoing. Advised to rest for another 1 hour or so until improvement noticed post-Epley. At final review after one hour [Dr C] noted: *Had some sleep, feeling a lot better now. Epley maneuver explained to be performed at home. Rizamalt and stemetil prescribed to take at home. Do ongoing Epley at home.* On 3 April 2018 the practice nurse has recorded: *Pt wanting to speak with [Dr C] … wondering when should start to get better vision, double vision, unable to focus and distorted causing headache. When to expect nausea to stop — not vomiting, has central abdo pain, what can she do for — anything [Dr C] can give her to help with vision and nausea. Has been talking meds as directed.* There is no outcome recorded following this discussion. On 7 April 2018 [Ms A] phoned the medical centre requesting a prescription (details not available from the notes provided) and this was issued by the duty GP Dr … Her notes include: *Needs review if limited improvement in next 48 hours or sooner if ongoing concerns. BPPV as below — txted — ok to text.*

Comments:

(i) [Dr C] notes in his response that clinical notes available to him ran from 2012 and there was no classification of suspected MS. He felt [Ms A's] symptoms were suggestive of vertebrobasilar migraine and benign paroxysmal positional vertigo (BPPV) and she appeared to respond to treatment for this. There is no record of [Ms A] mentioning previous neurological issues.

(ii) [Dr C] was conscientious in monitoring [Ms A] for a prolonged period on 31 March 2018. The differential diagnosis included migraine with brainstem symptoms but it would be unusual for neurological aura symptoms to last more than 60 minutes in this condition[4]. Some of the symptoms supported a diagnosis of BPPV, supported by the positive Dix-Hallpike test and apparent improvement with the Epley maneuver, although severe headache would not be characteristic of this diagnosis. Best practice in assessing a patient with acute vertigo includes establishing presence of absence of hearing loss, assessment of gait and balance and neurological examination (checking specifically for nystagmus, cerebellar signs and brainstem signs)[5]. While [Dr C's] neurological examination could have been documented in more detail, he did record nystagmus and the results of the Dix-Hallpike maneuver. If there was significant improvement in [Ms A's] symptoms by the time she left the surgery, I believe [Dr C's] management would be met with approval by my peers. Best practice is to document any safety-netting advice provided. Had [Dr C] been aware of [Ms A's] past neurological history, I believe greater consideration might have been given to a possible central (MS) cause for her symptoms with acute medical or neurological referral to exclude this possibility. However, in the apparent absence of any report from [Ms A] of previous neurological symptoms or investigations, and the history of optic neuritis or suspected

[4] Kadian R, Shankar Kikkeri N, Kumar A. Basilar Migraine. [Updated 2020 Jun 30]. In: StatPearls [Internet]. StatPearls Publishing; 2020 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK507878/ Accessed 22 February 2021

[5] Canterbury Community HealthPathways. Vertigo. https://canterbury.communityhealthpathways.org/ Accessed 22 February 2021

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

MS not readily apparent in the accessible clinical notes, I am not critical of [Dr C's] failure to diagnose MS (if this was the cause of [Ms A's] symptoms on this occasion).

(iii) On 3 April 2018 [Ms A] reported persistent visual symptoms to the practice nurse, including double vision. Such symptoms raised the possibility of an alternative diagnosis (not consistent with BPPV) and I believe should have resulted in prompt review of [Ms A] and further neurological assessment by the GP. A further prescription was provided to [Ms A] on 7 April 2018 (prochlorperazine 5mg tabs x 20) with persistence of some symptoms noted at that stage, but advice provided to review if the symptoms persisted. There is no record of [Ms A] presenting for review of neurological symptoms again until 28 June 2019 ([Dr F]) at which stage she was referred for urgent neurological assessment. I am mildly to moderately critical that [Ms A] was apparently not advised to return for review when she mentioned persistent visual symptoms, including double vision, on 3 April 2018 which were not consistent with the current diagnosis of BPPV and raised the possibility of a central cause for her symptoms (although planned management or advice provided on that date is not apparent from the clinical notes). Had such a review taken place, it may be that the prominent visual symptoms would have prompted [Ms A] to recall her previous vision issue in 2010 (as it did in June 2019 — see below) which should then have resulted in urgent neurology referral. However, I can only hypothesize on this issue. I recommend [Dr C] review the cited Canterbury Community HealthPathways guidance with respect to assessment and management of the patient with vertigo.

(iv) Addendum 16 March 2022

Responses to this advice have been received by practice nurse [RN E] and from [Dr C]. [RN E] does not have a clear recollection of the conversation she had with [Ms A] on 3 April 2018 but outlines her usual practice on receiving such a call. This includes discussing the case with the patient's GP (or on-call GP) and [Dr C] has a vague recollection of such a conversation taking place with advice that [Ms A] should be reviewed by a GP. If this was the case, and [RN E] advised she needed to make an appointment to see a GP, my only criticism is the failure by [RN E] to document this action and advice which, noting she had partly completed a record of the interaction, represents a mild departure from expected standards of clinical documentation. The practice has discussed this incident with a reminder to all staff on the importance of completing such documentation. [Dr C] discusses his impression that [Ms A] may have been suffering from vestibular migraine and I acknowledge this is a separate entity from migraine with brainstem aura (MBA), previously known as basilar migraine, and that the vestibular symptoms associated with vestibular migraine can last for many hours (unlike MBA) which was the case with [Ms A]. I remain of the view that [Ms A's] management by [Dr C] would be met with approval by my peers.

13. [Ms A] was seen by [Dr F] on 28 June 2019 complaining of *vertigo 1 year ago, since then worsening vision right eye, random parasthesiae legs and arms, left arm last 24 hours numb, reduced function and sensation. Reports right eye optic neuritis 2010. Also reports odd sounding seizures x 2 to left side of body 2015, whole body went numb and tingly. [A relative] has history of MS.* In his response, [Dr F] elaborates that [Ms A] had

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

a vague recollection of being seen for vision disturbance some years previously and this led [Dr F] to explore [the] shared electronic health record system (primary and secondary care) where he found DHB reports referring to [Ms A's] previous optic neuritis and abnormal MRI result. He queried MS as a diagnosis for [Ms A's] current symptoms and organized urgent neurology referral. [CDHB] discharge summary dated 14 July 2019 notes [Ms A's] recent admission with a new diagnosis of multiple sclerosis (following correlation of neurological symptoms and updated MRI findings). History provided by [Ms A] included: *Reports prior neurological symptoms* [following optic neuritis diagnosed in October 2010] *including: vertigo for around 10 days in April 2018; 3 days of 20 second episodes of L-sided sensory changes in 2013* [handwritten notes record 2015]*; few months of tingling legs bilaterally — walking feeling unstable at this point, but now resolved.*

Comment: [Dr F's] management of [Ms A] was conscientious and clinically appropriate.

14. Comments on DHB management:

(i) There are apparent deficiencies in the DHB internal referral processes which resulted in them misreporting to HDC the pathway the ophthalmology referral followed in early 2011. There was apparently no reporting back to the referrer (ophthalmology service) that the referral had essentially been declined (no neurology assessment to be undertaken) and that [Ms A's] care had been returned to her GP.

(ii) It was the expectation of the referrer that [Ms A] would be seen by the neurology service, her diagnosis of suspected MS confirmed and appropriate management advice provided to her. I believe it is likely discussion of possible MS diagnosis with [Ms A] was likely to be limited until the diagnosis had been confirmed and the content of the referral letter implies the belief the neurologist would undertake such discussion. I am not sure of the 'reasonableness' of the neurology service in the following areas:

failing to provide [Ms A] with an appointment when the referral was categorized as semi-urgent

failing to notify the referrer ([Dr G]) that an appointment would not be offered and the rationale behind this

failing to provide any diagnostic and management advice to the GP when care of [Ms A] was handed back to the GP

I recommend expert advice is obtained from a neurologist to comment on these issues although the DHB might be asked for further comment initially given the discovery the referral had been processed but no appointment provided or intended to be provided. (I am aware the sequelae of the January 2011 earthquake might have limited available resources).

(iii) Given the length of time since the events in question, further clarification of possible communication issues between [Dr G] and [Ms A] will be difficult although [Ms A] has

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

stated she does not recall any discussion regarding a possible link between her optic neuritis (which had largely resolved by the time of review) and MS.

(iv) The provider response does accurately outline (in hindsight) the likely trajectory of [Ms A's] management within the restricted drug access imposed by Pharmac at the time, indicating she may not have been eligible for definitive treatment until her second episode of neurological symptoms which was June 2015. Nevertheless, she was denied regular neurologist monitoring and treatment commenced in 2015 may have significantly altered the trajectory or her disease."

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Appendix B: Independent clinical advice to Commissioner

The following expert advice was obtained from a neurologist, Dr David Hutchinson:

"I am a full-time neurologist in the Department of Neurology at Auckland City Hospital. I have been a fully-qualified neurologist for 28 years. I have carefully reviewed the supplied material. I have summarised the material in chronological order then provided comments.

Summary

[Ms A], then [in her early twenties], was referred to [CDHB] on 30 September 2010 by her general practitioner with blurred vision in the right eye.

Assessment in the Ophthalmology Department that same day showed markedly impaired vision in this eye. She was diagnosed with optic neuritis and was administered standard treatment — a short course of high-dose corticosteroids.

A standard investigation in patients with optic neuritis is a brain Magnetic Resonance Imaging (MRI) scan. This is to i) exclude other causes of impaired vision, such as something compressing the optic nerve; and ii) look for evidence that the patient's optic neuritis may result from multiple sclerosis.

The MRI was performed on 5 October 2010 and showed abnormal signal in the right optic nerve, consistent with optic neuritis. It also showed five small zones of abnormal signal in the cerebral white matter, including 'two ovoid periventricular white matter lesions adjacent to the roof of the posterior body and trigone of the right lateral ventricle ... raising the possibility of primary demyelination'.

In this clinical setting (age of patient, optic neuritis), use of the word 'demyelination' in the MRI report has similar meaning to the term 'multiple sclerosis'.

At a follow-up visit in the Ophthalmology clinic on 8 February 2011, her right eye had shown partial improvement. Ophthalmologist [Dr G] dictated a referral letter to the Department of Neurology at [CDHB]. The information contained in it (age of patient, recent optic neuritis, family history of multiple sclerosis, MRI result) would lead any neurologist to be suspicious the patient had multiple sclerosis.

In its initial response dated 19 September 2019, CDHB stated they had no record of ever receiving the referral on [Ms A] and assumed it had gone missing after leaving Ophthalmology. Evidence later showed the letter had been received and was triaged by a neurologist sometime before 3 March 2011 as 'Semi-urgent'.

It has transpired that the policy in place at [CDHB] in March 2011 was that patients referred to Neurology and triaged to Semi-Urgent or Routine were not offered appointments. [Ms A] was sent a form letter to that effect and her general practitioner was sent a copy. No specific clinical advice letter was sent.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Eight years later, on 28 June 2019, [Ms A] was referred back to the Neurology Department with new weakness and sensory disturbance in the left arm. She deteriorated and was re-referred, then ended up being admitted to the hospital. Multiple sclerosis was confirmed and she started treatment.

Complaint

[Ms A] has complained that she was never seen in a Neurology clinic in 2011. Her recollection following review in the Ophthalmology clinic in February 2011 was that she 'heard nothing after this from any medical professional'. She came to the view that 'no news is good news' and 'nothing had been detected on the scan'.

Expert Advice Requested

1. The adequacy of the referral management in this case. Please advise what actions you would expect to be taken by a DHB neurology service upon receipt of a semi-urgent referral.

In any Neurology department, a substantial fraction of patients triaged as 'Semi-Urgent' will have serious neurological conditions. They should be seen, or at least specific communication made with the referring doctor/general practitioner.

Turning more specifically to [Ms A's] case, it should be noted that effective treatment has been available in New Zealand for multiple sclerosis since 1999. The information contained in the referral from the Ophthalmology department made it clear that [Ms A] almost certainly had either Clinically Isolated Syndrome (CIS) or multiple sclerosis.

CIS is defined as '*A monophasic clinical episode with patient-reported symptoms and objective findings reflecting a focal or multifocal inflammatory demyelinating event in the CNS … similar to a typical multiple sclerosis relapse … but in a patient not known to have multiple sclerosis'* [i i]. Patients with CIS do not qualify for disease-modifying treatment in New Zealand unless and until they have a second clinical episode which clarifies that they have multiple sclerosis.

Patients who are referred to Neurology clinics with what seems at first glance to be CIS often turn out to have multiple sclerosis, especially when they have an abnormal brain MRI scan. This upgrade to multiple sclerosis occurs when the neurologist obtains a history of earlier neurological symptoms. Examples might include an episode of transient weakness or numbness in a body region, symptoms which may have been dismissed by the patient or their general practitioner at the time.

The important point is that review by a neurologist is required to distinguish CIS from multiple sclerosis. Although not yet eligible for disease-modifying treatment, patients with CIS require i) counselling that a subsequent episode will change the diagnosis to multiple sclerosis; ii) education on what future symptoms to watch out for; iii) advice on smoking cessation; and iv) advice to get adequate sun exposure to promote vitamin D production.

In summary, regardless of whether she would turn out to have CIS or multiple sclerosis, [Ms A] required a visit to the Neurology clinic. I expect that my neurologist colleagues would view this as at least a moderate departure from the expected standard of care.

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.

Whether the neurology service should have notified/followed up with [Dr G] regarding the fact [Ms A] had not received an appointment.

Neurologists are the doctor group responsible for multiple sclerosis. In relation to establishing whether [Ms A] had multiple sclerosis, and what should be done next, ophthalmologist [Dr G] had largely discharged his duty by making the referral to Neurology. He should have been informed by Neurology that [Ms A's] referral had been declined. However, I expect that my colleagues would view this as a largely inconsequential, minor departure from the expected standard of care.

What information, if any, you would expect the neurology service to provide to [Ms A's] GP, when her care was handed back to [Medical Centre 1].

It is worth repeating that the Neurology service should have reviewed [Ms A]. A distant second-best option would have been a letter to her general practitioner. To have been barely acceptable, this would have needed to i) outline the situation; ii) ask the general practitioner to distinguish CIS from multiple sclerosis; iii) ask him/her to document the neurological examination; and iv) suggest that [Ms A] be referred back to Neurology if or when she qualified as multiple sclerosis.

This departure from the expected standard of care is inextricably connected to No. 1 and I believe my colleagues would consider they jointly qualify as at least a moderate departure.

4. Recommendations for improvement that may help to prevent a similar occurrence in future.

The clinical director has clarified that at some point since 2011, Neurology has modified their triage system so that patients are now either definitively accepted onto a waiting list, or are assigned to a 'virtual clinic' whereby the patients are not seen face-to-face but a neurologist instead communicates management advice back to the referrer. There is an additional 'Decline' triage option, presumably applied with a justification which is sent electronically to the referrer, and presumably for instances where a referral does not meet service criteria (eg driving assessement).

The organisation is also moving to an electronic referrals system.

These systems sound broadly similar to those in operation elsewhere in New Zealand and I do not have any additional recommendations.

DO Hutchinson
Neurologist"

[i] Alan J Thompson, Brenda L Banwell, Frederik Barkhof et al. Diagnosis of multiple sclerosis: 2017 revisions of the McDonald criteria. Lancet Neurology 2018;17(2):162–173

Names have been removed (except CDHB and the experts who advised on this case) to protect privacy. Identifying letters are assigned in alphabetical order and bear no relationship to the person's actual name.