HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Care of man with advanced Parkinson's disease

Decision 21HDC02248

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1. This Office received a complaint from a care home nurse on behalf of a resident, Mr A, about the care provided to him at Health New Zealand|Te Whatu Ora (Health NZ). Mr A suffers from early onset Parkinson's disease[1] with psychiatric symptoms. Mr A wears an apomorphine pump[2] 24/7 to manage his Parkinson's disease and the related symptoms.

2. On 16 September 2021, Mr A was taken to Hospital 1's Emergency Department (ED) for pain in his right ankle. Mr A was diagnosed with a re-ruptured[3] right Achilles tendon and transferred to a ward at Hospital 2 that evening.

3. On arrival at the ward, Mr A pressed the emergency bell because he was feeling stiff. He was noted to be agitated and 'unable to move his legs passively'. Mr A self-administered a PRN[4] dose of apomorphine and was noted to have improved within 15 minutes. Mr A raised concerns that his apomorphine pump was not working properly and had a blockage. The issue was discussed with the medical registrar, and the plan was for Mr A to remain under the care of the orthopaedic team until review in the morning and to continue to self-administer apomorphine if further episodes occurred.

4. At 2.56am on 17 September 2021, Mr A pressed the emergency bell as he could not feel the apomorphine medication working, and he asked for the cartridge to be changed. It is documented that 3ml of apomorphine remained in the pump. Mr A was showing signs of dyskinesia,[5] which the medical registrar felt was due to the use of apomorphine. The pump was stopped, with a plan to review Mr A in half an hour. The clinical records document that Mr A slept for the rest of the night and his observations were within normal limits. The apomorphine pump remained off, and the nursing handover documents that the apomorphine pump was not charted. The registered nurse explained to Mr A that they were trying to sort out the pump.

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[1] A progressive neurodegenerative condition caused by insufficient quantities of dopamine in the brain. Parkinson's has both motor and non-motor symptoms.

[2] A device used to deliver a continuous dose from a syringe inserted under the skin. Used to treat the symptoms of Parkinson's disease by helping to restore the balance of dopamine in the brain.

[3] Mr A had partially ruptured his right Achilles tendon several months prior.

[4] As needed.

[5] Involuntary movements of the face, arms, legs, or trunk, which can be a complication of Parkinson's disease medications.

5. When reviewed on the orthopaedic round at 8.19am, Mr A stated that his pump was not working and was told that the pump would need to come from home as it was not available on the ward.

6. Health NZ said that at 9.22am, nursing staff noted that Mr A was ringing his bell for his 'morphine' pump and was told that it could not be re-supplied as apomorphine had not been prescribed by the doctors. A pharmacist attended Mr A as part of the medicines reconciliation process to see whether Mr A had his own apomorphine pump. She found him to be visibly upset that his pump had run out. Health NZ told HDC that the pharmacist assisted the senior medical officer in prescribing the apomorphine,[6] and at 9.07am apomorphine was prescribed on MedChart. The pharmacist informed the nursing staff that a nursing advisor[7] from the supplier of Mr A's apomorphine and pump was available to assist with the pump if required.

7. At 9.42am, a general medical registrar reviewed Mr A and documented that he was asleep. The general medical registrar recorded that there was no confirmed problem with the apomorphine pump. At that time, the apomorphine prescription was being prepared by nursing staff.

8. At 9.51am, the apomorphine was dispensed and sent to the ward, but the pump was not restarted by the ward nurses as they were unfamiliar with its use, and the nursing advisor was required to assist. The nursing advisor arrived at approximately 10.30am and set up the infusion. Two bolus doses[8] of apomorphine were given, but the administration was not recorded on MedChart.

9. At 12.30pm an ambulance was booked to transport Mr A back to the care home. Nursing staff informed the care home staff of the discharge plan.

10. Health NZ told HDC that a review of the events was completed by the district's Medication Safety Pharmacists, who found that the medical staff lacked understanding of the apomorphine pump, both in the prescribing/administering and set-up, as demonstrated by the fact that on several occasions the clinical records refer to it as a 'morphine pain pump'. Health NZ commented on the limited neurology advice and support for staff and said that whilst there was a protocol available on the district's intranet, prescribing on MedChart is complicated. Health NZ acknowledged that whilst apomorphine is complex to prescribe, Mr A's current medication chart was sent with him by the care home, and the chart contained sufficient information for the ED or the orthopaedic house officer to prescribe Mr A's usual medicines.

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[6] The senior medical officer had been asked by nursing staff to prescribe apomorphine on MedChart (an electronic medication prescribing and administration system). The pharmacist assisted because the SMO was unfamiliar with how to prescribe apomorphine.

[7] A patient-focused registered nurse with expertise in Parkinson's disease and the management of an apomorphine pump. The nurse supports patients with severe symptoms who are prescribed apomorphine and provides education to staff.

[8] A single large dose.

11. Health NZ told HDC that there was also a delay in prescribing some of Mr A's regular medications, including Sinemet, which is used for breakthrough Parkinson's symptoms and could have been used while the apomorphine pump was not working or had been stopped.

12. Health NZ and Mr A were given an opportunity to comment on the provisional opinion. Health NZ advised that it accepted my proposed findings, recommendations, and follow-up actions. Mr A told HDC that he did not wish to make any comments.

13. Independent advice was obtained from Dr Nigel Millar, a general medicine specialist (Appendix A). Dr Millar identified deficiencies in the coordination of care between general medicine services and orthopaedic services and noted that it was not clear which service was responsible for Mr A. Dr Millar considered that the delays in providing a critically dependent patient with his regularly prescribed medication, and the lack of clinical processes around this, was a severe departure from the accepted standard of care.

14. Mr A was an at-risk consumer with a dual disability and complex needs, which were not well managed by Health NZ. Patients with Parkinson's disease suffer significant distress from uncomfortable and painful symptoms if regular medications are not prescribed or are given late. Therefore, it is fundamental that staff have sufficient education, and that safeguards are put in place to ensure that this does not occur.

15. On 4 July 2024 I notified Health NZ of HDC's investigation and proposed that HDC adopt the findings of Health NZ's internal review and the advice of Dr Millar. I proposed that I find Health NZ in breach of Right 4(1) of the Code of Health and Disability Services Consumers' Rights (the Code),[9] as Health NZ had acknowledged the lack of understanding about apomorphine pumps by the medical staff involved in Mr A's care, and that there was limited access to relevant guidance or support for staff. I also took into consideration the identified areas of improvement and the changes made by Health NZ as a result of these events. On 27 August 2024, Health NZ accepted HDC's proposed breach finding.

16. In my opinion, there was a systemic failure both to ensure that Mr A received his regular medication in a timely manner, and to have in place appropriate systems to facilitate this. In addition, there was inadequate coordination of Mr A's care between the general medicine and orthopaedic services, which contributed to the delays in Mr A receiving his regular medication. As such, I find Health NZ in breach of Right 4(1) of the Code in this regard.

17. Health NZ advised that the following changes have been made since the events:

- An agreed process for service provision to adults requiring admission within a secondary health setting who are identified as suitable for a shared model of care under general medicine and orthopaedic specialists.
- Provision of education to doctors at Grand Rounds, and to nurses via nurse educators and the nursing advisor, with two-yearly reviews.

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

- Revision and update of the apomorphine protocol.
- A move from ePrescribing of apomorphine to a specific paper chart — this process was rolled out in June 2022 together with education.
- The addition of a question on the patient admission proforma[10] whereby doctors must indicate whether they have prescribed all regular medications or only new medications.
- The addition of important contacts on the apomorphine protocol so that nurses know where to access help, together with a note that apomorphine is a complex medicine that may require assistance.

18. These changes indicate that Health NZ took responsibility for the errors identified in the district's Medication Safety Pharmacists' review to prevent a similar incident occurring. Considering the advice from Dr Millar, I am satisfied with the improvements identified by Health NZ and that these have been implemented.

19. Further to the changes made by Health NZ, I recommend that Health NZ provide a written apology to Mr A for the inadequate co-ordination of his care and for failing to provide him with the appropriate medication in a timely manner.

20. I recommend that Health NZ provide education to staff on the critical nature of medicines for people with Parkinson's disease to ensure a more general understanding of the importance of such people receiving their usual medications. Health NZ is to report back to HDC with evidence that this has occurred, within six months of the date of this report.

21. I recommend that Health NZ continue to liaise with the nearby Health NZ district's neurology service to request that care plans, including apomorphine prescribing regimens, be included in their clinical letter. Health NZ is to report back to HDC with an update on the progress of this recommendation within six months of the date of this report.

22. An anonymised copy of this decision (naming only Health NZ and my independent advisor) will be placed on the HDC website (www.hdc.org.nz) for educational purposes.

23. An anonymised copy of this decision (naming only Health NZ and my independent advisor) will be sent to the Head of Disability in the Office of the Chief Executive of Health NZ, who will be asked to consider whether systemic learnings from this case can be applied to other Health NZ services.

Rose Wall
Deputy Health and Disability Commissioner

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[10] A 'fill-in-the-blanks' form.

Appendix A: Independent clinical advice to Commissioner

The following advice was obtained from Dr Nigel Millar:

> ‘**Personal information and qualifications**
> My name is Nigel David Millar of Christchurch. I am registered with the Medical Council of New Zealand with vocational registration in internal medicine and medical administration. I graduated in medicine from the University of Newcastle upon Tyne, UK in 1980. I completed my post graduate training in the UK, Membership of the Royal College of Physicians (MRCP) 1984, advanced training in General (Internal) Medicine and Geriatric Medicine (JCHMT) in 1992. I was appointed as a Geriatrician to The Princess Margaret Hospital Christchurch in 1992 and shortly after as a General Physician to Christchurch Hospital.
>
> I hold Fellowships of the Royal Australian College of Physicians (1996) and the Royal College of Medical Administrators (2012). I worked as an acute medicine physician for 29 years until 2021 and continue clinical work as a consultant geriatrician. In 2003 I was appointed as Chief Medical Officer to Canterbury DHB and moved to the same role in Southern DHB in 2016. I continued clinical practice part time, in acute medicine, during my time as a chief medical officer with short intermissions related to the Christchurch earthquakes and Covid 19. During my time in Christchurch, I was regularly on call for the general medicine services and in Dunedin I also spent periods covering acute call in the internal medicine service.
>
> I am currently working independently providing advice to health services on systems, informatics, and leadership. I have a casual appointment to [Health NZ][Health NZ] in Canterbury Waitaha and Southern (Dunedin) where I work intermittently as a full-time specialist geriatrician.
>
> **Request and information from the Office of the Health and Disability Commissioner**
> I have been asked to provide an opinion on the care provided by [Health NZ] to [Mr A] between 16 September 2021 and 17 September 2021.
>
> **Background**
> This advice relates to the care provided to [Mr A] between the dates specified. I can see from the records that [Mr A] went through what must have been for him a distressing time. I hope that this report will assist [Mr A], his family and others close to him, as well as supporting the Health and Disability Commissioner in investigating the care provided to him.
>
> [Mr A], lived in a residential care facility because of disabling Parkinson’s disease which had affected him early in life. From the record it appears that [Mr A] had found it difficult to control Parkinson’s disease and was receiving a continuous infusion of Apomorphine supported by as required additional doses of Apomorphine and/or Sinemet. This therapy given by continuous infusion is used by specialist Neurology

services. Health professionals working outside that specialist area may only occasionally encounter a patient who is receiving it.

It appears from the record that [Mr A] had cognitive impairment at the time he was treated in [the public hospital]. It is noted that his capacity was impaired. He may have had a welfare guardian appointed either via enactment of an enduring power of attorney or through the Family Court. The appointed welfare guardian is not named in the records and there is not a record that they were contacted.

[Mr A] has a history of injury to his right Achilles tendon and presented to the Emergency Department at [Hospital 1] with pain in his right ankle. A diagnosis of rupture of the Achilles tendon was made. He was transferred to [Hospital 2] for evaluation by the orthopaedic service. He stayed in hospital overnight. It was determined that he did not require operative intervention and was discharged the next day. During his time in the ward at [Hospital 2] there were problems managing his medications. The Apomorphine infusion may not have been working and was stopped for a prolonged period. There were difficulties in reestablishing it related to prescribing, and access to the necessary expertise to operate the pump.

Process

I have reviewed the HDC's guidelines for independent advisors. I have also confirmed to the Office of the HDC that I do not know of any conflict of interest. I have confirmed that I have not worked with nor know any of the named clinicians personally. I have reviewed all the documents supplied to me by the Office of the Health and Disability Commissioner.

Expert advice requested

I have been asked to review documentation provided by the office of the Health and Disability Commissioner and to advise whether I consider the care provided to [Mr A] by [Health NZ] was reasonable in the circumstances, and why.

In particular, to comment on: [Health NZ's]care with regards to

1. The appropriateness of the co-ordination of care between General Medicine services and Orthopaedic services during [Mr A's] admission at [Hospital 2]
2. The adequacy of care provided to [Mr A] during his admission.
3. The adequacy of the recommendations and actions taken by [Health NZ] following the events of this complaint.
4. Any other matters that I consider warrant comment.

For each question I have been asked to advise:

a. What is the standard of care/accepted practice?
b. If there has been a departure from the standard of care or accepted practice?
c. How significant a departure (mild, moderate, or severe) do you consider this to be?
d. How would it be viewed by my peers?

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

Documentation provided by the office of the Health and Disability Commissioner
The following information was supplied to me by the office of the Health and Disability Commissioner:

- Complaint received from Registered Nurse at the residential care institution on behalf of [Mr A].
- [Health NZ's] response dated 29 October 2021
- Clinical records from 16 September 2021 to 17 September 2021 — in the form of print outs of computer records and other documents
    - i. Admission Note [Hospital 1] — dated 16/10/2021 21:00
    - ii. Admission Note [Hospital 2] — dated 16/10/2021 23:12
    - iii. Covid risk screening form
    - iv. Observation records [public hospital]
    - v. Transfer of Care to GP — Emergency Medicine — [Hospital 1]
    - vi. Transfer of Care to GP — Orthopaedics — [Hospital 2]
    - vii. [District] Clinical Notes — a series of notes printed from a computer system.
    - viii. Referral to Orthopaedic Fracture Clinic 17/10/2021
    - ix. Medication History Form — Orthopaedic
    - x. Medication Administration History Form — 9 pages

- Some [Health NZ] [district] policies
    - i. Apomorphine Adults — 11 pages
    - ii. Medication Management and Competence Assurance — 28 pages
    - iii. Medication Supply Outside Pharmacy Hours — 8 pages
    - iv. Medicine Administration and Monitoring (Adult) — 22 pages

Documentation of Events

The complaint

A Registered Nurse wrote a letter outlining concerns about the care of [Mr A] to the charge nurse at the ward, [Hospital 2] on the 19th of September 2021, which was two days after he returned there. The letter describes [Mr A's] description of his experience in [Hospital 2]. Some of the detail about the pump and the timing of it no longer supplying Apomorphine to [Mr A] is different. The letter states that it ran out at midnight whereas the notes indicate that [Mr A] reported that he felt it had stopped working and then it was turned off at about 3am. This is not a material difference, and both accounts give a story of distress for [Mr A] and a long period where the pump was not operating. [Mr A] reported that he was completely frozen for a very long period. The Registered Nurse points out that [Mr A] did not receive alternative medications such as bolus doses of Apomorphine or oral Sinemet to relieve his distress. This letter was written on behalf of [Mr A] and describes his intention of emphasizing the importance of giving people with Parkinson's Disease their medicines on time.

It is very clear from the letter that [Mr A] experienced a considerable period of being frozen, which is a very distressing and potentially serious experience for a person with Parkinson's disease.

Timeline of events listed in the printed clinical records.

16/10/2021 16:18	Presentation ED at [Hospital 1]
16/10/2021 18:23	Codeine 60 mg administered
16/10/2021 18:23	Ibuprofen 400 mg administered
16/10/2021 21:00	Discharged to [Hospital 2]
16/10/2021 21:35	Clozapine 100 mg administered
16/10/2021 21:35	Quetiapine 25 mg administered
16/10/2021 22:06	Admitted to [Hospital 2]
16/10/2021 23:07	Medical Note 1 (Emergency Bell) — Medical Registrars and HO
16/10/2021 23:12	Orthopaedic admission note completed
17/10/2021 02:56	Medical Note 2 (Emergency Bell) — Medical Registrar and HO
17/10/2021 03:26	Nursing note 1 (retrospective)
17/10/2021 05:25	Nursing note 2
17/10/2021 05:55	Nursing Note 3
17/10/2021 07:21	Nursing Note 4 — care taken over
17/10/2021 08:19	Orthopaedic Note 1
17/10/2021 08:37	Quetiapine 1 tablet administered
17/10/2021 08:37	Paracetamol 1 g administered
17/10/2021 09:22	Nursing Note 5 — patient "unable to move"
17/10/2021 09:24	Pharmacy note 1
17/10/2021 09:42	Medical note 3 Medical Registrar
17/10/2021 09:53	Orthopaedic note 2 — HO
17/10/2021 10:45	Nursing note 6

Attendance at [Hospital 1]

The records indicate that [Mr A] was promptly given analgesia and assessed at [Hospital 1]. A diagnosis was made by the emergency department team, and they consulted with the orthopaedic service at [Hospital 2] who requested that [Mr A] be transferred there. It appears from the records that the PRN Sinemet for breakthrough Parkinson's disease symptoms was not prescribed at this time, which it could have been, noting that [Mr A] was to be transported to [Hospital 2] which would take some time. The Apomorphine infusion was presumably running over this time and during transport. Analgesia, Quetiapine and Clozapine were prescribed.

Admission to [Hospital 2]

Admission documentation

[Mr A] arrived at [Hospital 2] late in the evening. The Orthopaedic House Surgeon completed an "Admission Note" at 23:12. This outlined the plan of care for the ankle injury overnight. It was to be reviewed by the SMO (meaning the Orthopaedic surgeon) in the morning. This included a note of discussion with the Medical Registrars who would be available to manage what is described as "stiffness" and the morphine (sic)[1] pump. (The end of this note is cut off because it is printed from a computer record from a text box)[2]. It is stated in the Admission Note that [Mr A] is to remain under the Orthopaedic team until review by the SMO in the morning.

The Admission Note includes information about [Mr A's] mental status and care arrangements.

First attendance by medical team 23:07

The first medical note describes what appears to be an acute exacerbation of Parkinson's disease symptoms. These were presumably severe because it is noted as an "Emergency Bell". It is hard to determine from the note whether this was a generalised dopaminergic crisis[3] or dystonia. However, the former seems more likely because of the rapid response to an additional dose of Apomorphine which was administered then. The Medical team had consulted some previous letters and concluded that the pump may be blocked as this had happened before. They planned to manage any further episodes with additional doses, which can be supplied by pressing a button on the pump.

Second emergency bell 02:56

[Mr A] is reported as saying that he could not feel the Apomorphine working. The medical registrar reported "dyskinesia" in the notes — this would usually (but not always) mean relative over treatment with medicines for Parkinson's disease which increase overall dopaminergic activity.

The doctors noted that there was 3 mls of Apomorphine left in the pump. The medicines records indicate that the programmed rate for [Mr A] should have been 100mg Apomorphine in 20ml over 24 hours. Assuming that to be the case, then the 3ml would

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[1] Referring to the apomorphine pump as a morphine pump suggests a misunderstanding of its intent and importance.

[2] This is a problem when web based medical records are not set up to print in total from a web browser.

[3] A dopaminergic crisis is when a patient with Parkinson's disease becomes immobile with muscle widespread stiffness. It is potentially serious if uncorrected and may lead to serious complications.

last 3 hours unless bolus doses were used — in which case it would be less. At this point the Apomorphine infusion and the Sinemet had still not been prescribed.

A decision was made to stop the pump and review in 30 mins. This seems reasonable noting the report of dyskinesia, but the second part — to review in 30 minutes was essential. There was also a plan to consult with the movement disorders specialist nurse during daytime. There is no record that this reassessment occurred as planned.

Overnight nursing notes (1,2,3 & 4)

The first nursing note, which was retrospective summarises the events, observations and that the pump had been switched off. Subsequent notes at 05:25 and 05:55 report that [Mr A] was sleeping. There is a note at 07:25 indicating a shift change. No comment was made in these notes about [Mr A's] muscle tone, ability to move or any observable distress.

Orthopaedic note 1 — 08:19

The Orthopaedic House Officer appeared to be of the understanding that a pump would need to be brought in from home. Plans are made for discharge from Orthopaedics with the statement that [Mr A] should be under the care of the medical service. There is no documentation if there was any communication or handover with the medical team about this.

Nursing note 5 — 09:22

This states that [Mr A] reports he is unable to move and has been ringing his bell. The Apomorphine was not yet prescribed. There was still no prescription available to administer a bolus dose of Apomorphine or oral Sinemet — both of which are treatments that may have helped relieve [Mr A's] distress. It appears that there was a plan to seek help from pharmacy. A person is identified in the notes who can connect the pump. (The representative from the pharmaceutical company.)

Pharmacy note — 09:24

This is immediately after the nursing note and summarises the problem plus the contact as above.

Medical note 3 — 09:42

Here it is documented that the Medical SMO (Physician) has charted the medication also that no specific fault can be found with the pump. The medical team made plans for discharge back to [Mr A's] usual home (residential care) and a plan to ask the Clinical Nurse Specialist to follow up after discharge. It is not clear from the records provided exactly when the Apomorphine infusion was recommenced.

Orthopaedic note 2 — 09:53

The House surgeon confirms that the Rest Home are happy to accept him back.

Nursing note 6

Confirms arrangements for discharge and communication with the rest home.

Additional information in the [Health NZ] report
The review carried out by [Health NZ] clarifies some of the timings. It does confirm the long period when [Mr A] was without any treatment for Parkinson's disease. It seems clear that [Mr A] had no Apomorphine between about 03:00 to 10:30 and no other specific treatment for his Parkinson's disease symptoms.

The report confirms that there was very limited experience of using an Apomorphine pump in Hospital 2. Whilst there was information in the form of formal policies and procedures it is not clear from the report how accessible these were to clinical staff. It appears from this report that there is no advice or support available to clinical staff out of hours by phone or otherwise. The report specifically states that there is no on-call Neurology Service available in [Health NZ] [district].

Despite the failure to treat [Mr A] being identified early in the morning, and the pump being prescribed at around 09:00, it was 10:30 before the Apomorphine could be administered to [Mr A] and this required [an employee of the pharmaceutical company] to complete it.

The report contains a number of recommendations which are discussed below.

Commentary
Parkinson's disease medication in hospital
Adverse events in hospital related to failure to provide patients with Parkinson's disease with their prescribed medication in a timely way has been reported as a concern in academic publications, for example recently from the Cleveland Clinic[4]. There is evidence that this has an adverse effect on patients who then have poorer outcomes and prolonged hospital stay as a result. They will also suffer distress from uncomfortable and painful symptoms when treatment is not prescribed, or is given late. When a person with Parkinson's disease presents at hospital, for example to ED, it should be a priority to ensure that their usual medication is provided to them either using their own supplies or prescribing and administering it quickly. The medications for Parkinson's should be treated as a priority. They should not be left to be prescribed and administered after a wait in ED. People with Parkinson's disease are often experts in their own care. Unfortunately, when they are admitted to hospital, they lose access to and control of their own medicines and therefore control over their own wellbeing.

[Health NZ] acute medical and surgical services, including ED, should have a specific plan to ensure that when people with Parkinson's disease present that their medication is not delayed and is appropriately prescribed as soon as possible in their stay. People who are not able to advocate for themselves need active support to ensure that they do not

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[4] Ariane Veilleux Carpentier, Ramzi G. Salloum, Michael S. Okun. Practical proactive and preventative Parkinson's disease strategies for management in the hospital setting, Parkinsonism & Related Disorders, 113, 2023, https://doi.org/10.1016/j.parkreldis.2023.105515. This is a recent paper and post-dates the events in this matter. However it does outline the problem and references earlier papers published before making the same point.

miss medications for Parkinson's disease. This is like other medications such as insulin for people with diabetes. There should also be regular reviews or audits to ensure that people do receive their medicines on time. Where there are electronic prescribing systems these should be a continuous monitoring of time of medicine administration versus prescribing time.

[Health NZ] should ensure that staff are trained and competent in the assessment of patients with Parkinson's disease. There should be recording systems available to staff where such assessments can be reliably recorded.

From comments in the notes it appears that [Mr A] had diminished cognitive ability upon admission to hospital. He may have already had a welfare guardian appointed. Nowhere in the records supplied by [Health NZ] [district] was there a mention of speaking to anyone else. If there was a welfare guardian, then the hospital team are required to make all reasonable efforts to contact that person. It is concerning to see that [Mr A] was distressed in hospital because of difficulties in reliably providing his essential medicines. But then to have him alone, potentially unable to understand what is happening without an attempt to contact relevant people is below an expected standard.

[Health NZ] should have systems to record when people have an activated Enduring Power of Attorney and a welfare guardian, or a Family Court appointed welfare guardian — including who that person is. Staff should be aware of their responsibilities to communicate with the welfare guardian.

Answers to the specific questions posed.
The appropriateness of the co-ordination of care between General Medicine services and Orthopaedic services during [Mr A's] admission at [Hospital 2]

a. <u>What is the standard of care/accepted practice?</u>
   The expected standard is that:
   - It would always be completely clear which is the responsible service and the clinical team which is responsible for a patient in hospital.
   - If there is to be a transfer of care, then it should be explicit, and both teams should agree upon the transfer. It should be clearly documented.
   - If there is uncertainty about which team is responsible, then both teams should communicate directly and resolve it — i.e. not attempt to resolve it indirectly through written records.

b. <u>If there has been a departure from the standard of care or accepted practice</u>
   Yes, there has been a departure from the expected standard of practice.

c. <u>How significant a departure (mild, moderate, or severe) do you consider this to be?</u>
   I consider this specific matter to be a moderate departure from accepted practice.

d. <u>How would it be viewed by my peers?</u>
   I believe that my peers would hold a similar view.

e. <u>Recommendations for improvement that may help to prevent a similar occurrence in future.</u>
[Health NZ] Hospitals should have continuous programmes aimed to improve culture — including collegiality, communication and professionalism.

The adequacy of care provided to [Mr A] during his admission.

a. <u>What is the standard of care/accepted practice?</u>
The expected standard is that:
- Patients with Parkinson's disease are identified early after their arrival at hospital as critically dependent upon their medication with processes to ensure that it is reliably prescribed and administered in a timely manner.
- Patients with Parkinson's disease should be provided with the appropriate medication in a timely and reliable manner.
- There are clinical processes for recording and reliably documenting the assessment of the neurological status of people with Parkinson's disease.
- Where patients have limited cognition, or do not have capacity, then relevant family and, if there is one, the welfare guardian should participate in decisions about care.

b. <u>If there has been a departure from the standard of care or accepted practice</u>
Yes there has been a departure from the expected standard of practice.

c. <u>How significant a departure (mild, moderate, or severe) do you consider this to be</u>?
I consider this specific matter to be a severe departure from accepted practice.

d. <u>How would it be viewed by my peers?</u>
I believe that my peers would hold a similar view.

e. <u>Recommendations for improvement that may help to prevent a similar occurrence in future.</u>
[Health NZ] Hospitals should develop and implement standard processes that ensure people dependent on medications for Parkinson's disease are not harmed by missing or delayed medication. [Health NZ] Hospitals should emphasise continuously in regular communications the need to involve families and the requirement to work directly with legally appointed representatives such as a welfare guardian.

The adequacy of the recommendations and actions taken by [Health NZ] following the events of this complaint.

[Health NZ] make 5 recommendations, which I have commented upon below

1. **Education for both medical and nursing staff around Apomorphine and the importance of continuing this.**
Whilst education on Apomorphine use would be beneficial it may only have a temporary effect unless the clinical scenario of a person receiving Apomorphine by

pump is common. It would be better to generalise this education to include the critical nature of medicines to people with Parkinson's disease. Then staff would be aware of the need to ensure that such people receive their usually prescribed medication, whether oral or by infusion pump. The important message is that people with Parkinson's disease can be critically dependent upon their medicines and that they may become unwell very quickly if medicines are delayed or not given.

2. **Pharmacy will continue to work on updating the existing Apomorphine protocol and transitioning prescribing of Apomorphine to a paper chart. The aim is to make it easier for doctors to prescribe Apomorphine.**
   This is a good recommendation. Whilst electronic systems can be set up to prescribe complex infusions this usually results in an interface that is hard to follow, especially if it is used rarely.

3. **Liaise with the [nearby district's] neurology service as their clinic letters do not currently have the information we need for the doctors to prescribe an Apomorphine infusion when a patient is admitted to hospital. We need to improve the format of these letters. Also to consider whether patients could have a specific alert card with information that they could bring in on admission to trigger appropriate actions by hospital staff.**
   It is certainly ideal if there is a care plan in the Neurology letters that would make it clear how apomorphine is to be used for a particular person. A readily accessible clinical guideline which describes the clinical and practical issues of Parkinson's disease treatment, including Apomorphine would add to this. This could then be updated regularly as new treatments are implemented. Whilst some of this is in the policy documents, they do not lend themselves to use "in the moment" when staff are short of time.

   A well-structured guideline which is designed to be easily assimilated into practice is a better plan. Good examples exist such as the Starship Paediatric guidelines[5] and HealthPathways. They would have to be part of a wider set of guidelines which are used regularly for many things rather than being special and constrained to apomorphine. Empowering patients by giving them a card or alert to give to staff is definitely a good thing. Patients with Parkinsons's disease are experts in their therapy and helping them explain the importance of medication would be a good thing.

4. **Improve regular medication prescribing on admission to hospital. [The district] is working on a proforma which the doctor admitting a patient will have to complete at admission. The form will require the admitting doctor to indicate whether they have prescribed all/some/none of patient's regular medication. It will then be obvious to the nurses and doctors caring for a patient once admitted**

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[5] Health Professionals (starship.org.nz)

if none, or only some, of their regular medications have been prescribed and trigger follow up.
This is a good recommendation. Prescribing on admission to hospital is a complex and high risk area. Ideally staff have access to a reliable record of medicines prescribed and dispensed in the community from a source that can be trusted. Finding a simple and quick process to document the rationale for prescribing — or not prescribing — on admission would be an improvement in safety.

Any other matters that I consider warrant comment.
Apomorphine infusion is a useful drug administration system that can provide benefit to people with advanced Parkinson's disease. A relatively small number of patients receive this treatment. Clinical staff working in mainstream services will only encounter it occasionally and it is unrealistic for them to be expected to have complete knowledge of it. Services who initiate treatments upon which the patient is continuously dependent should ensure that there are systems in place to ensure that health professionals from generalist services know who to contact for advice. Specialist support in these circumstances should be available on a 24 hours per day 7 days a week.

In this case it appears that there was no out of hours back up plan provided by [Health NZ] for this specialist treatment. This could have been included in the contracting arrangements with [the pharmaceutical company] providing the service, or provided by another means such as an on call specialist nurse or neurology service. Providing support 40 hours per week is helpful but that still leaves 128 hours per week uncovered where patients are at risk of ineffective treatment with the potential to cause them harm and/or distress. Health professionals are left unsupported to manage a complex problem. Clear accessible guidelines are a bare minimum which should be part of the mainstream guidelines set available to generalist services in hospital, and in the community.

Conclusion
The complaint and records suggest that [Mr A] was provided with inadequate treatment for Parkinson's disease for a significant period in hospital leaving him frozen and distressed. He was very likely hampered in his ability to advocate for himself due to his cognitive impairment and the difficulty of communicating caused by the (untreated) Parkinson's disease. This is a severe departure from the expected standard of care. It may reflect a lack of supporting systems that should ensure that health professionals have the necessary education and access to support resources and advice when caring for a person with complex Parkinson's disease.

The records indicate that there may have been some lack of clarity on the care plan and who was responsible between the two services providing care to [Mr A]. This may have complicated the situation.

Nigel Millar 01/12/2023'