An Opinion by the Aged Care Commissioner

(Case 20HDC00651)

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Executive summary

1. This report concerns the care provided to an elderly woman by nursing staff at Edmund Hillary Retirement Village (EHRV) prior to her death.

2. Visiting hospice nurses identified that the woman was experiencing end-stage heart failure. The woman's condition deteriorated, and a GP assessment indicated that she was nearing the end of her life. However, the nursing team at EHRV never commenced planning for the woman's end of life, and her care plan was not updated with her palliative care and end-of-life needs.

3. When the woman's daughter visited, on the understanding that COVID-19 restrictions allowed families to visit residents who were receiving palliative care or nearing the end of life, the Clinical Manager attempted to prevent the visit because she believed the woman was not receiving palliative care or nearing the end of life. The Clinical Manager's understanding of the woman's condition did not align with the views of the woman's nursing team.

4. This report highlights the importance of timely end-of-life care planning in partnership with family, and the importance of updating care plans in accordance with palliative and end-of-

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life needs, and ensuring an environment where staff feel comfortable questioning or correcting the views of those senior to them.

Findings

5. The Aged Care Commissioner was critical of the failure to commence end-of-life care planning for the woman following the hospice assessment and the GP assessment. The Aged Care Commissioner was also critical of the failure to update the woman's care plans when she experienced deterioration in the last days of her life, even as her needs changed significantly. The Aged Care Commissioner considered that EHRV failed to provide care in a manner consistent with the woman's needs, in breach of Right 4(3) of the Code.

6. The Aged Care Commissioner found that the woman did not receive regular systematic assessments for common symptoms during her last days of life and, therefore, EHRV did not provide services with reasonable skill and care, in breach of Right 4(1) of the Code.

7. The communication with the woman's family was also found to have been inadequate. This affected the level of care and support the woman received, and did not comply with relevant palliative care standards, in breach of Right 4(2) of the Code.

8. Adverse comment was made regarding the Clinical Manager's attempt to prevent the woman's daughter from visiting. The Aged Care Commissioner considered that the Clinical Manager behaved poorly in her interactions with the woman's daughter, and that nursing staff felt intimidated and did not feel comfortable questioning her judgement. It was noted that this dysfunctional team dynamic contributed to the failure to commence end-of-life planning.

Recommendations

9. The Aged Care Commissioner recommended that EHRV provide a written apology to the woman's family; complete an audit to confirm that residents are receiving appropriate planning for end-of-life care and that regular assessments for symptoms are carried out near the end of life; and use this report as a basis for staff training.

Complaint and investigation

10. The Health and Disability Commissioner (HDC) received a complaint from Mrs B about the care provided to her late mother, Mrs A, at Edmund Hillary Retirement Village (EHRV). The following issue was identified for investigation:

- *Whether Edmund Hillary Retirement Village Limited provided Mrs A with an appropriate standard of care during Month1[1] to Month5 (inclusive).*

11. This report is the opinion of Carolyn Cooper, Aged Care Commissioner, and is made in accordance with the power provided to her by the Commissioner.

[1] Relevant months are referred to as Months 1–5 to protect privacy.

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12. The parties directly involved in the investigation were:

Mrs B	Complainant/consumer's daughter
Edmund Hillary Retirement Village Ltd	Provider

13. Further information was received from:

Te Whatu Ora	Funder
Hospice	
General practice	
Registered Nurse (RN) C	Registered nurse
RN D	Registered nurse
RN E	Registered nurse

14. Clinical Manager RN F is also mentioned in the report.

15. In-house clinical advice was obtained from RN Hilda Johnson-Bogaerts (Appendix A).

16. Both Mrs B and Edmund Hillary Retirement Village were given the opportunity to comment on the provisional opinion, and their comments have been incorporated into this report where relevant. Attempts were made to contact RN F and provide her with the opportunity to comment, but she did not respond to HDC's requests.

Introduction

17. Mrs A (in her nineties) moved into EHRV on 11 Month1 to receive hospital-level care.[2] Her medical history included congestive heart failure, presumed pleural malignancy,[3] hypothyroidism,[4] and hypertension.[5] At the time of admission she was assessed as being at a low risk of falls, and she could mobilise independently and without aid, but needed one carer to provide some assistance with her activities of daily living.

18. A hospice had been involved in Mrs A's care, and hospice nurses continued to visit Mrs A following her admission to EHRV. On 17 Month2, the hospice noted: '[Mrs A] is in End Stage HF (heart failure). Completely palliative and comfort cares.' Hospice nurses continued to visit EHRV monthly, and reviewed Mrs A's symptoms. The final visit occurred on 4 Month5.

19. Aside from shortness of breath, Mrs A remained relatively well until late Month5. EHRV's progress notes on 22 Month5 record that Mrs A was suffering from nausea, vomiting, and light-headedness, and that her pain had increased significantly. Her appetite had decreased, and her oral intake was low. Mrs A's condition continued to decline until her death.

[2] Hospital-level care offers specialist clinical care for people with significant medical needs. It is a higher level of nursing and clinical care than rest-home care.
[3] Lung cancer.
[4] An underactive thyroid gland.
[5] High blood pressure.

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20. Mrs B raised the following concerns with HDC about the care Mrs A received from EHRV:

- On 23 Month5 the Clinical Manager, RN F, acted inappropriately towards Mrs B and her family when they visited Mrs A. Mrs B told HDC that RN F told her that Mrs A was not in palliative care and not in the act of dying, and made them feel unwelcome.
- An end-of-life care plan was never completed or initiated for Mrs A, despite her being assessed as 'completely palliative' by the hospice in Month2, and despite the decline in her condition during Month5.
- Mrs A's medications were not administered in a timely manner, and her falls risk was not managed adequately.
- When Mrs B visited on 29 Month5, EHRV staff did not prepare her adequately to see her mother in a state of significant deterioration.
- Mrs A was not provided with adequate reviews or appropriate medical interventions in the days leading up to her death on 29 Month5.

Opinion: RN F — adverse comment

21. On 23 Month5, Mrs B attended EHRV to visit Mrs A on the understanding that under the COVID-19 restrictions at that time, families could continue to visit residents who were receiving palliative care or were near the end of life. Mrs B shared with HDC the content of an email she received from EHRV dated 21 Month5, which stated:

> 'We are stopping all visits to all our care and serviced apartment residents … The only exceptions will be for the families of residents in palliative care or for end of life care, should you wish to visit.'

22. Mrs B told HDC that on arriving at the gates to EHRV, a man told her that Mrs A was not on the list of palliative care patients, although Mrs B was allowed to proceed to reception after the man made a telephone call.

23. Mrs B told HDC that after entering the reception area, accompanied by her daughter, she was greeted by the Village Manager. Mrs B recalled that the Village Manager apologised for Mrs A not being on the palliative care list and arranged for RN C to take Mrs B to see Mrs A. The Village Manager wrote 'palliative care' on the back of a business card and gave the card to Mrs B for visiting access.

24. Mrs B told HDC that while she was waiting in reception, she received a telephone call from RN D, who was unaware that Mrs B was already at the facility. RN D encouraged Mrs B to visit Mrs A because of her declining state of health. Mrs B said that while she and her daughter were still waiting in reception, she was confronted by Clinical Manager RN F. Mrs B recalled that RN F told her that Mrs A was not in palliative care and not in the act of dying. Mrs B said that during this interaction RN F spoke very aggressively and made her feel that she was in the wrong for visiting Mrs A. Mrs B told HDC that she and her daughter were surprised and distressed by the mixed messages provided about Mrs A's condition.

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25. RN C witnessed Mrs B's interaction with RN F. In a statement provided to HDC, RN C recalled that RN F acted 'rudely and very unprofessionally' towards Mrs B. RN F next called both RN C and RN D to the nurses' station. In a statement to EHRV, RN D recalled that RN F told them that she was the only member of staff who could decide whether a resident was dying, and that Mrs A was not 'actively dying' and could 'live for another ten years'. RN F's assessment did not align with the understanding of RN D and RN C that Mrs A was receiving palliative care. RN D told EHRV that RN F had visited Mrs A only 'one time' after not having visited 'for a long time' before concluding that she was not dying.

26. RN D described feeling 'intimidated, overwhelmed, and bullied' by RN F during their interaction at the nurses' station, and stated that she lost confidence in her own clinical judgement for some time afterwards as a result.

27. Following the discussion at the nurses' station, Mrs B was allowed to visit Mrs A briefly. Later that day, Mrs B emailed a complaint to the Village Manager about RN F's manner and behaviour, and her inaccurate assessment of Mrs A's condition. The Village Manager indicated that they would contact Mrs B the following day to discuss the incident. However, this intended follow-up did not occur, and the Village Manager later explained to EHRV that this was because of their workload and their desire to give Mrs B 'space'.

28. EHRV told HDC that at the time of this incident, staff were under pressure navigating their way through COVID-19 Alert Level restrictions and working with families on a case-by-case basis around visits to their loved ones. EHRV accepted that Mrs A met the criteria for visitation, and that RN F should have gained more information from the nurses and doctors caring for Mrs A, to ensure that RN F provided Mrs A's family with accurate information about her condition. EHRV also accepted that RN F's manner and behaviour towards Mrs B was inappropriate, and apologised to Mrs B that the Village Manager did not follow up to address her concerns as promised.

29. Te Whatu Ora carried out an investigation into the incident and found that on 23 Month5 EHRV did not follow its internal escalation process for visits.[6] Te Whatu Ora commented:

> '[EHRV] staff did not understand that approved visiting for [Mrs A's] family had been given, and what this meant. This uncertainty was further complicated by the communication and actions of the Clinical Manager [RN F], and the failure of [EHRV] management to follow up when it should have been recognised that the communication on visiting was not appropriate or fully understood at the time … We believe that the communication and actions of the Clinical Manager were inappropriate, and were not what we would expect from a staff member of a contracted aged residential care facility.'

30. In addition, I note that Te Whatu Ora's investigation found that Mrs A's progress notes on 28 and 29 Month5 suggest that at that time, EHRV staff were still not clear as to who was

[6] EHRV told Te Whatu Ora that the process in place for proposed family visits was for all pending visits to be reported to the Clinical Manager. EHRV said that staff did not follow this process on 23 Month5.

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responsible for approving visits to the facility, and what the internal escalation process was if needed. The investigation highlighted that EHRV's process for restricted visiting needed to be more responsive, giving families the opportunity to visit immediately if it was recognised that a resident was nearing the end of life, rather than having to wait for visiting approval to be granted the following day, as occurred on 29 Month5 for Mrs A's family.

31. I agree with Te Whatu Ora's findings, and I am concerned that there was an ongoing lack of clarity among EHRV staff around the process for approved visits. I discuss this further in relation to EHRV below.

32. It is clear on the evidence before me that RN F behaved inappropriately. Her manner was rude and abrasive, her communications lacked kindness and empathy, and her assessment of Mrs A's condition was not supported by Mrs A's nursing team. This was a time when accuracy and sensitivity were of the utmost importance, and I am concerned that RN F's communication with Mrs A's family members lacked these features, and that her inaccurate assessment of Mrs A's condition could have affected Mrs A's ability to receive support and visits from her family as she neared her end of life.

33. In making these comments, I am mindful that the Code of Health and Disability Services Consumers' Rights (the Code) confers the right to be treated with respect to consumers, rather than their family members. I therefore accept that RN F's actions were not in breach of the Code. In addition, I acknowledge that the incident on 23 Month5 occurred during COVID-19 restrictions. My in-house aged care advisor, RN Johnson-Bogaerts, noted that this was an unprecedented and stressful time for front-line staff. I accept that these were difficult circumstances, but this does not excuse the poor interaction that occurred with the family members whose loved one was nearing the end of life.

34. I also find it highly concerning that RN D felt 'intimidated, overwhelmed, and bullied' by RN F during their interaction at the nurses' station that day, and that as a result RN D lost confidence in her own clinical judgement for some time afterwards. RN C similarly described not feeling safe under RN F's leadership. I consider that such comments are suggestive of a workplace culture where staff did not feel comfortable exercising their clinical judgement, and that staff were concerned that this environment could compromise the standard of care provided to patients.

35. I am critical of RN F's conduct in asserting her opinion over that of the nurses who were familiar with Mrs A's condition and who were involved in her daily care. RN F's behaviour had the potential to affect Mrs A's palliative and end-of-life care and support. I consider that the absence of a shared understanding between RN F and Mrs A's nursing team regarding Mrs A's condition contributed to her family not being adequately informed of her condition, and not being adequately involved in her care during her final days. I further note that RN D told EHRV that an end-of-life care pathway for Mrs A was not initiated 'mainly due to [RN F's] statement of [Mrs A] not dying'. I will discuss these matters, including the lack of end-of-life care planning and the deficient standard of care Mrs A received during her final days, later in this report.

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36. I understand that RN F is no longer residing or practising within New Zealand. Nonetheless, I will bring the concerns raised about RN F's conduct to the attention of the Nursing Council of New Zealand so that it is aware of the events should RN F return to New Zealand.

Opinion: Edmund Hillary Retirement Village

Lack of end-of-life pathway planning and failure to update care plan — breach

37. EHRV utilises the Ministry of Health *Te Ara Whakapiri: Principles and guidance for the last days of life* (*Te Ara Whakapiri*),[7] which outlines the essential components and considerations required to promote quality end-of-life care. EHRV told HDC that the aim of *Te Ara Whakapiri* is to ensure that a resident has a peaceful and dignified death. EHRV's End of Life Plan Policy and Procedure includes the use of the *Te Ara Whakapiri* format in conjunction with the family, general practitioner (GP), and other health professionals as appropriate.

38. The *Te Ara Whakapiri* guidelines call for practitioners to develop an individualised care plan for a person in their last days of life, in collaboration with the person and their family. The plan should be documented and reviewed and updated to take account of regular assessments of the person's condition. The *Te Ara Whakapiri* guidelines also underline the importance of recognising when a person is dying or approaching the last days of life. The guidelines state:

> 'Health practitioners should identify as early as possible that a person is dying, to allow for timely, appropriate care and communication involving the person (where possible) and their family/whānau. Early identification enables the clinical team to prioritise the provision of comfort and support based on the person's preferences.'

39. EHRV told HDC that Mrs A was in a palliative condition when she was admitted to EHRV in Month1, but that her death was not imminent at that time, and therefore she did not meet the criteria for commencing *Te Ara Whakapiri* care documentation. EHRV explained that if a resident has a long-term palliative diagnosis, but death is not imminent, as was the case with Mrs A, the hospice works alongside the GP and nurse practitioner (NP) for palliative care planning. The nurses at the village are responsible for escalating any reviews required to the GP or NP, and, if a resident is deteriorating, the nurses are also required to inform their Unit Coordinator and Clinical Manager. This includes identifying that a resident appears to be in the end stages of life. The Clinical Manager at the village has oversight of all residents in the care centre. Along with the nurses at the village, GPs and NPs usually have the overall responsibility for activating *Te Ara Whakapiri* care pathways for residents in the end stages of their life, together with the resident's family.

40. EHRV told HDC that an end-of-life care plan was never put in place for Mrs A. EHRV accepted that there were missed opportunities to initiate a *Te Ara Whakapiri* pathway, when Mrs A's symptoms of chest tightness and nausea were increasing, and she had increased morphine requirements and a decreased oral intake. EHRV said that it was at this time that nursing

[7] Ministry of Health, *Te Ara Whakapiri: Principles and guidance for the last days of life*, 2nd edn, 2017.

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staff began to consider that Mrs A's death could be imminent. The progress notes record that on 11 and 12 Month5 Mrs A began to vomit, and on 13 Month5 she was seen by the GP. The 13 Month5 nursing progress notes report that the GP assessed Mrs A to be in 'steady decline', and that staff were to 'manage symptoms only'. EHRV told Te Whatu Ora that it was then agreed that the nursing team would follow a palliative, symptom management approach in light of the GP's assessment. However, neither the medical team nor the nursing team initiated *Te Ara Whakapiri* documentation.

41. My in-house aged care advisor, RN Johnson-Bogaerts, advised that end-of-life care pathways are activated only when a nurse recognises that death is imminent and may be measured in hours or days. In RN Johnson-Bogaert's opinion, for Mrs A this would have been between 24 and 28 Month5. At that time, the person and their family must be given the opportunity to understand what is happening, and that the end-of-life care plan is being activated. When initiated, the care plan then guides staff to assess the person systematically and control symptoms at an early stage. RN Johnson-Bogaerts was concerned that these expected actions did not occur in Mrs A's case because no *Te Ara Whakapiri* care plan was in place.

42. RN Johnson-Bogaerts noted that the failure to develop a *Te Ara Whakapiri* care plan was contrary to EHRV's policy.[8] She explained that usually such plans are developed and prepared with the patient and their family/whānau in advance of the last days of life, so that the plan can be activated when needed. She said that in addition to the missed opportunities acknowledged by EHRV, a good time to have commenced *Te Ara Whakapiri* planning with Mrs A and her next of kin was following the hospice assessment on 17 Month2, when Mrs A was noted to be in end-stage heart failure and requiring 'completely palliative and comfort cares'.

43. I accept EHRV's view that Mrs A did not meet the criteria for commencing *Te Ara Whakapiri* care documentation upon her entry into EHRV during Month1, as her death was not then imminent, nor had it been determined that she had end-stage heart failure. However, Mrs A's condition changed during Month2. While I acknowledge that EHRV has accepted that there was a missed opportunity to initiate end-of-life planning following the GP assessment on 13 Month5, I accept RN Johnson-Bogaert's advice that there was also an earlier missed opportunity to commence this planning during Month2 following the hospice assessment. I am very concerned that EHRV missed these opportunities to develop an end-of-life care plan for Mrs A, and that the omission played a role in the nursing team not taking appropriate actions during her end-of-life phase.

44. In its response to the provisional opinion, EHRV acknowledged and apologised that EHRV did not initiate *Te Ara Whakapiri* planning for Mrs A in Month5, and recognised that this pathway could also have been discussed in Month2. However, EHRV stated that the clinical team did not consider commencing *Te Ara Whakapiri* planning for Mrs A because she was

[8] EHRV's End of Life Plan Policy and Procedure in place at the time of events required the development of a *Te Ara Whakapiri* plan for residents to ensure that 'a resident has a peaceful and dignified death', and included the use of the *Te Ara Whakapiri* format in conjunction with the family, GP and other health professionals as appropriate.

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well enough to engage in village activities when visited by hospice nurses on two occasions during Month2 and Month4.

45. I acknowledge EHRV's explanation of the clinical team's decision-making. Nonetheless, I remain guided by RN Johnson-Bogaerts' advice that it would have been appropriate to commence *Te Ara Whakapiri* planning following the hospice assessment of end-stage heart failure.

46. RN Johnson-Bogaerts noted that Mrs A's nursing care plans were not updated when Mrs A experienced deterioration in the last days of her life, even as her needs changed significantly. RN Johnson-Bogaerts considers that the failure to update Mrs A's care plan to account for her palliative-care needs and end-of-life needs was a significant deviation from accepted practice. RN Johnson-Bogaerts stated:

> 'Not updating a care plan is not only a clinical documentation issue and an issue of care coordination between the different shifts and between the care teams, a care plan also serves to provide informed consent. In the circumstances I consider it unreasonable that there [were] no updates to the care plan for it to reflect palliative care needs and end of life needs. My peers would consider this in the circumstances a significant deviation from accepted practice.'

47. I accept this advice. Even without *Te Ara Whakapiri* documentation in place, Mrs A's care plan should still have been updated with her palliative-care and end-of-life needs as her condition declined.

48. In its response to the provisional opinion, EHRV acknowledged that Mrs A's clinical notes and care plan did not meet the standard it would expect.

49. EHRV told HDC that a contributing factor to Mrs A's care plan not being updated was that the nursing team was influenced by Clinical Manager RN F's view that Mrs A was not in the end stages of her life. EHRV provided statements from Mrs A's nursing team describing how RN F's behaviour when Mrs B visited on 23 Month5 influenced their decision-making.

50. The nursing progress notes on 22 Month5 record that Mrs A had nausea and vomiting and was light-headed. Her pain had increased significantly, her appetite had decreased, and her oral intake was low. RN D told HDC that she believes that by the time Mrs B visited on 23 Month5, Mrs A was deteriorating. RN D acknowledged that she should have initiated the *Te Ara Whakapiri* pathway at that time, beginning with escalation to the GP or NP, and holding a family meeting to discuss the goals of care. RN D explained that the pathway was not initiated 'mainly due to [RN F's] statement of [Mrs A] not dying'. RN C similarly stated that *Te Ara Whakapiri* was 'not initiated nor advised' due to RN F 'angrily' responding to any suggestion that Mrs A was dying.

51. RN E, another member of the nursing team, described the impact of RN F's views on Mrs A's care pathway as follows:

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> '[RN F] had challenged us that Mrs A is not dying so no need to start her on Te Ara Whakapiri. [RN F] also gave me strict instructions that she will be the one to decide which families are allowed to visit. [Mrs A] did not have a medical review [on 23 Month5] but I believe she was logged for review later in the week. Therefore, [Mrs A's] care plan was not fully updated.'

52. EHRV also told HDC that it conducted a debrief with RN F, during which she accepted that she should have listened to the views of the nursing team that Mrs A was in the end stages of life.

53. EHRV highlighted the added workload associated with COVID-19 restrictions as an additional contributing factor to the failure to plan for Mrs A's end of life and update her documentation to take account of her deteriorating condition. These added pressures included new procedures in the hospital unit, the management of visitors, increased communication with family members, and the use of personal protective equipment. In addition, district nurses were not able to provide wound care for independent apartment residents at this time, resulting in many nurses from the care home areas being required to assist with wound-care management. In its response to the provisional opinion, EHRV reiterated the significant pressure and anxiety for families and those working and living within the village as a result of the withdrawal of district nursing support for wound care and community home care services, with EHRV staff required to provide both services at short notice.

54. EHRV pointed out that some of Mrs A's care plans were nonetheless updated, for example ulcer prevention. The clinical records for Mrs A's care show that nurses and caregivers commented on how Mrs A presented, took sets of observations, recorded her intake of fluid and food, monitored bowel movements, assessed pain, and provided medication. In her statement to EHRV, RN D said that palliative care was provided, including doing intentional roundings[9] and checking on Mrs A's pain/nausea/ agitation.

55. None of the above information altered RN Johnson-Bogaerts' opinion that Mrs A's care plans were not updated adequately to take account of her end-of-life needs, and that this amounted to a significant deviation from accepted practice.

56. I am critical of Mrs A's nursing team for failing to commence *Te Ara Whakapiri* planning following the hospice assessment on 17 Month2, and after the GP assessment on 13 Month5. Both assessments recognised that Mrs A's condition was deteriorating, and should have prompted end-of-life care planning. As RN Johnson-Bogaerts noted, the lack of development of a *Te Ara Whakapiri* pathway for Mrs A was a failure to comply with EHRV's organisational policy. I am also critical that the nurses did not escalate to a GP or a nurse practitioner after they recognised further deterioration in Mrs A's condition from 22 Month5, so that her condition could be reassessed. However, I am most critical that Mrs A's

[9] A structured process whereby nurses carry out regular checks of patients, usually hourly, using a standardised protocol to address issues of positioning, pain, personal needs and placement of items.

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care plan was not updated to take account of her changing needs. I accept RN Johnson-Bogaert's advice that this omission was a significant deviation from accepted practice.

57. It appears that a dysfunctional team environment had a significant impact on the nurses' decision-making. It is clear that EHRV's staff did not work together effectively to provide Mrs A with timely, appropriate and safe services. This was due to a lack of shared understanding between RN F and Mrs A's nursing team regarding whether Mrs A was dying or approaching her last days of life. It is clear that there was a reluctance among the team to challenge the Clinical Manager's view that Mrs A was not actively dying or in her last days of life, despite believing her to be so. This fragmentation contributed to the lack of planning for her end-of-life stage, and to her care plans not being updated to reflect her changing needs.

58. EHRV held a duty of care towards Mrs A to ensure that its service operated efficiently and effectively, as required by the Health and Disability Services (CORE) Standards in place at the time of events, which provided as follows:

> 'Service Management Standard 2.2: The organisation ensures the day-to-day operation of the service is managed in an efficient and effective manner which ensures the provision of timely, appropriate, and safe services to consumers.'[10]

59. The statements of Mrs A's nursing team point toward an environment where staff did not feel comfortable questioning or correcting the views of the Clinical Manager and were hindered from performing their roles fully or freely exercising their clinical judgement. This posed a significant safety risk to residents, and the responsibility for managing the environment that created this risk fell upon EHRV as an organisation.

60. I accept that COVID-19 restrictions during Month5 had a significant impact on staff workloads and contributed to the deficiencies identified. However, I consider that this does not mitigate against a finding of a breach of the Code in this case, given that there were missed opportunities to initiate appropriate end-of-life care planning prior to the restrictions. EHRV itself acknowledges that there was a missed opportunity to initiate end-of-life planning when Mrs A showed early signs of decline on 13 Month5, and RN Johnson-Bogaerts advised that it would have been appropriate to have commenced *Te Ara Whakapiri* planning during Month2.

61. For the above reasons, I find that EHRV failed to ensure that Mrs A received services in a manner consistent with her needs, in breach of Right 4(3) of the Code.

Lack of family involvement in end-of-life care — breach

62. At 2.53pm on 28 Month5 Mrs B received a call from RN D updating her on Mrs A's deteriorating condition. Mrs A's progress notes record that Mrs B indicated that she would contact the Village Manager to arrange a visit the following day.

[10] 2008 Standards.

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63. A text message sent from Mrs B to the Village Manager at 10.58am on 29 Month5 thanked them for approving a visit and noted that she was on her way to the facility. Mrs B told HDC that when she arrived, the Village Manager met her in reception and said that the latest assessment was that Mrs A was not in palliative care and not in the dying stage. Mrs B told HDC that after the Village Manager's words she expected to find Mrs A in a slightly worse state than her last visit. Instead, she found that Mrs A had a blackened tongue and hands, was in pain and distressed, had laboured breathing, and was unable to understand her. Mrs B told HDC that the extent of Mrs A's decline came as a surprise to her, and she felt inadequately prepared to see her mother in this state. A text message sent from Mrs B to the Village Manager at 3.22pm conveyed that she was deeply shocked by what she had seen.

64. EHRV told HDC that it accepted that its communication with Mrs A's family in relation to her end-of-life care was inadequate. EHRV also noted that the fact that RN F did not assess Mrs A as being at the end of her life affected the way the rest of the nursing team approached Mrs A's care pathway. However, EHRV believes that its day-to-day communication with Mrs B was adequate. EHRV pointed out that throughout this time, discussions with family were documented in Mrs A's progress notes, such as on 22 Month5 when RN D recorded that she spoke with Mrs B and her husband regarding Mrs A's condition, and they agreed on symptom management. RN D informed the family, Clinical Manager, and NP on several occasions that she thought that Mrs A was entering the end stage of life. RN C also believes that their communication with Mrs A's family was 'regular, informative and compassionate'.

65. In its response to the provisional opinion, EHRV acknowledged that it did not keep Mrs A's family up to date and that it did not provide them with information on the dying process and what to expect as Mrs A approached the end of her life.

66. All healthcare providers have an obligation to provide services that comply with relevant standards. The relevant standard in this case was the Hospice New Zealand Standards for Palliative Care,[11] which includes a requirement to support and care for the family as part of service provision. RN Johnson-Bogaerts advised that good practice under this standard requires an aged residential care facility to involve family as part of the care planning, including the identification of their needs, expectations, responsibilities and desired level of involvement. Expected practice is for a family to be kept up to date as their loved one's health declines, and for them to be provided with information on the signs and symptoms of approaching death, the management available for the symptoms, and other details about the person's care.

67. The records for Mrs A's care do not show that her family was provided information on the dying process and what to expect, or how the family could contribute to her care. RN

[11] https://www.hqsc.govt.nz/assets/Consumer-hub/Partners-in-Care/Publications-resources/HNZ-standards-2019.pdf.

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Johnson-Bogaerts also noted that the anticipatory prescribing[12] of haloperidol[13] was not explained to Mrs B. RN Johnson-Bogaerts advised that EHRV's standard of communication with Mrs A's family was therefore inadequate and a moderate deviation from accepted practice.

68. I accept RN Johnson-Bogaert's advice that Mrs A's family received a substandard level of communication from EHRV in relation to her end-of-life care, and I am concerned that this affected the level of support and the standard of care she received as a result of her family not being advised how they could contribute. While I acknowledge that RN D informed the family on several occasions that she thought that Mrs A was entering the end stage of life, it is also clear that on 23 Month5 Mrs B received a very different assessment from RN F that Mrs A was not actively dying or nearing the end of life. When Mrs B arrived on 29 Month5, it appears that the Village Manager repeated RN F's assessment that Mrs A was not in palliative care and not in the dying stage.

69. I have discussed my concerns about the team environment at EHRV above, and the negative impact the absence of a shared understanding between RN F and Mrs A's nursing team had on Mrs A's care. In my view, ultimately this lack of co-ordination led to Mrs A's family not being adequately informed of her condition, and not being adequately involved in her care during her final days.

70. It is clear from RN Johnson-Bogaerts' advice that the standard of EHRV's communication with Mrs A's family fell considerably short of the expectations set out in the Hospice New Zealand Standards for Palliative Care, and it follows that this affected the level of care and support Mrs A received. Consequently, I find EHRV in breach of Right 4(2) of the Code, for failing to comply with a relevant standard when providing care to Mrs A.

Standard of care provided to Mrs A in the days prior to her death — breach

71. EHRV told HDC that Mrs A's nursing team provided palliative care for Mrs A despite not updating her care plan with her palliative-care or end-of-life needs. RN D told EHRV: '[W]e still provided palliative care for [Mrs A], doing intentional roundings and checking on her pain/nausea/agitation.' Similarly, RN C stated that 'staff still provided cares and interventions to ensure [Mrs A's] comfort'.

72. RN Johnson-Bogaerts reviewed Mrs A's clinical records to assess the standard of care provided to Mrs A in the days prior to her death.

73. RN Johnson-Bogaerts advised that Mrs A's haloperidol was managed appropriately. Anticipatory prescribing of haloperidol was in place so that the medication could be used as and when required, and RN Johnson-Bogaerts found that it was administered in a timely way. RN Johnson-Bogaerts also advised that Mrs A's falls risk was managed adequately, and

[12] Anticipatory prescribing is when medications are prescribed and dispensed in preparation for the time when a person needs them.

[13] A medication used to treat mental/mood disorders and to improve clarity of thinking. In end-of-life care, haloperidol is used to treat agitation/severe restlessness, and also to relieve nausea and vomiting.

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that it was appropriate that nursing staff checked on Mrs A every 30 minutes when she entered the dying stage. RN Johnson-Bogaerts found no deviations from accepted practice with regard to these matters, and I accept her advice that Mrs A's care met the expected standard in these areas. RN Johnson-Bogaerts' advice is set out in full in Appendix A.

74. However, RN Johnson-Bogaerts was concerned about the adequacy of the monitoring and assessment of Mrs A's condition. She explained that good end-of-life care, as per the *Te Ara Whakapiri* end-of-life pathways, includes systematically assessing for common symptoms at the end of life, such as performing regular pain checks, so that these symptoms can be managed when still mild. RN Johnson-Bogaerts found that Mrs A's clinical notes did not include or report on regular systematic assessments for symptoms, and that there was no documentation of such assessment in the clinical notes. RN Johnson-Bogaerts advised that these documentation omissions were a moderate to significant deviation from accepted practice.

75. I accept this advice, and I am concerned that there is no documented evidence to support that Mrs A received oversight and monitoring adequate to her palliative-care and end-of-life needs.

76. EHRV provided HDC with statements from Mrs A's nursing team suggesting that they monitored Mrs A's condition, and that measures were taken to ensure her comfort. However, EHRV acknowledged that the nursing documentation for Mrs A's care was incomplete. It highlighted that COVID-19 restrictions played a role, and that 'there were extra tasks during [the restrictions] which may have had some impact on their completion of some nursing documentation'.

77. In its response to the provisional opinion, EHRV stated that end-of-life care, the understanding of the principles of clear documentation, and the use of *Te Ara Whakapiri* have improved since Mrs A's death.

78. This Office has commented previously[14] that health professionals have a fundamental obligation to keep clear and accurate clinical records, and that in addition to providing evidence of what happened, adequate record-keeping is important to ensure continuity of care when a patient is being seen by multiple practitioners. While I accept that nursing staff monitored Mrs A and provided comfort cares, there is no indication from their responses that regular systematic assessments for symptoms were performed. I have discussed above how a lack of end-of-life planning affected the care Mrs A received and resulted in the failure to commence an end-of-life care pathway. It is also clear that there was division and conflict amongst EHRV staff and a lack of shared understanding of Mrs A's deteriorating condition. Given these circumstances, and in the absence of any documented evidence to the contrary, I find that it is more likely than not that Mrs A did not receive regular systematic assessments for common symptoms during her last days of life.

[14] See opinions 18HDC00740 and 18HDC00918.

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79. On the basis of RN Johnson-Bogaert's advice, I consider that Mrs A did not receive services of an appropriate standard during her last days of life. I acknowledge that the timeframe of Mrs A's decline coincided with COVID-19 restrictions that New Zealand experienced, and that immense pressures were placed upon aged residential care staff at that time. However, while I accept that this context mitigates against finding any individual member of EHRV's nursing team in breach of the Code, I hold EHRV as an organisation responsible for ensuring that Mrs A received an appropriate standard of service in the circumstances. There is also a lack of documentation to show that EHRV took reasonable steps in the circumstances to comply with its duty to provide Mrs A with an appropriate standard of service. For these reasons, I find that EHRV did not provide Mrs A services with reasonable skill and care in the days prior to her death, in breach of Right 4(1) of the Code.

Changes made since events

80. EHRV shared a Quality Improvement Plan with HDC and explained that it had followed up with individual team members to outline expectations, facilitated debriefing sessions on the learnings, and provided refresher training on relevant policies to all nursing and care staff, and that all nurses at EHRV were required to attend hospice training on *Te Ara Whakapiri*.

81. EHRV advised HDC of the following further changes it made to improve recognition of the signs of early deterioration, and to involve the family/whānau at the earliest point possible:

- A palliative care kit is now available on each floor. Staff understand the indications for use, and how to use the kit.
- Health Quality & Safety Commission Frailty Guides are now available on each floor.
- Palliative care training was held with the hospice.
- Palliative care assessment tool training has been carried out with all registered nurses.
- In-service training on palliative care has been provided for nurses, including 'Last days of life — recognising dying', 'Defining and recognising frailty', 'Acute deterioration', 'Gradual deterioration', and 'Communication', among others.
- Syringe driver training has been provided for registered nurses, including when to commence a syringe pump for symptom management.
- Mrs B's complaint has been discussed at a caregivers meeting in the context of palliative care and management of end-of-life care.
- A new section, 'End of Life Planning — assessment and Te Ara Whakapiri and escalation to GP', has been added to the ongoing weekly management team meeting.
- RN D now feels empowered and knows the importance of speaking up and advocating for her residents, even if someone senior to her has a different opinion. RN D has also completed further study to become a Palliative Outcome Initiative (POI) nurse. POI promotes early recognition of the need for palliative care in the last 6–12 months of life.

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RN D has found this training very useful for her role as a registered nurse working in residential aged care.

82. In its response to the provisional opinion, EHRV underlined that Mrs A's experience was pivotal in making sure that improvements to end-of-life care were embedded into the culture of the village. EHRV highlighted the following further actions completed:

- Mrs B's complaint was reviewed as part of an external surveillance audit of EHRV. The audit report recognised that appropriate quality improvements had been implemented in relevant areas such as recognising deterioration and dying, communicating with family members, and completing end-of-life care documentation.
- The actions taken in response to Mrs B's complaint were also noted when EHRV underwent a full certification audit. The audit report recognised that 'quality improvements (reported at the previous audit) linked to this complaint have been fully embedded, including *Te Ara Whakapiri* guidelines, regular pain checks and updating care plans to reflect changes in health care needs'. The audit report also found that family are involved appropriately in residents' care.
- Both the surveillance audit and certification audit stated that when a resident's condition alters, the registered nurse initiatives a review with the GP/NP.
- Six internal continuous service delivery audits have been completed at the village, including scrutiny of whether care plans have been updated when health needs change, as well as GP and family involvement. In the three years since Mrs B's complaint, the results from this audit have continued to improve, and the village achieved 100% compliance.
- Further education on end-of-life care and updating care plans has occurred to embed further the importance of accurate documentation that reflects the current needs of residents. Further education has been (and continues to be) provided on timely, accurate and compassionate communication in relation to end-of-life care.
- The relationship between EHRV and the hospice has strengthened with the provision of palliative support and advice, pain management and education support.
- *Te Ara Whakapiri* is now a topic of discussion at the weekly management meeting to ensure that all members of the leadership team receive the same information and plan for family meetings.

83. In response to the provisional opinion, EHRV also provided a statement from RN E supporting that there had been many positive changes at EHRV since Mrs B's complaint. RN E spoke positively of the team environment at EHRV, including the two Clinical Managers, and noted improvements in the areas of communication between staff, end-of-life care planning, family involvement in residents' care, and ongoing training regarding *Te Ara Whakapiri*.

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Recommendations

84. Having considered the changes made by EHRV since these events, I recommend that EHRV:

a) Provide a formal written apology to Mrs A's family for the breaches and deficiencies outlined in this report. The apology is to be provided to HDC within three weeks of the date of this report, for forwarding to Mrs B.

b) Conduct an audit of the records for at least 10 residents who received palliative care at EHRV to confirm that the care provided was in accordance with the Hospice New Zealand Standards for Palliative Care. In particular, the audit should:

   i) confirm that *Te Ara Whakapiri* end-of-life planning commenced at an appropriate time and/or identify any missed opportunities to have done so;

   ii) confirm that *Te Ara Whakapiri* documentation was completed when indicated;

   iii) confirm that care plans were updated to reflect palliative-care and end-of-life needs as a resident's condition declined; and

   iv) confirm that regular systematic assessments for symptoms were carried out near the end of life.

   The results of the audit, including the reasons for any instances of non-compliance and any corrective actions for improvement, are to be reported to HDC within six months of the date of this report.

c) Use an anonymised version of this report as a basis for staff training, focusing particularly on the breaches of the Code identified, and provide evidence of that training to HDC within six months of the publication of the anonymised report.

Follow-up actions

85. A copy of this report with details identifying the parties removed, except Edmund Hillary Retirement Village Limited (trading as Edmund Hillary Retirement Village) and my in-house advisor on this case, will be sent to the Nursing Council of New Zealand, and it will be advised of RN F's name.

86. A copy of this report with details identifying the parties removed, except Edmund Hillary Retirement Village Limited (trading as Edmund Hillary Retirement Village) and my in-house advisor on this case, will be sent to HealthCERT and to Te Whatu Ora, and will be placed on the HDC website, www.hdc.org.nz, for educational purposes.

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Appendix A: In-house clinical advice to Commissioner

The following aged care advice was obtained from RN Hilda Johnson-Bogaerts on 15 February 2021:

‘1. Thank you for the request that I provide clinical advice in relation to the complaint about the care provided by Edmund Hillary Retirement Village. 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.

2. I was asked to review the documentation and advise whether I consider the nursing care provided to [Mrs A] was reasonable in the circumstances and why. In particular I was asked to comment on:

   a. Whether the decision not to escalate [Mrs A’s] care for further GP/NP review on 24 [Month5] was reasonable in the circumstances.
   b. Whether the decision not to initiate an end of life pathway for [Mrs A] in response to her deteriorating condition on 24 [Month5] was reasonable in the circumstances.
   c. Whether the decision to administer Haloperidol was made in a timely manner, in light of [Mrs A’s] condition at the time.
   d. Whether there were adequate measures put in place for managing [Mrs A’s] falls risk.
   e. The adequacy of the communication between rest home staff and [Mrs A’s] family between 22 [Month5] and 29 [Month5].
   f. The adequacy of [the care facility owner’s] policies relating to the end of life plan, restraint minimisation and falls prevention/management.
   g. Any other matters in this case that you consider warrant comment.

3. **Documents reviewed**

   - Letter of complaint, dated …
   - [The care facility owner’s] initial response to Mrs B’s complaint, dated …
   - Mrs B’s comments on the above response, dated …
   - [The care facility owner’s] response to HDC’s request for information, dated …
   - Relevant clinical documentation from Edmund Hillary Retirement Village.
   - [The care facility owner’s] policies relating to the end of life plan, restraint minimisation and falls prevention/management.
   - [Mrs A’s] GP records from 13 [Month5].

4. **Complaint as presented to me**

   [Mrs B] complains about the standard of palliative/end of life nursing care [Mrs A] received at Edmund Hillary Retirement Village immediately prior to her death on 29 [Month5]. [Mrs B] considers that the care provided to her mother was

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"questionable", and that there was a lack of medical intervention in the days leading up to [Mrs A's] death. She is also concerned about staff members' communication with herself and other family members.

5. **Provider response(s)**

The provider acknowledged in their letter of response that at the time their Te Ara Whakapiri (end of Life) pathway documentation was not completed by the medical and nursing team although this is their policy to complete this for residents who are deemed palliative. The provider further explains that the nursing team monitored [Mrs A], provided symptom management and comfort care, and escalated to the medical team whenever there were uncontrolled symptoms. The team provided daily updates to the complainant.

6. **Review of clinical records**

[Mrs A] was a [lady in her nineties] who moved in to Edmund Hillary Retirement Village's care home on 11 [Month1] to receive hospital level care. Her medical history included Congestive Heart Failure, Presumed Pleural Malignancy, Hypothyroidism, Hypertension. At that time she was assessed as being at low risk of fall, she could mobilise independently and without any aid and she needed some assistance from one staff with her activities of daily living.

The medical progress notes show that the hospice were involved in her care since [Month1] and visited monthly until 5 [Month4] reviewing her symptoms. I did not find notes of a hospice review after this date for input into the care or medication. The notes from the Hospice of 17 [Month2] include that "*[Mrs A] is in End Stage HF (heart failure). Completely palliative and comfort cares".*

The forwarded nursing care plans included the Vcare Audit Report and, the Resident Clinical Notes Front Page which included a subtitle "Current Care Information" with instructions for care.

The care instructions on this document do not include any reference to a palliative care approach or end of life care. It would appear that the care instructions were not updated when [Mrs A] experienced deterioration towards the last days of her life and when her care needs changed significantly. In particular I am concerned that while there was no Te Ara Whakapiri pathway developed also care instructions were not updated for provision of holistic end of life care, symptom management (pain, shortness of breath, nausea), pressure injury prevention, family support, other items that would provide comfort.

Until early [Month5], [Mrs A] had been relatively well with occasional nausea and shortness of breath. During [Month5], her nausea, vomiting, light-headedness and pain significantly increased. Her appetite decreased and her oral intake was low.

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Because she was assessed at this time by Hospice as "*Completely palliative and comfort cares*" it would have been a good time to commence the process of the development of an end of life care plan with [Mrs A] and her close family. The provider's End of Life Plan Policy and Procedure includes the use of Te Ara Whakapiri format in conjunction with the family, GP, and other health professionals as appropriate.

20 [Month5], [Mrs A's] Progress Notes include that she has been sick, lethargic and experienced tightness of her chest. She was administered morphine with minimal effect. The notes include that her mattress was changed to an air mattress as requested — I did not find in the documentation who requested this and for what purpose. I did not find a pressure injury prevention plan, she previously had been assessed as being at high risk. The instructions on the Current Care Instructions Sheet are silent on pressure injury prevention and the use of an air mattress.

23 [Month5], the nursing notes include that [Mrs A] had not eaten, had vomited and was feeling very lethargic and short of breath. Morphine and anti-emetics were given with good effect, observations were taken which were all within normal range. Later that afternoon when the family visited she was feeling unwell again and [Mrs A] asked for something stronger "to make herself more comfortable".

The medical notes include notes from the Nurse Practitioner who was requested to review the medication. The instructions include to continue as needed, suggested 5mg Morphine and review again in 24 hrs, and monitor bowels. The progress notes include that a sub-cut line was inserted to administer the increased dosage of Morphine to good effect relieving symptoms.

Meanwhile and due to [COVID-19 restrictions], family visits were stopped with exception for families with residents receiving end of life care. The progress notes include that there had been an altercation between [Mrs A's] family members wanting to visit that evening and a registered nurse who communicated that visiting is "only allowed for actively dying or palliative care residents" and that [Mrs A] at this stage was "not actively dying". The Village Manager was involved and agreed that [Mrs A] met the criteria for visitation and clearance was provided to visit. I note that this happened [during COVID-19 restrictions] and it needs to be recognised that this was an unprecedented and stressful time for providers who were navigating their way through the [situation] and implementing measures to keep all safe. The provider extended an apology to the family.

24 [Month5] the notes include that a text message was sent to the family to inform that [Mrs A] was seen (again) by the Nurse Practitioner who prescribed Haloperidol for nausea, vomiting and delirium. The medication administration

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sheet does not show this was administered until 29 [Month5] and appears to be part of anticipatory prescribing.

25 [Month5], the notes include that a Pressure Risk Assessment, Nutritional Assessment and Pain Assessment were due including a review of the skin section of the current care status. I did not find in the provided clinical documentation an updated care plan or current care status.

In the days following and according to the clinical notes [Mrs A] experienced a more settled time however continued to have a very poor appetite and fluid intake.

28 [Month5], [Mrs A] was reported to be very lethargic, refused meals and cares saying she was too tired. It was noted that the tips of her fingers were blue, this is an indication that the dying process has started. The nurse spoke with the next of kin giving an update on the situation. Oxygen therapy was given with good effect. [Mrs A] was reported to be comfortable however said she was too tired to speak. Arrangements were made for the family to visit the next day.

29 [Month5], [Mrs A] continued to be very weak and showing indications of dying. The nurses provided comfort cares, withheld meals because she was too weak. Her daughter visited, medication was given via the subcutaneous line to keep her comfortable including Haloperidol.

In the afternoon [Mrs A] was found sitting on the floor next to her bed and about 20 minutes after she last had received care. Earlier she was lying with one leg off the bed which seemed to provide her comfort. No falls prevention measures were implemented preventing her from falling out of bed. The nurse assessed for injury, none were found. The next of kin who was not there at the time was notified via the phone. [At approximately 3.16pm] nurses found [Mrs A] had passed away. Family was contacted.

7. **Clinical advice**

Whether the decision not to escalate [Mrs A's] care for further GP/NP review on 24 [Month5] was reasonable in the circumstances.

The notes show that on 24 [Month5] [Mrs A] was seen by the Nurse Practitioner who updated her medication prescribing with Haloperidol. This was communicated to the next of kin in a text message. It would appear that medical review and prescribing was part of anticipatory prescribing. This is part of good practice and a way to make sure that the dying person has access to medicines if they develop symptoms without delay. This is particularly important for after hours and for weekend planning when access to a GP/NP is difficult. I note that this explanation doesn't seem to have been provided to the family. When anticipatory prescribing is in place, the need for further GP/NP input is not

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required unless unexpected developments occur. **Deviation from accepted practice — nil.**

Whether the decision not to initiate an end of life pathway for [Mrs A] in response to her deteriorating condition on 24 [Month5] was reasonable in the circumstances.

The documentation shows that in [Month2] the assessment from the hospice practitioner included that she was in end stage heart failure, "*completely palliative and comfort cares*". In my opinion this would have been a good time to commence the development of the Te Ara Whakapiri[15] (end of life) care pathway/care plan together with [Mrs A] and her next of kin. Part of the development of such a pathway is providing information to support informed participation in care planning and decision making so that the care plans reflect the unique and holistic needs of the person and their family in the last days of life. The Te Ara Whakapiri documentation includes the most common potential symptoms at the end of life (pain, agitation, respiratory tract secretions, nausea, and breathlessness) as well as a focus on spiritual and social needs.

Such an end of life pathway/care plan is only activated when the nurse recognises that death is imminent and may be measured in hours or days. For [Mrs A] this would have been between 24 and 28 [Month5]. At that time the health consumer and their family must be given the opportunity to understand what is happening and that the end of life care plan is being activated. The care plan when initiated will then guide care staff to systematically assess the person and control symptoms at an early stage

The provider acknowledged that although it is the organisation's policy, such a care pathway had not been developed. In addition and as mentioned earlier I am concerned that in the absence of such a care pathway [Mrs A's] usual care plan was not updated when her needs changed significantly. Not updating a care plan is not only a clinical documentation issue and an issue of care coordination between the different shifts and between the care teams, a care plan also serves to provide informed consent. In the circumstances I consider it unreasonable that there were no updates to the care plan for it to reflect palliative care needs and end of life care needs. **My peers would consider this in the circumstances a significant deviation from accepted practice.**

Whether the decision to administer Haloperidol was made in a timely manner, in light of [Mrs A's] condition at the time.

In end of life care Haloperidol is prescribed and used to treat agitation/severe restlessness and is also used in the treatment of nausea and vomiting. Restlessness at the end of life is not uncommon and can be distressing for the

[15] https://www.health.govt.nz/system/files/documents/publications/te-ara-whakapiri-principles-guidance-last-days-of-life-apr17.pdf

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person experiencing it and for their family. Haloperidol was in this case prescribed prn meaning as and when required. The notes include that on 29 [Month5] at 11.30hrs the registered nurse gave this medication through the sub-cut line and "*for comfort*". The notes do not include details about the presentation of discomfort before this time but include that at 12.39hrs [Mrs A] was still uncomfortable and was given further morphine. The clinical notes covering the 24 hours leading up to this time don't include reports of restlessness or nausea or pain. Unless there are other reports of restlessness and discomfort I found that Haloperidol was administered in a timely way. **Deviation from accepted practice — nil.**

I would like to add however my concern about the lack of regular symptoms assessments. Good end of life care as per the Te Ara Whakapiri end of life pathway includes a systematic assessing for common symptoms at the end of life as for example regular pain checks so that these symptoms can be managed when still mild. I am concerned that the clinical notes did not include or report on regular systematic assessments for symptoms including the documentation of assessment results in the clinical notes. This would be seen by my peers in the circumstances as **a moderate to significant deviation from accepted practice.**

Whether there were adequate measures put in place for managing [Mrs A's] falls risk.

[Mrs A] experienced some restlessness the last day of her life. She received medication (Haloperidol and morphine) to provide more comfort. As mentioned above it is however not clear from the clinical notes what the severity of the symptoms were. At 1330 hrs it was reported that she was lying with her "*left leg dangling outside the bed, touching the ground*". Family who were present at that time said that she seemed to find it more comfortable lying like that. The family left at 13.40hrs. She was checked again at 14.00 hrs by a carer and was asleep. 20 minutes later she was found sitting on the floor next to her bed. It seemed she had rolled out of bed. There were no falls prevention measures in place. It is unusual for falls prevention measures to be put in place unless the person experiences agitation not responding to medication. **I conclude that this fall could not have been anticipated and did not find any deviation from accepted practice.**

The adequacy of the communication between rest home staff and [Mrs A's] family between 22 [Month5] and 29 [Month5].

The Standards for Palliative Care[16] includes a standard dedicated to supporting and caring for the family as part of the service provision, recognising the important role family and whānau play in the provision of care beyond being kept informed. Good practice requires for family to be part of the care planning

[16] https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/HNZ-standards-2019.pdf

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including the identification of their needs, expectations, responsibilities and desired level of involvement. Along the way they are being kept up to date and are provided with information on the signs and symptoms of approaching death, symptoms management available and other particulars about the care.

The documentation on file shows that family was kept informed at times when [Mrs A's] health status changed and when there was a fall, mostly by phone and text messages. I did not find notes referring to information being provided on the dying process, what to expect, explanation about the prescribing of anticipatory medication or how they could contribute to the care. **Therefore I have found the communication with family inadequate and a moderate deviation from accepted practice.**

The adequacy of [the care facility owner's] policies relating to the end of life plan, restraint minimisation and falls prevention/management.

I reviewed the provided policies and have found them adequate and reflective of good practice. **Deviation from accepted practice — nil.**

Hilda Johnson-Bogaerts, BNurs RN MHSc PGDipBus
Aged Care Advisor
Health and Disability Commissioner'

On 26 June 2022, RN Johnson-Bogaerts provided the following further advice:

'Thank you for giving me the opportunity to review the various responses. In response I note the following:

[The care facility owner's] response to question a) seems to be answering the question from the point of view of "activating" the Last days of life care plan, while the question relates to the "development" of the plan, which usually is developed with the consumer and their family/whānau beforehand.

Further in answer to the question from the family if it is common practice to only check in every 30 min on a person who is actively dying, I can report back that it depends on the time of the day and on the amount of workload at the time. For example, during the night when staff have down time it is common practice to sit with the dying if no whānau present, however during the morning or afternoon duties there may not be availability of staff to stay and sit with the dying. It is accepted practice to check in every 30 min at those times.

Reviewing all information, I did not find a reason to reconsider my advice.'

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