Investigation of a complaint against the Western Health and Social Care Trust and the Northern Ireland Hospice

Report Reference: 202002867 and 202001016

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The Role of the Ombudsman

The Northern Ireland Public Services Ombudsman (NIPSO) provides a free, independent and impartial service for investigating complaints about public service providers in Northern Ireland.

The role of the Ombudsman is set out in the Public Services Ombudsman Act (Northern Ireland) 2016 (the 2016 Act). The Ombudsman can normally only accept a complaint after the complaints process of the public service provider has been exhausted.

The Ombudsman may investigate complaints about maladministration on the part of listed authorities, and on the merits of a decision taken by health and social care bodies, general health care providers and independent providers of health and social care. The purpose of an investigation is to ascertain if the matters alleged in the complaint properly warrant investigation and are in substance true.

Maladministration is not defined in the legislation, but is generally taken to include decisions made following improper consideration, action or inaction; delay; failure to follow procedures or the law; misleading or inaccurate statements; bias; or inadequate record keeping.

The Ombudsman must also consider whether maladministration has resulted in an injustice. Injustice is also not defined in legislation but can include upset, inconvenience, or frustration. A remedy may be recommended where injustice is found as a consequence of the failings identified in a report.

Reporting in the Public Interest

This report is published pursuant to section 44 of the 2016 Act which allows the Ombudsman to publish an investigation report when it is in the public interest to do so.

The Ombudsman has taken into account the interests of the person aggrieved and other persons prior to publishing this report.

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Listed Authority: Combined – Trust and Hospice

SUMMARY

This complaint is about care and treatment the complainant's mother (the patient) received from the Western Health and Social Care Trust (the Trust) and NI Hospice (the Hospice) on 9 March 2021 and from 25 to 31 March 2021 while receiving palliative care in the community. The complainant was concerned that the patient's syringe driver had been removed, causing her unnecessary pain and suffering.

The patient was diagnosed with stomach cancer in April 2019. In February 2020 the patient's condition deteriorated leading to hospital admission. Following discharge from hospital in May 2020, the patient was referred to receive palliative care[1] in the community. Since 4 September 2020 the patient was fitted with a syringe driver[2] to provide effective pain relief in liquid form as she was unable to take oral medications. From 26 March 2021 the patient's deterioration became significant with increasing pain and agitation. Sadly, the patient died at home on 31 March 2021. She was 85 years old.

The investigation considered information from the complainant, both authorities, relevant nursing and medical records available together with relevant guidelines. I also sought advice from three Independent Professional Advisors (IPA): a Hospice Nurse, District Nurse and a Consultant Physician.

The investigation found both the Hospice and Trust provided appropriate care and treatment to the patient on 9 March and from 25 to 31 March 2021. Although I did not uphold the complaint, I recognised the complainant's clear focus on ensuring her mother received the most effective and timely pain relief in her final days. I hope my findings reassure the complainant that the care and treatment the patient received was appropriate and in line with guidance and standards.

[1] Care for an illness that can't be cured that makes the patient as comfortable as possible by managing pain and other distressing symptoms. End of life care is a form of palliative care received close to the end of life.
[2] Used to manage symptoms such as pain, nausea and vomiting. They continuously deliver a controlled amount of medication through a needle or catheter under the skin to help manage symptoms in a comfortable way.

THE COMPLAINT

1. This complaint is about care and treatment the Western Health and Social Care Trust (the Trust) and Northern Ireland Hospice (the Hospice) provided to the patient on 9 March 2021, and from 25 to 31 March 2021. The complainant is the patient's daughter. I determined to produce one composite investigation report to for clarity on the actions taken by staff in both the Trust and the Hospice.

Background

2. The patient was diagnosed with stomach cancer in April 2019. In February 2020 the patient's condition deteriorated leading to her experiencing vomiting and high levels of pain. Following discharge from hospital in May 2020, the patient was referred to receive palliative care[3] in the community.

3. In August 2020, a CT scan[4] showed the patient's stomach could not absorb tablets prescribed for pain relief. From then the patient was prescribed liquid medication and placed on a liquid diet. On 4 September 2020 the patient was fitted with a syringe driver[5] to provide effective pain relief in liquid form.

4. On 26 March 2021 the patient had an episode of vomiting which was blood stained together with bleeding from her nose. From then her deterioration became significant with increasing pain and agitation.

5. Sadly, the patient died at home on 31 March 2021. She was 85 years old.

6. The complainant was the patient's full-time carer. She raised concerns with the Hospice and Trust regarding care and treatment they provided to the patient on 9 March 2021, and from 25 to 31 March 2021. The Hospice and Trust conducted a joint investigation into the concerns raised. They issued their final responses to the complainant on 22 March 2022 and 4 May 2022 (respectively).

[3] Care for an illness that can't be cured that makes the patient as comfortable as possible by managing pain and other distressing symptoms. End of life care is a form of palliative care received close to the end of life.
[4] A computerised tomography (CT) scan using X-rays and a computer to create detailed images of inside the body.
[5] Used to manage symptoms such as pain, nausea and vomiting. They continuously deliver a controlled amount of medication through a needle or catheter under the skin to help manage symptoms in a comfortable way.

Issue of complaint

7. I accepted the following issue of complaint for investigation:

Whether the Trust and Hospice provided appropriate care and treatment to the patient on 9 March and from 25 to 31 March 2021.

INVESTIGATION METHODOLOGY

8. In order to investigate this complaint, the Investigating Officer obtained from the Trust and Hospice all relevant documentation together with its comments on the issues the complainant raised. This documentation included information relating to the complaints process for both authorities. The Investigating Officer also obtained information from the patient's General Practitioner (GP).

Independent Professional Advice Sought

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

- A Hospice Nurse with experience in palliative care nursing (HN IPA);
- A Consultant Physician and Geriatrician (C IPA); and
- A District Nurse with 18 years' experience providing care in the community including palliative care (DN IPA).

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

10. The information and advice which informed the findings and conclusions are included within the body of this report. The IPAs provided 'advice'. However, how I weighed this advice, within the context of this particular complaint, is a matter for my discretion.

Relevant Standards and Guidance

11. In order to investigate complaints, I must establish a clear understanding of the standards, both of general application and those specific to the circumstances of the case. I also refer to relevant regulatory, professional, and statutory guidance.

The general standards are the Ombudsman's Principles[6]:

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

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

The specific standards and guidance relevant to this complaint are:

- National Institute for Health and Care Excellence's Clinical Knowledge Summary Palliative Care – General Issues, updated March 2021 (NICE CKS);
- National Institute for Health and Care Excellence's Guidelines on Care of Dying Adults in Last Days of Life, 16 December 2015 (NICE NG31);
- Nursing and Midwifery Council The Code, 10 October 2018 (NMC Code);
- The Northern Ireland Hospice Clinical Services Policy CSP 02/2018, Community Operational Policy, August 2018 (NIH COP);
- The Northern Ireland Hospice Clinical Services Policy CST 01/2014, Operational Policy for doctors working with the NI Hospice Community Specialist Team, April 2019 (NIH CST);
- Northern Ireland Hospice Statement of Purpose Adult Community Services, October 2020 (NIH SOP); and
- Trust's Guidance for the Management of Parenteral and Transdermal Controlled Drugs in the Community Setting by Nurses and GPs, February 2016 (Trust's CD Guidance).

I enclose relevant sections of the guidance considered at Appendix three to this report.

13. I did not include all information obtained in the course of the investigation in this report. However, I am satisfied I took into account everything I considered relevant and important in reaching my findings.

[6] These principles were established through the collective experience of the public services ombudsmen affiliated to the Ombudsman Association

14. A draft copy of this report was shared with the complainant, the Trust and Hospice for comment on factual accuracy and the reasonableness of the findings and recommendations. The complainant, Trust and Hospice submitted comments in response. I gave careful consideration to all the comments I received before finalising this report. I also decided to seek some further IPA advice to provide further clarity on some of the issues raised.

Relevant Hospice / Trust records

15. I enclose relevant extracts of Hospice and Trust records at Appendix four to this report.

THE INVESTIGATION

Issue 1: Whether the Trust and Hospice provided appropriate care and treatment to the patient on 9 March, and from 25 to 31 March 2021.

In particular this will consider:

- The presentation and consideration of the patient's pain relief at the meeting on 9 March 2021;
- The Hospice discussion with the patient and the complainant on 25 March 2021;
- The involvement in the patient's care from 26 to 31 March 2021;
- The management of the patient's pain relief from 26 to 31 March 2021; and
- Whether the patient's syringe driver was removed and if so, whether the Trust and / or Hospice were involved in the driver being removed.

Presentation and consideration of patient's pain relief on 9 March 2021

Detail of Complaint

16. A Hospice Nurse presented the patient's case to a community palliative care multi-disciplinary meeting (MDM) via Zoom on 9 March 2021. A Trust Consultant (the Consultant) was present at the meeting to consider pain relief for the patient. The complainant said that based on her review of the Hospice records, there was '*nothing in that discussion that was for [the patient's] benefit*.' She felt the Hospice did not consider the potential impact to the patient when it presented her case to the Trust.

17. The complainant understood the Trust decided to remove the syringe driver and return the patient to tablet medication based on the Hospice Nurse's presentation

the patient at the MDM. She said the Trust failed to consider the patient's medical history when it made this decision. The complainant explained the Trust should have seen from the patient's medical records that since August 2020, she was taking liquid medication, and from 4 September 2020, a syringe driver was in place. The complainant said the driver '*transformed [the patient's] life*' as it provided 24-hour pain and anti-sickness relief. She felt the Trust '*completely failed'* the patient as this advice removed her pain relief and caused her suffering.

In response to the draft Investigation Report the complainant and the Trust highlighted an inaccuracy in the C IPA's advice that the patient was on the syringe driver for *'18 months*' rather than six months at the time of the MDM meeting. I accepted this correction and have highlighted the IPA's response at para 45.

Hospice's response

18. The Hospice said its nurse sought advice from the Trust's Consultant and presented the patient '*as a complex patient*.' Referring to the record, the Hospice said its nurse updated the Consultant on the patient's condition and discussed her diagnosis and prognosis. The Hospice stated this demonstrated the patient's history was considered and its presentation was a '*key component*' in determining the plan of care on 9 March 2021.

19. The Hospice believed the Consultant suggested a trial to convert the patient's medication from the syringe driver back to oral medication, as her symptoms were '*well controlled for some time*.'

20. The Hospice said, '*this exchange was not seen as a treatment decision, rather as an option for further discussion with the patient and family*.' The nursing records evidence that the Hospice Nurse presented her perception that the family were anxious about symptom management and the driver was of immense benefit. The Hospice suggested that this confirmed it considered the potential impact on the patient, which it shared with the multidisciplinary team.

Trust's response

21. The Trust referred to the Hospice's Statement of Purpose regarding the level of doctor involvement in decisions affecting the patient's care and treatment discussed at

MDMs. It stated its doctors are limited to the issues raised by the presenting nurse and the questions they wish to have answered. This focused on the management of symptoms. Decisions relating to underlying disease management are referred to the appropriate specialist teams.

22. The Trust's Consultant had no recollection of the discussion about the patient's case on 9 March 2021. He stated it would '*always*' be his practice to consider the patient's medical history before offering advice in relation to changes in management. The Consultant explained the nurse responsible gives a summary of the patient's history together with the key issues and investigations regarded as relevant.

23. The Consultant stated there is no specific time limit for how long a patient can access a syringe driver. He explained where a patient was consistently settled on medication by the syringe driver route, is not rapidly deteriorating, and is eating and swallowing well, sometimes switching from the syringe driver to oral or patch routes are considered as a trial. He added such a trial is introduced following consultation with the patient and family.

24. The Consultant stated it is '*very out of character to be absolutely adamant about removing a syringe driver from a patient*.' He said he would be concerned if his name was specifically used to enforce a particular management plan given he seldom met patients or directly assessed their need. The Consultant said it is '*clearly documented*' the nurses did not remove the syringe driver from the patient.

Relevant Independent Professional Advice

HN IPA

25. The HN IPA advised: when the Consultant suggested the possibility of removing the syringe driver, the Hospice Nurse responded that the patient and family found the driver of great benefit and would be displeased if it was removed. The patient was '*discussed appropriately*' during the meeting on 9 March 2021.

26. The HN IPA advised: Following the MDM, the Hospice Nurse contacted the patient's GP to direct the questions raised about swapping the driver to oral delivery and the question of the patient's diagnosis. The GP appeared to show hesitation for removing the driver and suggested they continue to use it. The GP felt a review of the patient's

diagnosis would be best dealt with by an oncology specialist. The '*evidence suggests that this was agreed and the [Hospice Nurse] continued the treatment*' with the syringe driver.

27. The HN IPA referred to NICE CKS GI. She advised '*according to the notes [the Hospice] followed all available guidelines*.' She '*did not see any failings from this meeting*.'

C IPA

28. The C IPA advised: the role of the Trust's Consultant is to advise the palliative care team on '*suitable clinical decisions*.' Receiving care in the community, the patient '*remained under the care of [her] GP while palliative care needs are met by the palliative care nurses…or district nurses.*' The Trust's practice of clinical care of patients in the community '*not taken over by the clinician in the Trust is appropriate*.'

29. The C IPA advised: on 9 March 2021 there is a record of a Zoom call between the Hospice Nurse and the Consultant where he was '*updated*' about the patient's condition. Consideration was given to the period of time[7] the patient received medication through the syringe driver. The Consultant asked two questions; whether the syringe driver needed to be reviewed, and whether the patient needed to be reviewed by her GP or oncologist regarding her diagnosis and prognosis.

30. The C IPA advised: as the Trust did not take formal notes of the proceedings / outcomes of the MDM on 9 March, *'it is not possible to give a specific answer to the question regarding discussion about pain relief*.' There is no record of the Consultant offering any '*advice*' concerning pain relief at the MDM. The C IPA referred to the Consultant's response that he could not recall advising the syringe driver to be removed, adding '*the district nurses are clear that the syringe pump was not removed*.' In general, the Consultant said removing a long-standing syringe driver is '*always a significant step'* and not one he would '*take lightly*.'

[7] The C IPA's original advice says the syringe driver had been used for a '*period of 18 months'*. The records document the patient was diagnosed with cancer 18 months prior to the MDM and had the syringe driver for a '*long period*.' The C IPA confirmed this error on his reading of the MDM record.

31. The C IPA advised: there is no evidence in the medical records that '*the [syringe driver] infusion was ever actually stopped*.' There are documented discussions with the Consultant and others, after 9 March, about adjusting the dose of drugs in the syringe driver. In particular, Trust notes refer to a telephone discussion with the Consultant, on 30 March, who advised of medication being increased, Oxycodone[8] to 40mg, Midazalam[9] to 40mg and Levomepromazine[10] to 15mg. In response to the question from this Office whether the Consultant told the Hospice Nurse to remove the syringe driver, the C IPA advised '*No. This was not recorded as an instruction from the [Consultant].*'

32. The C IPA advised the Trust's decisions at the MDM on 9 March 2021 concerning a review of the patient's diagnosis, based on the records available, '*appears to be reasonable*.' The C IPA advised the Trust appropriately considered the patient's care and treatment at the MDM on 9 March 2021.

Analysis and Findings

The Hospice

33. The complainant raised concerns about how the Hospice presented the patient's case at the MDM on 9 March 2021. She felt the Hospice said, '*nothing for the patient's benefit*' and did not consider the potential impact to the patient when she presented her case to the Trust.

34. The Hospice said its nurse presented the patient to the Trust as a '*complex patient*.' The Hospice said it considered the potential impact to the patient when the Hospice Nurse expressed the family's anxiety about symptom management and their views on the benefits of the driver. The Hospice records document that the Hospice Nurse updated the Consultant on the patient's condition and they discussed her diagnosis and prognosis. They also discussed the ongoing '*impact*' of the burden of the disease on the patient. The records evidence that the Consultant suggested reviewing the syringe driver. However, the Hospice Nurse expressed concern regarding this, basing it on the family's consideration that there was *'immense benefit*' in symptom management. She was also concerned that this change would cause

[8] An opioid painkiller. Used to treat severe pain.
[9] Used to control symptoms such as anxiety, agitation, and seizures.
[10] Used to control symptoms such as anxiety, agitation, and seizures

the family anxiety. Furthermore, I note from the records that the Hospice Nurse sought advice from the patient's GP, who had concerns about stopping the syringe driver.

35. The HN IPA's advice that the patient was '*discussed appropriately*' during the MDM. I accept this advice. I did not identify any documentary evidence to suggest the Hospice Nurse did not present any information for the patient's benefit. In contrast, the note of the MDM evidences that the Hospice Nurse raised concerns following the Consultant's suggestion to review the syringe driver. I also note the HN IPA referred to NICE CKS GI and advised the Hospice Nurse '*followed available guidelines'* and did not identify any failings in her presentation of the patient's case to the MDM.

36. NICE CKS GI states, '*Care of people with advanced cancer requires a multidisciplinary team because of the potential multidimensional nature of problems in palliative care.*' As highlighted above, I accept the HN IPA's advice that the Hospice followed this guideline.

37. Having considered the evidence available, I am satisfied the Hospice's presentation of the patient's case on 9 March 2021 was appropriate.

The Trust

38. The complainant said the Trust did not consider the patient's medical history at the MDM on 9 March 2021. She felt the Trust's '*decision*' to remove the syringe driver '*completely failed*' the patient who did not receive effective pain relief and suffered as a result. The complainant also felt the Trust acted inappropriately in questioning the patient's cancer diagnosis.

39. I note the Trust's response that the MDM focused on symptom management. It said, any decisions relating to underlying disease management would be referred to the appropriate specialist teams. The Consultant had no recollection of the MDM on 9 March 2021. He stated it would be '*very out of character*' for him to have '*absolutely adamant*' about removing a syringe driver from a patient. He said that it was '*clearly documented'* the driver was not removed from the patient.

40. The C IPA advised the role of the Consultant at an MDM regarding a patient cared for in the community is to provide '*suitable clinical decisions*' with the duty of care staying with the GP. The different palliative care nurses would implement the clinical decisions made by doctors. The C IPA advised this was '*appropriate*.' I accept this advice.

41. I reviewed the available records. The nursing record of the MDM on 9 March 2021 documents the Consultant requested the GP is contacted regarding the patient's original cancer diagnosis and possible review of the continued use of the syringe driver. There are records of the Hospice Nurse telephone call with the GP the same day. The nursing record documents[11] the GP was updated on the discussion at the MDM, namely the Consultant's query with the original cancer diagnosis and management of symptoms. This record documents the GP's concerns in him questioning the diagnosis and his feeling that the syringe driver should continue. The GP records[12] document the GP's feeling any diagnosis query would best be raised '*from consultant to consultant*.' No reference to the syringe driver is documented. The nursing record documents this was relayed to the Consultant the following day.

42. On review of the records, I am satisfied the Trust followed the protocol in maintaining the GP's clinical responsibility for the decisions affecting the patient's care and treatment. I note the C IPA's advice that the Consultant's rationale for questions raised at the MDM was '*a reasonable approach*.' I accept this advice.

43. I note the C IPA's advice, as the Trust did not take formal notes of the proceedings and outcomes of the MDM on 9 March, *'it is not possible to give a specific answer to the question regarding discussion about pain relief*.' However, the Hospice Nurse notes of the MDM do not document the Consultant offering any advice concerning pain relief on 9 March.

44. I reviewed the nursing notes provided. These document the Consultant '*feels [syringe driver] would need reviewed*.' I am satisfied while the Consultant does not discuss the type or dose of pain relief medication, his documented query about reviewing the syringe driver shows a consideration of the patient's pain relief at the

[11] Appendix 4.
[12] Appendix 5

MDM which was followed up with the GP who maintained clinical responsibility for the patient. I note the C IPA's advice that future discussions with the Consultant about the patient's pain relief include clinical advice on increased doses of medication being added to the syringe driver. The C IPA advised there is no medical evidence that '*the [syringe driver] infusion was ever actually stopped*.' I accept this advice. This indicates the likelihood that the Consultant's suggested review of the syringe driver took place and the decision was made that the driver remain in place which is supported by the documentation and C IPA and HN IPA's advices outlines above. I therefore do not uphold this element of the complaint.

45. I considered the C IPA's additional advice[13] that he misread the MDM record to '*assume*' the syringe driver had been in place for 18 months. He advised his original advice is '*not materially changed'* by the duration on the driver being six months rather than 18 months. As detailed above, the patient's GP maintained clinical responsibility for her and was consulted following the MDM discussion about the syringe driver on 9 March 2021. The Trust's Consultant considered the patient's ongoing use of the syringe driver and sought input from her GP. It is this that the C IPA advised was the appropriate action. I continue to accept this advice.

Appropriateness of Hospice discussion with the patient and complainant on 25 March 2021

Detail of Complaint

46. The complainant said that on 25 March 2021, the Hospice Nurse informed her and the patient of the decision to remove the syringe driver and return to tablet medication. She explained the Hospice records evidence that the patient's GP felt the driver should continue. The complainant believed the Hospice Nurse disregarded the GP's advice.

47. The complainant felt the Hospice Nurse should not have discussed this with the patient as it caused her '*major anxiety and mental suffering*.' The complainant believed the conversation contributed to the patient becoming more unwell later that day.

[13] Enclosed in Appendix 2 C.

The Hospice Response

48. The Hospice Nurse attended meetings as part of the Hospice's internal investigation. She stated that on 25 March 2021, she made the patient and complainant aware of the discussion she had with the Consultant at the MDM about managing the patient's medication going forward. She noted the family's preference for the syringe driver to continue and said she reassured them that '*we would continue as was*.' The Hospice Nurse said she believed the issue was '*finished*.'

49. The Hospice stated that on 25 March 2021, the Hospice Nurse assessed the patient as '*relatively comfortable*' and proceeded to explore, with the complainant and patient, the possibility of a transition from the syringe driver to oral medication. The Hospice stated it became clear during the discussion that the complainant, patient and her GP were against the transition. The Hospice stated, *'the decision was then made to continue with the syringe driver*.'

50. The Trust and Hospice investigation team stated palliative care communication guidelines indicate that healthcare professionals should communicate directly with the patient on all matters unless the patient expressly declined this. The team said it '*recognises the level of distress this conversation caused the patient and family*.' It found the intention of the proposed change in keeping with exploring '*best care*.' The Hospice noted in correspondence to the complainant on 22 March 2022 that it apologised for the distress caused.

Relevant Independent Professional Advice

51. The HN IPA advised: on 25 March 2021 the patient '*was stable (their symptoms controlled)*' and this '*appeared to be an appropriate time*' to update the patient and complainant on the discussion at the MDM. The Hospice Nurse discussed the possibility of changing medication administration to oral and it was jointly agreed to continue with the driver as this was patient preference. This allowed the patient to be '*at the forefront of their care and decision-makin*g' which was appropriate and in line with the NICE CG138 and the NMC Code.

52. The HN IPA advised she identified no failings relating to the Hospice Nurse's discussion with the patient and complainant on 25 March 2021.

Analysis and Findings

53. The complainant felt the Hospice discussion about the removal of the syringe driver should not have happened and it showed a disregard for the GP's advice that the driver should continue. The complainant said no option was given and they were told the Consultant decided to stop the driver and return the patient to tablet medications.

54. The Hospice Nurse said she made the patient and complainant aware of the discussion at the MDM about managing the patient's medication going forward. She noted the family's preference for the syringe driver to continue and said she reassured them that '*we would continue as was*.'

55. The Hospice said the conversation on 25 March 2021 proceeded after their Hospice Nurse assessed the patient as '*relatively comfortable*.' When it became clear during the discussion that the complainant, patient and her GP were against the transition, the Hospice stated, *'the decision was then made to continue with the syringe driver*.' The joint investigation team found the intention of the proposed change was in keeping with exploring '*best care*.'

56. Records of the conversation are documented by the Hospice Nurse and a District Nurse also present in the patient's home. The contemporaneous[14] nursing notes at the time both record the complainant's explicit preference for the driver to remain and her '*anxiety / concern*' if it was to be removed. The Hospice records document: this was a '*possible change*' to oral medications; the complainant was '*reassured this was an option but only with [the patient's] consent*' and continuation of the driver was '*agreed*.' The District Nurse records document the Hospice Nurse was to '*express [the complainant's] concern to the [Consultant]*.'

57. I note the HN IPA advice that on 25 March 2021 the patient '*was stable (their symptoms controlled)*' and this '*appeared to be an appropriate time*' to update the patient and complainant on the potential of changing to oral medication. She advised this allowed the patient to be '*at the forefront of their care and decision-makin*g' which was appropriate and in line with the NICE CG138 guidance and NMC Code[15]. I accept this advice.

[14] Existing at or occurring in the same period of time.
[15] See Appendix 3

58. Having considered the evidence available, I am satisfied the Hospice discussion with the patient and complainant on 25 March 2021 was in line with guidance to communicate possible medication changes and involve the patient in decisions about their care and treatment. I accept the HN IPA's advice that this was done at an appropriate time. I have not identified a failure in care and treatment. As such I do not uphold this element of the complaint.

59. I note the complainant said this conversation caused the patient '*major anxiety and mental suffering*.' I also note the Trust and Hospice investigation team recognised the conversation caused the patient and family distress and the Hospice apologised for this in correspondence to the complainant on 22 March 2022. I appreciate the discussion of the removal of the driver which had provided '*great benefit*' to the patient understandably caused concern as this conversation would increase the distress at a difficult time for any patient and family. However, as I am satisfied the conversation itself was appropriate as a nursing standard requirement and find no failing.

Management of patient's pain relief from 26 to 31 March 2021

Detail of Complaint

60. The complainant said the patient's syringe driver was removed on 26 March 2021. She explained this caused a delay in the patient receiving pain relief causing her to experience unnecessary pain. She said the patient was '*screaming, roaring in pain, crying [and] hallucinating*.'

61. The complainant said that to obtain the necessary pain relief, the patient was injected every four to five hours. The patient's family had to source the medication and seek medical assistance to administer the medication. She felt the Hospice '*neglected*' the patient during these last days.

62. In response to the draft Investigation Report the complainant said the Marie Curie Nurse did not attach a second line to the patient on 26 March 2021. She said that morning the District Nurse already put two short lines in the patient's upper left arm.

The Joint Investigation Team Response

63. The Trust and Hospice investigation team said, '*it was apparent the patient did have difficult symptoms that were difficult to control at the end of life*.' The patient received medication via the syringe driver and required multiple breakthrough doses of medication. There were multiple visits from District Nursing, Marie Curie Rapid Response and Marie Curie Nursing through the Out Of Hours GPs. The Investigation Team noted these necessitated changes to the syringe driver on Saturday, Sunday, Monday and again on Tuesday to attempt to *'manage these distressing symptoms*.'

64. The team said it understood how difficult it was for the family to see the patient in distress with these challenging symptoms. It said the Hospice and Trust's actions were '*in line with current practice for managing difficult symptoms at the end of life.*'

The Hospice Response

65. The Hospice explained its nursing team *'is commissioned to deliver the service 5 days per week, Monday to Friday, 9am to 5pm (excluding bank holidays).*' The Hospice stated the service therefore was not operational on the weekend of 27 and 28 March 2021.

66. The Hospice referred to its involvement in the patient's care during this time as follows. It said this approach was in-keeping with the partnership approach to delivering palliative care in the community:

- 26 March 2021: Liaison with the District Nurse to agree a plan of care. The Hospice's investigation highlighted the patient's condition deteriorated quickly following a bleeding episode. The District Nurse contacted the Hospice Nurse for specialist advice on the management of chest secretion. It provided advice in line with the request. The patient's condition was noted as comfortable.
- 29 March 2021: Liaison with District Nursing, GP and Consultant in Palliative Medicine. Appropriate changes were advised and made to the syringe driver on 29 and 30 March.
- 30 March 2021: Speaking to a District Nurse the Hospice offered a home visit. However, it was understood that from the family perspective a visit was not required on this date.

The Trust Response

67. The Trust stated in addition to the syringe driver the patient required daily breakthrough medication via a subcutaneous line, which a Marie Curie Nurse inserted on 26 March 2021.

68. The Trust stated there were multiple visits from District Nursing and Marie Curie staff from 26 to 31 March 2021 to renew the syringe driver medication and administer subcutaneous medications.

69. The Trust acknowledged there was a delay in the replenishment of syringe driver medication on 27 March 2021. This was because a prescription was required from the GP, who was unavailable until 16:00. It stated despite this delay, the District Nursing Team managed the patient's symptoms through the subcutaneous line.

Relevant Independent Professional Advice

HN IPA

70. The HN IPA advised: the Hospice Nurse continued to update the Multi- disciplinary Team (MDT) and notes and reviewed the patient's symptoms from 26 March 2021 onwards within the Hospice working days. The Hospice Nurse continued to give appropriate advice on medication and symptom management. When further guidance was required, she contacted doctors for their advice. This was '*appropriate and expected behaviour*.'

71. The HN IPA advised: The Hospice did not work weekends. During weekends the District Nurse would co-ordinate care with the Out of Hours (OOH) doctor. The HN IPA found '*no evidence the Hospice neglected the patient*.' She advised the Hospice appeared to be greatly involved as a go between and communicated between the GP, District Nurse and the Consultant.

72. The HN IPA advised: the Hospice followed the guidelines listed below:
    - Palliative Care RPMG Guidance for the Management of Symptoms in Adults in the Last Days of Life
    - Marie Curie National Guidelines for End of Life Care
    - Marie Curie A Guide to End of Life Services
    - NI Direct End of Life Care and Palliative Care

73. The HN IPA advised: the care was '*patient-centred'*, symptoms were managed and reviewed daily by professionals, and treatment was given to make end of life as comfortable as possible. Also, family were often updated and included in decision-making. The Hospice provided care as it should, individualised and managed by multiple types of healthcare professionals so that all needs are considered.

74. The HN IPA advised she found no failings relating to the Hospice's involvement in the patient's care from 26 to 31 March 2021.

DN IPA

75. The DN IPA advised: the Trust's involvement in the patient's care from 26 to 31 March 2021 was to ensure she was in as little pain as possible by ensuring she received medication as prescribed. The Trust followed its own CD Guidance and NICE NG31 in this regard.

76. The DN IPA advised: various Trust nursing staff administered all medications to the patient (see Appendix two, DN IPA Q2). They administered medication through both the syringe driver and as breakthrough (when the patient might experience pain despite the syringe driver running as intended). It was '*rare that the patient is waiting for any length of time for pain relief.*' She identified two occasions when there was a delay on 26 / 27 and 29 March 2021.

77. The DN IPA advised: overnight on 26 / 27 March 2021 there was a four-hour delay in the replenishment of the syringe driver due to the requirement of a new prescription for increased doses to manage the patient's symptoms. The Trust addressed this delay by having Marie Curie nurses in place overnight after this date.

78. The DN IPA advised: on Sunday 28 March 2021, the Trust District Nurse ordered more prescribed medication at increased doses during out of hours due to the patient's continued deterioration. On Monday, 29 March 2021 the family collected the medications ordered. The DN IPA advised this was '*reasonable and appropriate*.'

79. The DN IPA referred to the Trust's CD Guidance and advised: these state, there should be forward planning of the transportation (delivery / collection) of controlled

drugs for the patient. '*In the case of the patient this did not happen on 27 or 29 March*' and the family had to collect the medication. Although this was the case, this occurred out of hours and following an *'unexpected deterioration'* of the patient where the medication '*suddenly became inadequate*.' This '*would be very difficult to plan for.*' It is '*very common practice'* for family members to agree to collect medication on behalf of their loved ones.

80. The DN IPA advised: it was clearly documented that the patient woke in pain at times during the last days of her life. The patient settled with each administration of breakthrough medication and despite increasing the strength of the medications in the syringe driver, she continued to have these episodes. '*The impact was minimal*' as the nurses and services responded *'incredibly quickly*' each time they had to be called, as outlined in Appendix two D.

81. The DN IPA, based on the medical records, provided a table outlining the medication given to the patient by injection (Appendix two D, Q3).

82. The DN IPA advised: these injections were not the only form of pain relief given between 26 and 31 March 2021. There is '*unmistakable evidence'* that a syringe driver is running all through these dates which administered ongoing pain relief in the form of Oxynorm[16]. The patient's sudden deterioration meant she required '*additional medication*' to address breakthrough pain. The DN IPA explained the doses she identified in the table were considered '*breakthrough*' medication which were '*reasonable and appropriate*.'

83. The DN IPA advised: the patient was dependent on the breakthrough injections for pain relief as the syringe driver was adjusted at the same time. This was *'reasonable and acceptable for somebody who had rapidly deteriorated over the weekend in the "out of hours" period*.' This had a positive impact on the patient as any breakthrough pain while the syringe driver was also running was '*responded to very efficiently*.'

[16] Strong opioid painkiller

84. The DN IPA advised: Trust staff followed its policy and '*worked with the GP and Hospice staff to meet the needs of their patient*.' The paperwork was *'filled in well and provided a good reflection of the work done and care provided*.' The delays identified '*would not be described as failings.*' As the patient had been stable for a long time, and had a sudden and '*drastic*' deterioration on the Friday, this meant changes to medication had to be done out of hours, which '*is always much longer.*' Despite this difficulty, '*the Trust was successful in overcoming the problems*' and the patient had breakthrough medication administered to her in the time between the delays identified.

85. The DN IPA advised: some learning can be taken from the case. This is in relation to having '*anticipatory drugs*' in the home even if a patient is very stable. Such an '*emergency pack'* would have allowed the syringe driver medications to be changed quicker on 27 March 2021. This meant the patient would have received symptom relief earlier than she did and the family would not have had to travel so far to collect medication. However, '*the patient's deterioration could not have been anticipated*' due to how long the patient had been stable.

86. The DN IPA advised based on the information provided, '*the Trust did not fail this lady*.' The District Nurses managed the patient's unexpected deterioration well with additional support from Rapid Response nurses, Marie Curie nurses and the palliative care nurses [Hospice Nurses] giving advice. Although symptom management in the patient's last days of her life were challenging, the '*Trust staff did everything that they could to ensure both the patient and her family were well supported and she was always as comfortable as possible.*'

Analysis and Findings

87. The complainant said the Trust removed the patient's syringe driver on 26 March 2021. She said from this date the patient experienced delays receiving pain relief that was solely given by injections administered every 4 to 5 hours. The complainant felt the Hospice neglected the patient during this time. In response to the draft Investigation Report the complainant refuted the Trust's position that a Marie Curie nurse attached a second line to the patient on 26 March 2021. She said the District Nurse already put two lines in place that morning when she removed the syringe driver.

88. The Trust and Hospice investigation team accepted during this period the patient had '*difficult symptoms*' that were '*difficult to control*.'

The Hospice

89. The Hospice outlined its involvement during its operational hours at paragraph 65 above.

90. The Hospice's Community Operational Purpose supports the Hospice response that the Adult Community Specialist teams delivered a service Monday to Friday, 9am – 5pm (see Appendix three). I therefore accept the Hospice was not operational the weekend of 27 and 28 March 2021.

91. I reviewed the Hospice records. These show it last saw the patient on Thursday, 25 March 2021. Records on the Friday, Monday, and Tuesday document the Hospice's involvement during its operational hours. This included acting as a liaison between the nurses in attendance with the patient, Trust's Consultant and other consultants and the patient's GP regarding the medication and doses needed for the syringe driver and injections to manage breakthrough pain.

92. The HN IPA advised the Hospice continued to give '*appropriate advice*' on medication and symptom management and sought further guidance from doctors when required. She advised this was '*appropriate and expected behaviour.*' The HN IPA found '*no evidence the Hospice neglected the patient*' and advised the Hospice appeared to be '*greatly involved*' as a go between and communicated between the GP, District Nurse, and Consultant. The IPA advised the Hospice provided '*care as it should be*' which was individualised and managed by multiple types of healthcare professionals so that all needs were considered, and the family were often updated and included in decision- making. The HN IPA said the Hospice followed relevant palliative care guidelines and there were no failings in the Hospice's management of the patient's pain relief.

93. The MC Guidelines states one of the principles for quality palliative care is to '*provide relief from pain and other distressing symptoms*.'

94. The focus of RPMG is on managing common end of life symptoms including pain. When it is recognised a person may be entering the last days of life, RPMG recommends healthcare professionals should:
    - *'Review their current medicines.*
    - *Stop any prescribed medicines not providing symptomatic benefit or that may cause harm.*
    - *Discuss and agree any medication changes with the dying person and those important to them (as appropriate).'*

95. I considered the guidelines referred to. I am satisfied that whilst the Hospice staff did not physically visit the patient during these last days, it had no requirement to do so. Having reviewed the records, I am satisfied in its role as a liaison, the Hospice provided quality palliative care in providing pain relief to the patient, namely by reviewing and communicating the required adjustments to the patient's medicines under doctors' advice. I accept the HN IPA's advice that the Hospice followed these guidelines. I accept the HN IPA's advice that there was no failing in the Hospice's management of the patient's pain relief from 26 to 31 March 2021. I therefore do not uphold this element of the complaint against the Hospice.

The Trust

96. The Trust stated the patient's symptoms were managed by medication via the syringe driver with additional breakthrough medications also being required daily from 26 March 2021 via a subcutaneous line inserted by a Marie Curie nurse. The Trust acknowledged a delay in the syringe driver being replenished on 27 March 2021.

97. I considered the complainant's belief that the subcutaneous line was inserted on the morning of 26 March 2021 by the District Nurse rather than the Marie Curie nurse that night. I sought additional advice from the DN IPA. She advised the District Nurse visited the patient that morning and the syringe driver '*was running via a line in the patient's right arm*.' The records document the nurse gave the patient breakthrough medication to control her secretions[17]. The DN IPA advised, at the point in time '*the patient has one line which was being used for the syringe driver*.'

[17] During the terminal phase of a person's illness, airway secretions may accumulate and result in gurgling and rattling noises

98. The DN IPA also advised the same nurse returned with another nurse later that day. These nurses replenished the syringe driver and checked the line and site. The DN IPA advised after the nurses' afternoon visit '*the patient had one line in – that of the syringe driver*.'

99. I reviewed the nursing records[18] which document the District Nurse visited the patient on the morning of 26 March 2021. The syringe driver was '*delivering*.' As secretions were present the District Nurse administered Glycopyrronium[19] 200mg by '*subcutaneous injection'* at 10:00hours[20]. At 13:20hours the District Nurse documented the '*syringe driver replenished as per prescription chart 02048.*'

100. The prescription chart,[21] completed by two nurses in attendance with the District Nurse, document the syringe driver, '*day four'* in the patient's '*right arm*', was replenished at 13:30hours.[22] The breakthrough chart does not document any additional medication administered that afternoon. I am satisfied the records confirm the patient had one line in her right arm on the morning and afternoon of 26 March 2021. I accept the IPA's advice in this regard.

101. I also considered the Trust's position, which the complainant disputes, that the Marie Curie nurse inserted the subcutaneous line during the night of 26 March 2021. The IPA advised the patient's family called the Marie Curie Rapid Response Team as the patient was symptomatic. She advised a Rapid Response Nurse attended the patient. The nurse documented they '*checked the syringe driver was running*.' As the patient was showing signs of agitation and restlessness, '*with the family's consent*' the nurse '*inserted a subcutaneous line for the delivery of breakthrough medications*.' The IPA advised by the end of the night on 26 March 2021, the documentation is *'clear'* that there were '*two lines in the patient*' – one for the syringe driver and one for breakthrough medications.

[18] Completed by the DN as enclosed in Appendix 8.
[19] An antimuscarinic drug to reduce saliva production.
[20] Documented in the breakthrough chart enclosed in Appendix 6.
[21] Enclosed in Appendix 7.
[22] There were no changes to the medications or doses.

102. The nursing record,[23]signed by the Marie Curie Nurse, documented the line being inserted '*with consent*.' The breakthrough charts[24] documented pain relief medications were via '*SC route'* on 26 March 2021 at 23.55hrs by the Marie Curie nurse. Using the records enclosed in Appendix six, the DN IPA provided a table[25] of medications administered by *'injection'* (the subcutaneous line) starting from 23.55hrs on 26 March. She advised the patient received regular pain relief via both the syringe driver and subcutaneous line from 26 March 2021. I accept the IPA's advice. I am satisfied the evidence confirms the subcutaneous line was inserted by the Marie Curie Nurse.

103. She advised the doses '*are considered to be breakthrough medication'* and are '*both reasonable and appropriate*.'

104. The DN IPA identified two occasions when there was a delay in the patient receiving pain relief on 27 and 29 March 2021. Both delays related to the doses of medications in the syringe driver being increased and the prescriptions being updated.

105. I reviewed the medical records regarding this issue, they document:
    - the syringe driver was replenished on 26 March at 13:20 hours and on 27 March at 17:15 hours. Between the hours of 13:20 to 17:15 on 27 March the Subcutaneous Prescription Card documents the patient received one subcutaneous injection at 15:45 hours. This contained Midazolam 2mg, Oxynorm 2mg and Levomepromazine 2mg.
    - the syringe driver was replenished on 28 March at 13:00 hours and on 29 March at 14:05 hours. The Subcutaneous Prescription Card documents the patient received one injection at 12:05 hours. This contained Midazolam 2mg and Oxynorm 2mg.

106. I note the DN IPA's advice that given the quick deterioration of the patient's illness that pain management that had been providing effective relief for some time was unexpected and difficult to plan for. Her advice is therefore that the delays were minimal, well managed by nurses in attendance and '*had no impact on the patient*.'

[23] Enclosed in Appendix 9: Daily Evaluation of Nursing Care.
[24] Enclosed in Appendix 6.
[25] Enclosed in Appendix 2 D, DN IPA.

Having reviewed the records which document the nurses in attendance, arranged increases in the syringe driver doses and breakthrough medication was given during the delays, I accept the DN IPA's advice.

107. I considered the complainant's belief that the Trust administered pain relief solely given by injections administered every 4 to 5 hours from 26 to 31 March 2021. The DN IPA advised the medications given to the patient by injection '*were not the only form of pain relief given*.' She advised, there is '*unmistakable evidence*[26]' that the syringe driver was running through these dates which administered '*ongoing pain relief*' in the form of Oxynorm.

108. In addition to the medical records outlined at paragraph 102 above, the records also document the syringe driver was replenished, for the last time, at 14:25 hours on 30 March 2021. The Syringe Driver Prescription Cards recorded daily that Oxycodone or Oxynorm was prescribed in different strengths from 26 to 30 March 2021 (see Appendix four).

109. I note the DN IPA's advice that the Trust's administration of Oxynorm by subcutaneous injections '*were not the only form of pain relief given*.' Having reviewed the records I accept this advice. In response to the Draft Investigation Report, the complainant said everyday the nurses filled a syringe with '*a cocktail of drugs'* to inject directly into the patient's arm as the syringe driver was not there. She said the nurses prepared these medications in the living room which were witnessed by the family and by the GP on 29 March 2021. I considered the GP record for 29 March 2021[27]. It documented the distinction between medication prescribed to run over 24 hours and those for *'breakthrough'* symptoms. The DN IPA advised it is '*standard practice*' for a syringe driver to run over a period of 24 hours and syringe driver medication charts[28] provided '*evidence of this being the prescribed rate.*' I note the GP signed off the syringe driver chart on 29 March 2021[29]. Whether or not the GP witnessed the nurses is not recorded. What is documented supports all other records that the syringe driver was in place. Based on the available evidence I am satisfied

[26] Records the IPA referred to are enclosed in Appendix 4.
[27] Copy enclosed in Appendix 5.
[28] Enclosed in Appendix 7.
[29] Enclosed in Appendix 7.

that the syringe driver was in place on 29 March 2021 and other medication was prescribed to treat any breakthrough symptoms by subcutaneous injections.

110. I considered the complainant's belief that the patient was dependent on the family sourcing medication and seeking medical assistance to have the medication administered. I also considered the records and the DN IPA's advice. The DN IPA advised it was '*reasonable and appropriate*' that the family collected medications on the two instances recorded. I accept this advice. The DN IPA advised *'the evidence shows that medical assistance was not required*.' She explained administration during out of hours was met by the Rapid Response team with the District Nurses and Marie Curie Nurses administering medications at other times. I accept this advice.

111. I note the DN IPA's suggested learning regarding anticipatory drugs. Although this was not raised as concern and therefore did not fall under the remit of this investigation, I would ask the Trust to consider the DN IPA's suggestion as a possible service improvement.

Overall

112. I am satisfied from 26 to 31 March 2021 both the Hospice and Trust worked together, in line with guidance, to ensure the patient received pain relief by 24- hour infusion through the syringe driver and any breakthrough pain was managed by subcutaneous injection as quickly as possible. I acknowledge that the complainant and the patient's family clearly wanted the patient to receive the most appropriate pain relief in the most timely manner. However, I note the advice that any delays were minimal and occurred while guidance was being followed to ensure the necessary adjustments being made to make the patient as comfortable as possible. I find the Hospice and Trust's involvement in the patient's pain management was appropriate. As such I do not uphold this element of the complaint.

Whether the syringe driver was removed and if so, whether the Trust and/or Hospice was involved in the driver being removed

Detail of Complaint

113. The complainant believed, under instruction from the Hospice, the Trust removed the syringe driver from the patient on 26 March 2021. The complainant said the patient

suffered an '*extremely painful death'* which could have been prevented with continued use of the syringe driver.

114. The complainant said injections given to the patient from 26 to 31 March 2021 were not given as medication to control breakthrough pain[30]. However, they were the only medication the patient received following removal of the syringe driver.

115. The complainant said Dexamethasone[31] had always been used in the patient's syringe driver. She stated this medication being stopped indicated the driver was no longer in place.

116. In response to the draft Investigation Report the complainant queried the DN IPA's advice that the syringe driver was '*not removed'* and was in '*constant use*.' The complainant said the patient had '*two short lines'* on her upper left arm '*each with stoppers at the end*.' She said she witnessed a nurse who attended the patient on 29 and 30 March 2021 inject one line, close it, and then take a stopper out of a second line, administered an injection and put the stopper back on.

117. In response to the draft Investigation Report the complainant said the report '*incorrectly*' stated the syringe driver was replenished between 26 to 31 March 2021. Her position continues to be that the Trust removed the syringe driver on 26 March 2021. She believed the '*increasing strength*' of the medication given '*in each injection'* caused the patient *'severe pain in her left upper arm/ shoulder.*' She 'now believe[d]' the nurses recorded the administration of the '*injections/ meds*' were given to the patient '*via a syringe driver'* to hide this.

Joint Investigation Team Response

118. The Trust and Hospice investigation team was satisfied the syringe driver was neither stopped nor removed and it remained in-situ throughout the duration of the patient's care.

[30] Pain that comes on very quickly and severely when a patient is already being treated with long-acting pain medication.

[31] A steroid that can be used to help reduce the side effects of cancer treatment, or some symptoms during end of life care.

The Trust Response

119. The Trust stated that the records show the patient's syringe driver was in place throughout 26 to 31 March 2021. The two lines in place during this time were the syringe driver and a subcutaneous line used to give top-up injections for the patient's symptoms.

The Hospice Response

120. The Hospice stated its investigation considered written evidence including syringe driver charts, clinical notes and testimony from Hospice and Trust staff involved in the patient's care. It concluded '*there is no documentary or staff testimony evidence to support the reported removal of the syringe driver*.'

121. The Hospice said at approximately 11:15 on 26 March 2021, the District Nurse telephoned the Hospice Nurse. It said the nurses made a contingency plan to add '*adjuvant*'[32] medications, both through subcutaneous breakthrough injections and the syringe driver over the weekend to maintain the patient's comfort. This would be '*normal practice for management of end-of-life symptoms*.' Based on its records, '*there was no evidence to suggest that the syringe driver should be or was removed*.'

Relevant Independent Professional Advice

HN IPA

122. The HN IPA advised: '*there is zero evidence to suggest that the syringe driver was removed*.' The nursing notes and prescription records '*all attest to the fact that the driver remained in situ and was replenished daily as per protocol*.' The Hospice followed NICE CKS SD guidelines.

123. In relation to the complainant's concern that the Hospice had too much control over the patient's care, the HN IPA advised the level of input from multiple team members such as the District Nurse, GP and palliative care team shows '*there was never an imbalance of control in the patient's care*.'

[32] A drug or other substance, or combination of substances, used to increase the efficacy or potency of certain drugs.

124. Overall, the HN IPA advised the Hospice acted within guidelines and protocol and provided appropriate care and treatment to the patient on 9 March 2021, and 25 to 31 March 2021.

DN IPA

125. The DN IPA advised: there was evidence that '*the syringe driver was not removed at any point between the 26 to the 31 March 2021*.' The DN IPA referred to the '*well documented'* District Nurse notes which document each time the syringe driver was running, replenished and the site of the line was checked. There is also *'clear documentation*[33]*'* of the medications added to the driver and signed for as is '*standard practice*.' What is clear from the evidence, is that although the Consultant questioned whether the syringe driver should remain or be changed, '*the syringe driver did in fact remain in situ and was in constant use*.'

126. The DN IPA advised: the evidence of changing the syringe drivers regularly as well as administering breakthrough pain was '*reasonable and appropriate'* and demonstrated a '*clear adherence*' to guidance, NICE NG31.

127. The DN IPA advised: it is clear from the evidence that the patient began a stage of rapid deterioration from 26 March 2021. From then, in addition to the syringe driver medications, the patient required breakthrough medications for pain relief.

128. The DN IPA advised: the discontinuation of Dexamethasone in the syringe driver '*does not indicate that the syringe driver was no longer in place, but rather, that the syringe driver medications were changed*.' The patient had been on a driver with the same medications for a '*considerable amount of time*.' It is clear from the evidence that on 27 March the driver that had been running with Dexamethasone was left on until it was changed later that day. In response to the patient's changing needs, prior to the driver being changed,[34] the patient received breakthrough medications of Oxynorm, Midazalam and Levomepromazine[35] to help settle her symptoms. The new syringe driver was then set up with new medications as per the drug charts and evidence in the notes.

[33] In the syringe driver record sheets.
[34] Syringe drivers are normally changed every 24 hours.
[35] As referenced above.

129. The DN IPA advised: Trust staff '*clearly documented well'* the work that went into trying their best to alter the medications to manage the patient's symptoms. There was clear communication with other external teams and services. There was also evidence that medications were being regularly checked '*which when considering patient safety is essential in the management of symptoms in a patient's home*.' This was in line with the Trust's CD Guidance.

Analysis and Findings

130. The complainant said the Trust removed the syringe driver from the patient on 26 March 2021 under instruction from the Hospice Nurse. The complainant felt because of the removal the patient '*suffered an extremely painful death which could have been prevented*.' The patient believed from this date the patient was reliant on breakthrough injections for pain relief.

131. I note the Hospice and Trust investigation team concluded '*there is no documentary or staff testimony evidence to support the reported removal of the syringe driver*.'

The Hospice

132. I considered the Hospice's response that during the telephone call between its Nurse and the District Nurse on 26 March 2021 that there was no suggestion that the syringe driver should be removed.

133. I reviewed the nursing records regarding this issue. Both the Hospice and Trust records document this telephone call, neither documents any discussion of the syringe driver being removed. Both records document discussion regarding the medications in the syringe driver and the use of breakthrough injections when required.

134. I also reviewed the medical records. It is documented that on 26 March the driver is replenished, by other Trust nurses, as per the prescribed medication in place. It is also documented that subcutaneous medication for breakthrough pain was also given. There are clear records from numerous contributors that the syringe driver remained in place after this date. I note 12 different nurses, from the Trust[36] and

[36] Including nurses from its Rapid Response Team.

Marie Curie, completed records between 26 to 31 March 2021. The nursing records made specific reference to the syringe driver being checked, monitored, replenished, infusing, delivering, being set up late on 27 March, with the site of the driver also being checked. These nurses also updated the Syringe Driver Card daily, documenting the site of the driver and number of days in this location. The Marie Curie Verification of Death Record[37] documented the syringe '*pump*' was removed from the patient on 31 March 2021.

135. The HN IPA advised there is '*zero evidence*' to suggest the syringe driver was removed following the call between the Hospice and Trust nurses. Having reviewed the records, I accept this advice.

The Trust

136. I considered the Trust's response that the patient had two lines in place during this time, one being the syringe driver and the other being a subcutaneous line used to give '*top up*' injections for the patient's symptoms.

137. I considered the complainant's comment on the draft Investigation Report that the patient's pain medication was given by '*two short lines on her upper left arm*' which supported her position that the syringe driver was no longer in place. She said she witnessed nurses taking stoppers out to give medication on 29 and 30 March 2021. I sought additional advice from the DN IPA.

138. The DN IPA advised the documented evidence '*does not support'* the complainant's version of events regarding the lines. It is '*clearly documented*' the line for the syringe driver and line for the breakthrough medication were in '*different arms*.' The syringe driver line was sited in the patient's right arm since 23 March 2021 and remained there '*until the patient passed on the morning of 31 March 2021*[38].' She advised the syringe driver line was changed on 30 March 2021 and '*remains in the right arm*.' She advised it is not clear '*where the site is'* on the patient's right arm. However, as the site is recorded as day one, it had been '*re-sited…into the same arm*

[37] Enclosed in Appendix 11.

[38] The DN IPA advised the patient's syringe driver medication doses and the line were changed on 30 March 2021 and remained in her right arm '*recorded as being day 1*.'

(right).' The breakthrough line was sited in the patient's left arm since 26 March 2021.

139. I reviewed the records. The syringe driver charts document on 22 March 2021 the driver line was '*day six*[39]' in the patient's '*left arm*[40].' On 23 March 2021 the driver line was changed to the patient's '*right arm'* ('*day one*') until 29 March ('*day seven'*)[41]. On 30 March the syringe driver line is recorded as remaining in the '*right arm*' with the '*days site in use*' recorded as '*day one*.'

140. The breakthrough charts do not require the '*site*' of the injection or line to be recorded. Some nurses have documented this information in the nursing records[42]. Entries on 28 March at 23:20hours, 30 March at 11:05, 14:30 and 23:00hours and 31 March at 02:30 and 03:20hours refer to breakthrough '*subcut line'* in '*left'* shoulder/arm.

141. Having considered the records I accept the DN IPA's advice that the syringe driver was on the patient's right arm from 23 to 31 March 2021; and that the breakthrough medication line was on the patient's left arm from 26 to 31 March 2021.

142. Regarding the complainant's query about nurses '*taking stoppers out'* to give medications. The DN IPA explained the different ways stoppers may be present[43]. She advised, the Saf-T Intima line used[44] to administer the patient's breakthrough medication, '*suggested*' that it had a '*stopper at the end*' that '*did not need to be removed'* as medication could be given '*through the stopper using a syringe*.' She advised the nurses did not document whether or not they removed the stopper but this would '*not ordinarily be expected to be documented*.' She added the nurses documented '*what would be expected'* such as the medication given and the route administered. I accept the DN IPA's advice. I am satisfied such a line was used in the patient's case together with a separate line used for the syringe driver.

[39] 'Days site in use.'
[40] 'Site.'
[41] As recorded daily in the records enclosed in Appendix 7.
[42] Enclosed in Appendix 6.
[43] As detailed in Appendix 2 E.
[44] As enclosed in Appendix 10.

143. I also reviewed the records regarding Dexamethasone. The syringe driver prescription cards[45] documented the driver medication was last changed on 5 March 2021. From this date until the evening of 27 March 2021, the patient was prescribed Oxycodone 9mg, Midazolam 3mg, Cyclizine 150mg and Dexamethasone 0.5mg. On 27 March a new syringe driver prescription card documented Oxycodone 10mg, Midazolam 5mg and Levomepromazine 2mg. The records documented the driver was changed with this medication at 17.15hrs. From this change to the patient's medication, Dexamethasone was no longer used. The DN IPA advised the discontinuation of Dexamethasone '*does not indicate the syringe driver was no longer in place but rather, that the syringe driver medications were changed*.' She advised the patient's deterioration on 26 March resulted in breakthrough medication being needed to meet the patient's changing needs. On 27 March the medication in the syringe driver was also changed to continue to meet the patient's changing needs as per the drug charts.[46]

144. As outlined in paragraphs 102 and 105, the records document the syringe driver was replenished, and the prescription cards document the medications and doses prescribed. I am satisfied it is appropriate to give weight to this evidence.

145. I also reviewed the statements provided as part of the Hospice and Trust joint investigation. The statements support the contents of the medical records provided.

146. The DN IPA advised, based on the evidence, the syringe driver *'was not removed at any point between 26 and 31 March 2021*.' I am satisfied the records clearly document the driver remained in place and I accept the DN IPA's advice.

147. I considered the complainant's belief that the increased medication doses caused the patient '*severe pain*' in her upper left arm/ shoulder. The nursing records document on 30 March 2021 the patient was '*extremely agitated*' and in '*pain*' and at 14:30hours a Versatis patch[47] was '*applied to back left shoulder.*' The DN IPA advised this was applied due to the patient feeling '*ongoing pain'* in that area '*despite all the other medication she was given*.' As detailed above, I am satisfied the syringe driver remained in place and delivered through the patient's right arm from 23 to 31

[45] Prior to 26 March 2021 when the complainant stated the driver was removed.
[46] Enclosed in Appendix 4.
[47] Provides localised pain relief.

March 2021. I am also satisfied breakthrough medication was delivered via a line in the patient's left arm..

148. The DN IPA set out the medication and doses the patient received by syringe driver[48] in right arm and the breakthrough line[49] in her left arm. She advised the increased dosage of the medication given for breakthrough symptoms in the patient's left arm was *'not as significant as that of the syringe driver*.' She advised[50] the breakthrough doses given were '*reasonable and appropriate*.' I accept this advice.

Overall

149. I acknowledged and considered the complainant's strongly held belief that the Trust removed the syringe driver from the patient on 26 March 2021. On review of the various records available and consideration of the advice from the HN IPA and DN IPA, I am satisfied, on the balance of probabilities, that the syringe driver was not removed on 26 March, and it remained in place from then until the patient's death on 31 March 2021. I find both the Hospice and Trust followed relevant guidelines, outlined above, regarding the use of the syringe driver during the patient's last days.

150. I also acknowledged and considered the complainant's belief that the patient '*suffered an extremely painful death*.' I note the DN IPA's advice the Trust responded to the any breakthrough pain while the syringe driver was running was done so '*very efficiently'* and *'there was also periods of time where she was relaxed, comfortable and pain free*.'

151. I find the syringe driver was in place and provided 24-hour medications with additional medications administered to address breakthrough symptoms when required. I do not uphold this element of the complaint.

CONCLUSION

152. This complaint is about the care and treatment the Trust and Hospice provided to the patient on 9 March and from 25 to 31 March 2021.

[48] Copy records enclosed in Appendix 7.
[49] Copy records enclosed in Appendix 6.
[50] In the original advice provided enclosed in Appendix 2 D.

153. I did not uphold the complaint for the reasons outlined in this report.

154. I offer through this report my condolences to the complainant for the loss of their mother. Throughout my consideration of this complaint, I recognised the complainant's concern regarding the treatment provided in the last days of her mother's life. It is clear the complainant was focused on ensuring her mother was as comfortable and pain free as possible. I hope my findings reassure the complainant that the care and treatment provided by the Trust and Hospice was appropriate and in accordance with relevant guidelines.

MARGARET KELLY

Ombudsman

October 2024

Appendix 1

PRINCIPLES OF GOOD ADMINISTRATION

Good administration by public service providers means:

1. Getting it right

- Acting in accordance with the law and relevant guidance, with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

2. Being customer focused

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to its commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances

- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

3. Being open and accountable

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating its criteria for decision making and giving reasons for decisions

- Handling information properly and appropriately.

- Keeping proper and appropriate records.

- Taking responsibility for its actions.

4. Acting fairly and proportionately

- Treating people impartially, with respect and courtesy.

- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.

- Dealing with people and issues objectively and consistently.

- Ensuring that decisions and actions are proportionate, appropriate and fair.

5. Putting things right

- Acknowledging mistakes and apologising where appropriate.

- Putting mistakes right quickly and effectively.

- Providing clear and timely information on how and when to appeal or complain.

- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

6. Seeking continuous improvement

- Reviewing policies and procedures regularly to ensure they are effective.

- Asking for feedback and using it to improve services and performance.

- Ensuring that the public body learns lessons from complaints and uses these to improve services