PRISONS AND PROBATION OMBUDSMAN
for England and Wales
Independent investigations

A Report by the Prisons and Probation Ombudsman Nigel Newcomen CBE

Investigation into the death of a man at HMP Leyhill in June 2013

Our Vision

‘To be a leading, independent investigatory body,
a model to others, that makes a significant contribution to
safer, fairer custody and offender supervision’

This is the investigation report into the death, in June 2013, of a man at HMP Leyhill. He was 61 years old and had been suffering from lung cancer which had spread to other organs. I offer my condolences to his family and those who knew him.

An investigation was carried out and a review of the man's clinical care in custody was carried out by a clinical reviewer. HMP Leyhill cooperated fully with the investigation.

The man was diagnosed with terminal cancer in November 2012. Healthcare staff at the prison referred him to hospital quickly when he reported his symptoms and there was no delay in his treatment. Although his pain was generally well managed during his illness, the investigation has identified the need for better arrangements to enable terminally ill patients at Leyhill to receive continuous pain relief through a syringe driver whenever the need is indicated. Nevertheless, I am satisfied that overall he received very good medical care and commendable and compassionate support from staff of all disciplines at Leyhill.

This version of my report, published on my website, has been amended to remove the names of the man who died and those of staff and prisoners involved in my investigation.

Nigel Newcomen CBE
Prisons and Probation Ombudsman **November 2013**

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SUMMARY

1. The man reported shortness of breath on 23 October 2012, and a prison doctor referred him to hospital the same day for investigations. He had various tests over the following three weeks and a biopsy on 12 November confirmed that he had terminal lung cancer. He was diagnosed appropriately, and received very good support from prison staff immediately after and in the months following his diagnosis.

2. The man received chemotherapy treatment, to slow down the growth of the tumour, from December 2012 to February 2013. The treatment was initially regarded as successful. However, in mid-March, his health deteriorated and scans showed that the tumour had spread to his brain. He was prescribed steroid medication, which improved his symptoms.

3. Later in the month, the man had a five-day course of radiotherapy. In mid-May, his health deteriorated again and he became confused. Out of hours agency healthcare staff were employed to help him take his medication as prescribed. A further course of steroids again helped and his symptoms improved.

4. The man's health deteriorated more significantly in the second week of June and he moved to the prison's palliative care unit on 13 June. His condition deteriorated over the following weekend and he died a few days later. He received appropriate pain relief at the end of his life but the use of a syringe driver to administer medication might have been more effective.

5. The clinical reviewer concluded that the man received care of a high standard at Leyhill. We agree with this assessment and commend the commitment shown by staff throughout the prison for their caring approach. We make one recommendation about the need to ensure appropriate arrangements for pain relief for end of life care.

THE INVESTIGATION PROCESS

6. On 17 June 2013, notices were issued announcing the investigation to staff and prisoners at Leyhill, inviting anyone who had relevant information to contact the investigator. No one came forward.

7. The investigator visited Leyhill on 19 June. During the visit he saw B wing, where the man lived for several weeks after being diagnosed with cancer and the prison's palliative care unit, where he spent the last five days of his life. He spoke to the healthcare manager, an officer who knew the man well and two prisoners who had been friends of his. He met the Governor and a member of the local Independent Monitoring Board.

8. The investigator returned to Leyhill on 7 August and interviewed two members of staff and gave the Governor feedback on the preliminary findings of the investigation.

9. A clinical reviewer carried out a review of the man's clinical care in custody on behalf of the local PCT.

10. The investigator contacted the local Coroner to inform him of the investigation and request a copy of the post-mortem and toxicology reports. A copy of this report has been sent to the Coroner.

11. One of the Ombudsman's family liaison officers spoke to the man's step-mother, his nominated next of kin, on 10 July, to explain the investigation. She said she thought her step-son was very well cared for in prison and had no specific issues she wished the investigation to cover.

12. The man's step-mother received a copy of the investigation draft version of the report as part of the consultation period. She told the family liaison officer that she was satisfied with the findings of the investigation and information detailed.

HMP LEYHILL

13. Leyhill is an open prison in South Gloucestershire, holding up to 527 male category D prisoners who require only minimum security. Some are life-sentenced prisoners preparing for release, as the man was.

14. The prison has a palliative care unit based on the design of a hospice in Bristol. It consists of two en-suite patient rooms and a family room for visiting relatives, plus a nurses' office. When occupied, the unit is staffed by prison healthcare staff during the working week and by local agency staff overnight and at weekends. Officers from B wing also work on the unit throughout the day and night when it is occupied.

15. Health services are provided at the prison from 7.30am to 4.30pm on Monday to Friday, with an out of hours service at other times. Primary care services at Leyhill are provided by a private company and a local NHS centre provides GP and out of hours services.

HM Inspectorate of Prisons

16. The most recent inspection of Leyhill was in April 2012. Inspectors found a high standard of care at the prison, although there was some concern about the staffing mix and the disproportionate responsibility carried by healthcare support workers. Inspectors described the palliative care unit as a good initiative and found that an excellent palliative care service was provided. They were concerned about whether there would be funds to staff the unit out of hours.

Independent Monitoring Board

17. Each prison has an independent Monitoring Board (IMB) of unpaid volunteers from the local community who monitor all aspects of prison life to help ensure that prisoners are treated fairly and decently. In its most recent annual report, for the year ending January 2013, the IMB commented on the good service provided by healthcare staff. They added that the provision of palliative care facilities at the prison was likely to be of great benefit but, like the Inspectorate, were concerned about how this would be staffed and funded out of hours.

Previous deaths at HMP Leyhill

18. The man is the fifth prisoner to die of natural causes at Leyhill in the last two years. Three of the previous deaths were due to terminal cancer. Our investigations into these deaths found that the men received a good standard of care at the prison.

ISSUES

The diagnosis of the man's terminal illness

19. The man was sentenced to life imprisonment in 1977, and released on licence in 1994. He was recalled to prison in 1999 and transferred to Leyhill in September 2010. At that time, he had little significant medical history, other than a recent hip replacement.

20. On 23 October 2012, the man told a healthcare assistant at Leyhill that he had recently felt short of breath when walking and had experienced discomfort in his abdomen. He was referred to a prison doctor later that afternoon, who decided to admit him to hospital for further investigations.

21. The man remained in hospital overnight and had fluid removed from his lung and was prescribed antibiotics by a respiratory consultant. A follow-up appointment was arranged for 6 November, to be preceded by a scan on 2 November.

22. The scan showed a large pleural effusion (excess fluid on the lung) and pleural thickening (damage to the film that covers the lung), which appeared cancerous. At his follow-up appointment, the consultant arranged for the man to return for a two-night inpatient admission on 12 November, so a biopsy could be taken. The results of this biopsy showed that he had lung cancer that had spread to the pleural cavity.

23. The man was referred to hospital when he first presented with respiratory symptoms. As the clinical reviewer notes, this led to a rapid diagnosis. We are satisfied that his terminal cancer was diagnosed in a timely manner.

Informing the man about his condition and treatment

24. The discharge memo issued on 14 November, after the man's biopsy, included a note that a follow-up appointment had been arranged but the original date was erroneous. A healthcare administrator queried this with the hospital and the appointment was made for 28 November.

25. A specialist cancer nurse telephoned the prison on 21 November and explained the man's test results to a prison nurse. The specialist cancer nurse visited him the next day and spoke to him with a nurse and a Healthcare Assistant (HCA). She explained his diagnosis and that his cancer could be treated, but not cured, with chemotherapy. She recorded that the man understood this.

26. On several occasions over the following week, the man asked the HCA and a prison nurse questions about his diagnosis and prognosis. The nurse and the HCA were appointed as his named nurses and both accompanied him to his appointment with the oncology (cancer) consultant on 28 November, at which the man's treatment plan was outlined and discussed.

27. We are satisfied that the man was informed of his diagnosis and treatment options in a timely and appropriate manner and was well supported by his named nurses.

The man's medical appointments and treatment

28. The man's treatment plan was four chemotherapy sessions, at three week intervals, starting on 14 December and finishing on 15 February 2013. Each session involved an overnight stay in hospital, preceded by outpatient blood tests two days earlier. The aim of the chemotherapy was to slow or stop the growth of his tumour and therefore slow the onset of symptoms and deterioration in his health. The man attended all his appointments (although on one occasion the appointment was postponed by a day due to an administrative error at the hospital) and told prison staff that he felt happy with his progress. Towards the end of January 2013, a light exercise programme was devised for him as he was very keen to stay active.

29. A scan taken on 7 February, before the man's final chemotherapy session, showed that the tumour was stable. He told the consultant that he was keen to finish his treatment and for radiotherapy to be considered afterwards. He reiterated his wish to remain active.

30. After the man completed his course of chemotherapy, the specialist nurse telephoned the prison to confirm that his tumour had not grown or spread since the start of chemotherapy. It was then planned that he would start a course of radiotherapy over five consecutive weekdays, starting on 20 March.

31. However, the man's health deteriorated before he started radiotherapy. On 11 March, he was taken to the prison's healthcare centre in a wheelchair and said that the pain under his rib cage had increased and he was unable to walk due to a left sided weakness. A prison doctor arranged for him to attend hospital for a scan on 13 March and, in the meantime, prescribed dexamethasone, a steroid, to control his symptoms.

32. The scan showed that the man's tumour had spread to the centre of his brain and that he had excess fluid on the right side of his brain which had caused his recent weakness. The consultant told him that his prognosis was now poor. He increased the dose of dexamethasone to alleviate his symptoms. This was successful and just over a week later he said he could now walk around the entire prison.

33. The man attended all his radiotherapy sessions as planned. A follow-up clinic, including a scan to monitor disease progression, was arranged for 15 May. The scan showed that his primary tumour had increased in size and had also spread to his liver. The man was told that his life expectancy was now around four to six months. He was offered the chemotherapy drug erlotinib, (used to restrict the growth of cancer cells), which he said he would think about. He decided to accept the treatment and started on 22 May. The treatment was stopped on 13 June, when the man's health deteriorated and he moved to the prison's palliative care unit.

34. We are satisfied that the man received appropriate treatment after his diagnosis and was able to attend all appointments. There was good communication between healthcare and hospital staff and the clinical reviewer commented that his care was of a high standard and well managed by prison healthcare services.

Palliative care plans

35. The NHS document 'The route to success in end of life care – achieving quality in prisons and for prisoners' sets out how an end of life care pathway might be implemented in prisons. Among the benefits of an end of life pathway are that it helps plan when and how care will be delivered and helps patients make choices about how they are cared for towards the end of their lives.

36. Two named nurses were appointed for the man within a week of his diagnosis. They accompanied him to many of his hospital appointments and supported him throughout the remainder of his life. From 14 March 2013, weekly multi-disciplinary meetings were held to discuss all aspects of the man's ongoing care and support. The meetings were attended by managers, healthcare staff and prison staff.

37. On 4 April, after he had completed his radiotherapy treatment, the man was referred to the local palliative care support service. Two weeks later, specialists from a hospice visited to assess him and discuss the support they were able to provide.

38. Before this visit, on 12 April, a 'do not attempt cardiopulmonary resuscitation' (DNAR) order[1] was agreed and completed. The prison doctor who completed the order discussed it with the man beforehand and recorded that he understood the implications.

39. On several occasions in May, prison healthcare staff sought advice from specialist nurses on appropriate pain relief and other treatment. Two nurses from the hospice visited the man on 15 May and suggested changes to his medication. Various care plans were established, detailing the assistance he required with daily living but there does not appear to have been one over-arching end of life pathway as envisaged by the NHS guidance. The Head of Healthcare told the investigator that the key principles of an end of life pathway for the last days and hours of life were followed when it was apparent the man was dying.

40. On 7 June, a specialist from Bristol Community Health visited the man to assess his care needs. The specialist concluded that he did not require any additional support other than that he was already receiving at the prison.

[1] A DNAR order means that in the event of cardiac or respiratory arrest no attempt at resuscitation will be made. All other appropriate treatment and care will continue to be provided.

41. The man's health deteriorated significantly over the following week and, on 13 June, he moved into the prison's palliative care unit and hospice specialists advised about end of life medication. He died a few days later.

42. The clinical reviewer comments that care plans were developed by healthcare staff with the active involvement of the man and specialists from the hospice. He concludes that the man received care of a high standard. The use of a formal end of life pathway might have helped enhance the coordination of his care, but we agree with the clinical reviewer that he was well cared for at Leyhill and commend the commitment shown by staff of various disciplines to support the man in his final illness.

The man's pain relief and medication

43. The man experienced little pain after his initial diagnosis and was prescribed co-codamol[2] to manage this. The consultant also prescribed dexamethasone, to manage the side effects of chemotherapy.

44. The man experienced slight discomfort but no significant pain during and after chemotherapy. In early March he decided to stop taking co-codamol, but his pain quickly escalated and he restarted the medication. On 19 March, a prison doctor spoke to the specialist cancer nurse about the man's recent increase in pain. She recommended that oramorph[3] be prescribed in addition to co-codamol for him to take when he felt he needed it.

45. The man was initially reluctant to take oramorph and did not do so for several weeks. On 8 April, he told the HCA that the pain had increased in the left side of his chest and she reminded the man that he could take oramorph. He declined as he said he was expecting to have further radiotherapy to help manage the pain. The HCA checked that no further radiotherapy was planned and persuaded the man to start taking oramorph. As with his other medication, this was stored in a safe in his room to which he had the combination so that he could take his medication as required.

46. A specialist nurse from the hospice visited the man on 19 April. He told her that he had some pain under his left ribs, but did not want to take too much pain relief at that time. Three days later, he complained of increasing discomfort and agreed to increase the strength of his oramorph.

47. On 4 May, the man told a doctor that his pain was worse. The doctor prescribed morphine sulphate[4] (MST) tablets as a replacement for co-codamol. Over the following days, the man reportedly became very confused and, on the morning of 7 May, it was discovered that two MST tablets were missing. Funding was obtained to employ agency nurses to work overnight and weekends (when the prison's healthcare centre was shut) to ensure the

[2] Co-codamol is a combination of codeine and paracetamol and, depending on the strength, can be used to manage medium or severe levels of pain.

[3] Oramorph is morphine-based painkiller used to treat severe pain.

[4] Morphine sulphate (MST) is a morphine-based painkiller used to treat severe pain. MST tablets are designed to release morphine slowly over 12 hours to provide prolonged pain relief.

man took his medication at the right time. Agency staff began work on 15 May. In the meantime the Head of Healthcare voluntarily visited out of hours to supervise the man's medication.

48. The man was also prescribed a course of dexamethasone, as his confusion was thought to be caused by the spread of the cancer to his brain. This worked well and within a week he was reportedly back to his normal self.

49. On 10 May, a doctor changed the man's painkiller from MST to a fentanyl patch, which is applied to the skin and provides continuous pain relief for several days. After discussion with specialists at the hospice on 21 May, the strength of the fentanyl patch was increased, and again on 29 May.

50. The man's health deteriorated significantly in the second week of June. On 14 June, a doctor wrote a prescription for stronger painkillers to be administered via a syringe driver[5] if they were needed later in his life. The Head of Healthcare told the investigator that advice was sought from a district nurse, who did not think the syringe driver was required at that time.

51. On Sunday 16 June, the man was given painkilling injections twice but a syringe driver was not used. The Head of Healthcare explained that prison (and agency) nurses are not trained in the use of a syringe driver and they rely on the community nursing team to initiate its use. The community nurses were not available over the weekend and had planned to visit on the Monday but the man died before this visit could be arranged. We understand that it is difficult for Leyhill to ensure they have trained staff available to use a syringe driver for the relatively rare occasions when one is required, but as long as it offers palliative care we consider there should be arrangements to set up and use a syringe drive whenever one is needed, including at weekends. This might be achieved by training its own staff, employing suitably trained agency staff or using other community resources.

52. Although he was often reluctant to take his prescribed medication, we note that changes to the man's prescription were made in line with his complaints of increasing pain. The clinical reviewer comments that the pain relief provided was appropriate, but suggests that it might have been better to start administering pain relief using a syringe driver in the last 24-48 hours of his life. We make the following recommendation:

The Head of Healthcare should ensure that there are appropriate arrangements to initiate the use of a syringe driver in the palliative care suite whenever the need is indicated.

Liaison with the man's family

53. Prison Service guidance states that prisons must engage with the families of seriously or terminally ill prisoners and encourage a terminally ill prisoner to

[5] A syringe driver is a small portable pump that can be used to give a continuous dose of painkillers or other medicines. It is often used when the patient has difficulty taking oral medication.

do likewise. A trained Family Liaison Officer (FLO) was appointed in March 2013, with a back-up when she was unavailable. She introduced herself to the man on 20 March, when they discussed visiting his step-mother, his nominated next of kin. He had not yet told her he had cancer.

54. The FLO accompanied the man to visit his step-mother on 28 March, after he had completed radiotherapy. They also visited a friend of his together on 15 April.

55. On 14 May, the FLO asked the man if he would like her to give his step-mother an update on his condition. Although he was a little confused at the time, they agreed to wait until the results of his scan were available on 15 May. The FLO subsequently telephoned the man's step-mother on 20 May to update her about his treatment. The FLO also referred to the possibility of him going to a hospice near her home.

56. On 31 May, the FLO asked the man if he would like his step-mother to be contacted but he said he would rather wait until he knew more about whether he could move to a hospice. By the middle of June, his health had deteriorated significantly and the man said that he would like his step-mother contacted. Another FLO telephoned her on 13 June and explained the change in her step-son's health. They arranged for her to visit him on 16 June.

57. After the man's death a third family liaison officer, whom his step-mother had met during her visit, telephoned her to break the news of his death. This arrangement had been agreed with his step-mother in advance. The funeral was arranged and conducted by a prison chaplain and the prison paid costs in line with national guidance.

58. While it would have been best practice to appoint a member of staff to liaise with the man's family when he was first diagnosed with a terminal illness, we are satisfied that once a family liaison officer was appointed good efforts were made to support his contact with his family.

The man's location

59. The man lived on A wing at the time of his diagnosis. In March 2013, when he experienced short-term weakness on his left side, he moved to a ground floor room on B wing. Shortly afterwards, on 24 March, he moved to a larger room for terminally ill prisoners or those with mobility difficulties. His friends helped him with everyday tasks such as cleaning his cell and doing his washing. One of his friends told the investigator that he thought he was very well looked after at Leyhill by dedicated staff who were always there when he needed them.

60. Shortly after his move to the larger room, the man was assessed to determine whether he needed a wheelchair. The assessor concluded that he would benefit from walking sticks for short distances and a wheelchair was provided for longer distances.

61. The man had a parole hearing scheduled for early May and it was initially thought that he might move to an approved premises[6] in Somerset if his release was approved. However, his health deteriorated and his parole hearing was postponed. The approved premises was now not an option. From May onwards, consideration was given to him moving to a hospice in Birmingham, near to his step-mother. Arrangements had not been finalised by the time he died. (See section on compassionate release.)

62. In the second week of June, the man's health deteriorated significantly and it was apparent that he was nearing the end of his life. On 13 June, he moved to the prison's palliative care unit, where agency staff provided nursing care outside the healthcare staff's working hours. He was also supported by B wing staff. He lived in the unit until his death.

63. The man's accommodation in the prison was managed according to his symptoms and mobility and he spent his last days in the impressive palliative care facility. His friends told the investigator that they were able to visit him in the palliative care suite and they agreed he received very good care from staff at the prison. We are satisfied that his location within HMP Leyhill was managed appropriately.

Compassionate release

64. Early release on compassionate grounds is a means by which seriously ill prisoners can be permanently released from custody before their sentence has expired. The criteria for early release for indeterminate sentenced prisoners are set out in Prison Service Order (PSO) 4700. They include that the risk of re-offending is expected to be minimal, further imprisonment would reduce life expectancy, there are adequate arrangements for the prisoner's care and treatment outside prison and release would benefit the prisoner and his family. Prisoners are usually expected to have less than three months to live. An application for early release on compassionate grounds must be submitted to the Public Protection Casework Section (PPCS) of the National Offender Management Service (NOMS).

65. The man's case was due to be considered by the Parole Board in early May, to consider whether he was suitable for release on licence. This hearing was deferred by his solicitor, who asked that an oral hearing be arranged instead. No date was set for this hearing before his death but, in the second week of May, his solicitor contacted Leyhill to ask that early release on compassionate grounds be considered.

66. Initially it was expected that the man would be released to an approved premises if his release was approved by the Parole Board, but as his health deteriorated this became unrealistic and other options needed to be considered. By mid-May, a hospice was regarded as the most suitable

[6] Approved premises accommodate offenders released from prison on licence and provide an enhanced level of residential supervision.

option. He said he would prefer to move to Birmingham to be near his step-mother.

67. On 20 May, a hospice near the man's step-mother's home agreed to consider him for admission and faxed their referral form to Leyhill. He first needed to be registered with a community GP in the hospice's catchment area. On 23 May he consented to the transfer of his care to a local GP. However, the hospice referral form was not completed before his death and it was not firmly established that he would be offered a place.

68. The Head of the Offender Management Unit at Leyhill was tasked with leading the man's application for early compassionate release. He told the investigator that the application form was started around five or six days before the man died, but there was insufficient time to complete it before his death. He said that the application was not supported by senior managers at the prison as the man was judged to present an ongoing risk. (This view was supported by the Governor when she met the investigator.) The evidence to support the man continuing to be a risk to the public at this stage of his life is unclear.

69. Another key factor to consider in a potential application for compassionate release is the prisoner's prognosis. The man was given a life expectancy of around four to six months by the consultant oncologist at a clinic on 15 May. This prognosis would not usually be sufficient to support an application for early release. Over the next three weeks, he remained relatively stable and he did not begin to deteriorate significantly until just a week before his death. The man also began a two month course of the chemotherapy drug erlinotab on 22 May, and it would have been appropriate to see how he responded to this treatment and reassess his prognosis before determining whether the release criteria might be met.

70. With the speed of the deterioration in his health in the last week of his life, and the outstanding questions about life expectancy, treatment, risk and hospice accommodation, it does not appear that the man would have met all the criteria for early compassionate release, which would have required the support of the Governor. Nevertheless, the lower level of risk posed by terminally ill prisoners in open prisons would usually mean that they are likely to be strong candidates for early release (as long as the other criteria are met). For that reason, it would have been preferable for the possibility of early compassionate release to have been documented and kept under review once he was diagnosed as terminally ill, as experience indicates that there is often an unexpected rapid decline in health. However, we accept that as late as mid-May the man's consultant indicated that he had between four and six months left to live and that once his condition deteriorated there was little time left to pursue an application for compassionate release.

Restraints, security and bedwatch

71. As a category D prisoner, the man was released on temporary licence[7] for each of his medical appointments, including chemotherapy and radiotherapy sessions and inpatient stays. For support he was accompanied by a prison officer and often a prison nurse on each hospital visit, but no restraints were used.

[7] Release on temporary licence (ROTL) is a form of release usually used to enable prisoners to participate in activities outside the establishment that directly contribute to their resettlement into the community. For example, the man had previously been released on temporary licence to work outside the prison in the community. ROTL was also used when he visited his step-mother to tell her about his diagnosis.

RECOMMENDATION

The Head of Healthcare should ensure that there are appropriate arrangements to initiate the use of a syringe driver in the palliative care suite whenever the need is indicated.

ACTION PLAN: The man – HMP Leyhill

No	Recommendation	Accepted/Not accepted	Response	Target date for completion	Progress (to be updated after 6 months)
1	The Head of Healthcare should ensure that there are appropriate arrangements to initiate the use of a syringe driver in the palliative care suite whenever the need is indicated.	Accepted	One of the nurses at HMP Leyhill completed the syringe driver training in September 2013. As this nurse works in the community they will be able to keep their skills up to date. The Head of Healthcare will meet with the current providers of district nurses to discuss alternative arrangements when this nurse is not on duty in order to avoid any delay in commencing the syringe driver when required.	November 2013	