

# People who are in secure and detained settings

## A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE



Care for older people, including end of life care, is becoming an increasingly important aspect of prison healthcare. The UK prison population is ageing, and people aged over 50 and 60 are the two fastest growing prison population groups. However, there is currently no national older prisoner strategy, or sufficient investment to meet the increasing needs of elderly prisoners. There are challenges in delivering good end of life care in prison, and the experience of prisoners at the end of life is variable.<sup>1</sup>

### Quality of care

The Prisons and Probation Ombudsman (PPO) investigates all deaths of prisoners in custody. In a review of investigations of foreseeable, natural cause deaths, PPO found that the majority of prisoners received care that was equivalent to the care they may have received in the community.

However, quality of care is not consistent. In some cases, the person did not have a palliative care plan or support for the prisoner was lacking. Support for families was also variable, and efforts to obtain temporary or compassionate release to allow prisoners to die with dignity in the community were not always good enough as decisions were not made in time. The PPO has also frequently identified the inappropriate use of restraints on prisoners who are at the end of their life as an area of concern, as in the following example.

### AN EXPERIENCE OF POOR QUALITY CARE IN PRISON

A man who received a three-month prison sentence was noted as being dependent on drugs and alcohol and a reception nurse noted that he appeared jaundiced and unwell on arrival in prison. He was prescribed medication for his drug and alcohol dependence, but his jaundice was not investigated.

Ten days later, the man told a prison doctor that he had abdominal pain and had passed blood. He was taken to hospital where he died a few weeks later of liver failure.

A review of his case found that the care he received was not equivalent to the care he could have expected in the community. Although healthcare staff were aware that he was a heavy drinker, they did not investigate his jaundice. The review concluded that although earlier diagnosis of his condition is unlikely to have changed the outcome, it might have helped to make him more comfortable and reduce his pain.

In addition, there was a delay of several hours when he was sent to hospital as an emergency, and he was subject to a high level of restraint in hospital without appropriate risk assessment, although he was in bed and very ill. The man's next of kin were only contacted by prison staff after he had been in hospital for 10 days and they had very limited time to spend with him before he died.

<sup>1</sup> Prisons and Probation Ombudsman, **Learning from PPO investigations: end of life care**, 2013

Data from the PPO for deaths in 2013 and 2014 in England shows that there were 259 deaths by natural causes. From a sample of 196 deaths that PPO reviewed, 78 deaths were reasonably foreseeable. In 81% of these cases there was a palliative care plan in place, and the prisoner was involved in the care plan in 89% of cases. The PPO found the health care was 'equivalent' to care outside of prison in 70 cases (90%), and 'partly equivalent' in three cases (4%).

## Release into the community

Compassionate release or release on temporary licence (ROTL) may be considered for prisoners at the end of life. Early release on compassionate grounds is only granted in exceptional circumstances when prisoners are usually expected to have less than three months left to live. In addition, the risk of re-offending must have passed.

ROTL and compassionate release both appear to be routinely considered, but they either happen too late or decision-making happens too slowly. ROTL had been considered in 19 of the cases reviewed by PPO; it was only granted for six prisoners, and was still under consideration when the prisoner died in seven cases. Compassionate release was considered for 51 people. However, out of these 51, it was granted for only two prisoners, and was still under consideration when the prisoner died in 21 cases.

As part of our review, we spoke to staff and prisoners at Leyhill Prison. Leyhill has a palliative care unit with two beds, as well as a family room, and was caring for a number of people approaching the end of life at the time of the visit. People felt that the system for release into the community at the end of life was designed around a younger and healthier prison population, where prisoners may be able to be released on temporary licence first. People said that prisoners approaching the end of life who have a life expectancy of less than three months were often too ill to leave.

## Care in prison

For prisoners who remain in prison at the end of life, the prison environment can present challenges in providing good end of life care. We identified some prisons that have addressed this by building a palliative care unit, or by developing good links with a local hospice to enable prisoners to receive treatment there. The following is an example of good care in a prison palliative care unit.

### GOOD END OF LIFE CARE AT HMP PRESTON

HMP Preston is a local prison holding up to 842 adult men. There is an inpatient unit for up to 30 prisoners, which is used for end of life care, and acts as a regional facility. The Prisons and Probation Ombudsman's report into the death of a man in July 2014 describes the good care he received on the unit.

On entering prison, the man had an existing diagnosis of Alzheimer's disease for which he was prescribed medication, and he was transferred to a specialist wing for elderly and infirm prisoners at HMP Wymott two months after arriving in prison.

In April 2014, after a hospital admission, a prison GP referred the man urgently to hospital and tests revealed that he had pancreatic cancer, which had spread to his liver. His condition was not curable. He was discharged from hospital and moved to the inpatient unit at HMP Preston for palliative care. He received good care at HMP Preston and died peacefully in July 2014.

The PPO's investigation showed that the man had received good care. The inpatient unit had a close working relationship with a local hospice; nurses used a comprehensive care plan; the prison liaised with community palliative care services; and the prisoner and his partner were actively involved in decision-making about his care.

In the last days of his life, the prison left his door open to allow healthcare staff immediate access at any time; he received appropriate pain relief. A nurse looked after the man throughout the night before he died, and was with him when he died in the morning.

In general, prisoners felt that the quality of health care at Leyhill was very good or excellent. One prisoner with a life-limiting muscle-wasting condition said “they saved my life coming here”. For some offenders who had served very long sentences, or had no family or friends outside prison, their preference was to die in prison. The following is one person’s experience of planning for the end of life phase.

### GOOD PRACTICE AT LEYHILL PRISON

The prisoner was diagnosed last year with throat cancer and given chemotherapy to extend his life by around six months. He is hoping to spend the last three months of his life outside prison, with his family. His parole hearing has been moved up due to the short amount of life he is estimated to have left. He is optimistic about being released as the probation service are in favour of it and if refused he says he can reapply for compassionate release. He has also had discussions about being moved closer to his family, transferring notes, and arranging care and support at home. He is also aware that the palliative care unit in Leyhill allows family to stay over and he has been to see it.

#### Prisoner, HMP Leyhill

### CQC ENCOURAGES:

- Commissioners and providers of prison health services to consider the end of life care needs of people who are in prison, and to learn from good practice to develop an effective approach to delivering good care that meets prisoners’ needs locally.

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### OVERVIEW REPORT

### GOOD PRACTICE CASE STUDIES

### PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BME) groups
- Lesbian, gay, bisexual or transgender people
- People with a learning disability
- People with a mental health condition
- People who are homeless
- Gypsies and Travellers

