

Learning from PPO Investigations

End of life care

March 2013

Contents

Foreword	5
Executive Summary	7
1. Introduction	9
1.1 What is end of life care?	9
1.2 Why is end of life care important for prisoners?	9
2. Policy overview	10
2.1 General policies on end of life care in England and Wales	10
2.2 Prison specific policies about end of life care and prison responsibilities	10
2.3 Age and end of life care: now and what the future holds	13
3. End of life care in PPO investigations	15
3.1 Introduction	15
3.2 Demographic make up of the sample	15
3.3 Primary cause of death	16
3.4 Type of establishment	17
3.5 Location of deaths	17
3.6 Themes	17
3.6.1 Palliative care plans	17
3.6.2 Restraints	19
3.6.3 Early release	21
3.6.4 Family involvement	23
4. Lessons to be learned	26
4.1 Concluding remarks and moving forward	27
References	28

Foreword



I am pleased to introduce this thematic report describing learning from my independent investigations into deaths of prisoners in custody due to a terminal or incurable disease. The report reviews end of life care for these prisoners by looking at the 214 such deaths which were investigated by my office between 2007 and 2012.

With an increasingly ageing prison population, the care for those at the end of their life is a growing responsibility for the Prison Service. Prisoners of all ages can suffer serious health problems, but it is older prisoners who are most likely to require end of life care. Remarkably, as more prisoners serve longer sentences and more are sentenced later in life, those aged 60 and over have become the fastest growing segment of the prison population with the number imprisoned increasing by 142 per cent in the last ten years. So prisons face the prospect of having to care for ever increasing numbers of prisoners dying in places originally designed for younger men.

Of course, society as a whole is ageing and care for the elderly and infirm is an increasing priority for the National Health Service, but there are particular challenges in providing this care in prison. It is therefore commendable that this report finds that prisons are making headway in providing adequate end of life care and geriatric facilities. Thus, in 85 per cent of cases, my investigators and the clinicians with whom they work, judged the care received by the deceased to be equivalent to that which might have been expected in the community.

However, care is not universally good. For example, over a quarter of prisoners in the

sample of foreseeable deaths had no palliative care plan, support for families was variable and greater efforts could have been made to obtain temporary or compassionate release to allow prisoners to die with dignity in the community. Above all, as I have reported numerous times, prisons need to achieve a better balance between care and security in the use of restraints on the terminally ill. While a prison's first duty is to protect the public, too often restraints are used in a disproportionate, inappropriate and sometimes inhumane way.

I would like to thank my colleague, Ms Sarah Colover, for preparing this report. It is part of a series reflecting my commitment to publish regular reports and bulletins setting out the lessons from my investigations which, if learned, could help ensure custody is a safer, fairer and more effective place.

A handwritten signature in black ink, reading 'Nigel Newcomen'. The signature is written in a cursive style with a long horizontal stroke at the end.

Nigel Newcomen CBE
Prisons and Probation Ombudsman

Executive summary

- This report presents a review of 214 Prisons and Probation Ombudsman (PPO) fatal incident investigations into foreseeable natural cause deaths in custody. These deaths were due to terminal or incurable diseases in prisons in England and Wales between January 2007 and October 2012.
- The review of end of life care in the 214 investigations is placed in the wider context of an ageing prison population. The national and local responses to the changing prison demographic are considered.
- The average age at death was 61 years old. Fifty eight per cent of these deaths were of prisoners aged 60 years and over (123 of 214).
- The majority of prisoners (85%) in the sample received care which was judged by investigators and their clinical counterparts to be equivalent to that they could have expected to receive in the community.
- However, the level of end of life care provided to prisoners varied between prisons. Over a quarter (29%) of prisoners in the sample did not have a palliative care plan in place to support them and their families with their terminal illness.
- Eight fatal incident investigations are summarised as case studies, with learning highlighted. The cases address the following themes:
 - Palliative care plans
 - The use of restraints
 - Compassionate release and release on temporary licence
 - Family involvement
- The learning identified is categorised into four groups:
 - The importance of implementing an end of life care plan from the point of terminal diagnosis to support for the family after death.
 - The need for prisons to place sufficient weight on a prisoner's current health and mobility when assessing the risk they pose to justify any use of restraints. The concordat between the Prison Service and NHS should be followed by every prison to assess the level of restraint required
 - Where appropriate, applications for early release on compassionate grounds should be completed at the earliest possible opportunity.
 - The need for families to be involved, where appropriate, in the care planning and how prisons can facilitate and support this.

1. Introduction

With a large and ageing prison population, the Prison Service has to deal with more foreseeable deaths from terminal and incurable illnesses than ever before. This brings new challenges for both prison regimes and prison facilities to accommodate the end of life care needs for those prisoners who require them. This report looks at how the Prison Service is responding to these challenges and is focused on a sample of 214 prisoners who died from a terminal illness in prison between January 2007 and October 2012.

1.1 What is end of life care?

End of life care can be defined as care that helps those with an advanced, progressive, incurable illness to live as well as possible until they die. End of life care is about the total care of a person with an advanced incurable illness and does not just equate with dying. The end of life care phase may last for weeks, months or years.

There are a number of terms used when describing care that people may need as they approach the end of life, and they are often used synonymously.

Palliative care is the total care of patients whose disease is unresponsive to active medical treatment. Control of pain and other symptoms and support to manage psychological, social and other problems are paramount. The goal of palliative care is to provide the best quality of life for patients and their families.

Palliative care comes into the picture when the person's condition deteriorates and active treatment does not control the disease. Here, progressive deterioration and death is anticipated and the emphasis of care moves from active treatment of the disease to treatment to give comfort and control symptoms such as pain.

End of life care enables the palliative care needs of the patient and the support needs of the family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support.

1.2 Why is end of life care important for prisoners?

Prisoners are entitled to an equivalent level of healthcare in prison as they could have expected to receive in the community¹. This includes care for a terminal illness or incurable disease. An end of life care pathway is viewed as the best way to deal with the last stages of life and so should be equally offered to those in prison as it is to those in the community.

With a prison population which is ageing and also has many individuals with health deficits, the provision of end of life care has become increasingly important as more prisoners die of old age and incurable and terminal diseases. Because of this, some charities have increasingly been working with the Prison Service and in partnership with the NHS Offender Health Division to provide specialist services to prisoners with terminal illnesses. A recent example of partnership working is a guide² for prisoners diagnosed with terminal cancer that Macmillan Cancer Support has published. The booklet provides practical advice and outlines what is likely to happen, how prisoners may feel and what support they may need.

Older prisoners (aged 60 and above) have more major illnesses than younger prisoners and those of a similar age in the community³. Most prison buildings and facilities were not designed with an elderly population in mind. This can mean that those who are less mobile and in poorer health have difficulty accessing services or taking part in meaningful activity in order to lead a purposeful active life in prison. The architecture also sometimes poses problems for delivering end of life care to terminally ill prisoners. It is therefore a challenge for the Prison Service to meet the needs of this group.

In order to overcome these challenges, a number of prisons have built palliative care cells or units to accommodate the palliative care needs of prisoners requiring specialist end of life care. Other prisons have developed links with local hospices to enable prisoners to receive treatment outside the prison.

2. Policy overview

2.1 General policies on end of life care in England and Wales

Two main pathways existed before the national end of life care programme was established. These were, the Liverpool Care Pathway for the Dying Patient⁴ and the Gold Standards Framework⁵. In response to recent publicity about the way the Liverpool Care Pathway has been used and accusations about the care of end of life patients, an independent review⁶ has been set up to look at how the Liverpool Care Pathway is being delivered in practice. The Liverpool Care Pathway is still internationally recognised as best practice and the Department of Health continue to recommend its use in their End of Life Care Strategy.

The Liverpool Care Pathway was developed during the late 1990s at the Royal Liverpool University Hospital, in conjunction with the Marie Curie Palliative Care Institute. It was intended to provide the best quality of care possible for dying patients in the last days and hours of life, whether they were in hospital, at home, in a care home or in a hospice. It was widely seen as a way of transferring the model of “excellence” in the care provided in hospices to other healthcare settings such as hospitals and care homes.

The Gold Standards Framework was developed in 2000 as a grass roots initiative to improve palliative care from within primary care. The main goal of the programme is to enable more people to die where they choose (usually at home or in a care home) to reduce the number of inappropriate admissions to acute hospital wards and to provide a best practice of care for those at the end of their life.

The National End of Life Care Programme was set up in 2004 with the intention of ensuring good quality end of life care for all adult patients, irrespective of diagnosis or care setting. In 2008, the first National End of Life Care strategy⁷ was published outlining a 10 year strategy for improving care at the end of life. The document highlights, as the National End of Life Care Programme did, the need for high quality end of life care to be provided in all care settings, including prisons.

2.2 Prison specific policies on end of life care and prison responsibilities

The transfer of responsibility for the provision of healthcare from the Prison Service to the National Health Service (NHS) was arguably a defining moment in the Prison Service’s history. The transition began in 2003 and, in 2006, prisoner healthcare became the sole responsibility of the NHS with the majority of prison healthcare commissioned by Primary Care Trusts. Most commentators agree that a step change improvement was subsequently achieved by this transition⁸. Delivery models differ and a small number of privately run prisons are still responsible for commissioning their own healthcare – as a condition of their contract. There are also a number of public prisons who outsource their healthcare provision to private healthcare providers and staff are employed by the healthcare contractor. However, both public and private healthcare suppliers are subject to the same rules and regulations in regards to their healthcare provision in prisons.

Prison Service Order (PSO) 3100⁹ covers clinical governance and the quality of prison healthcare. It does not explicitly refer to palliative care, but does state that governors should ensure that healthcare is dedicated to improving the quality of clinical care and strategies for identifying and reducing risk. PSO 3100 is delivered in parallel with the Health Services for Prisoners standard¹⁰. The standard requires establishments to develop *needs* based health services, which effectively deliver evidence based care to both the individual prisoner, and the prison population as a whole. If a needs-based approach is followed, prisoners who require end of life care would be identified and their individual needs provided for.

In 2007, the Department of Health issued guidance¹¹ on care for older prisoners which references the importance of end of life care in the face of an ageing prison population. In 2011, the National End of Life Care Programme created a guide¹² for delivering end of life care in prisons. This guide provides practical advice for implementing high quality, end of life care by improving the quality of care offered and enhancing the dignity and choice for prisoners approaching the end of their life. The guide sets

out the six point end of life care pathway (Figure 1). The programme promotes the use of the Liverpool Care Pathway and the Gold Standards Framework as end of life care tools designed to increase choice, improve standards of care and facilitate communication between professionals, prisoners and their families. There is currently a project underway to create a workbook of best practice for delivering the Gold Standards Framework in prison. The Preferred Priorities for Care¹³ should also be available to all prisoners, and is a document which can help prisoners to record their wishes and choices for the care they would like to receive.

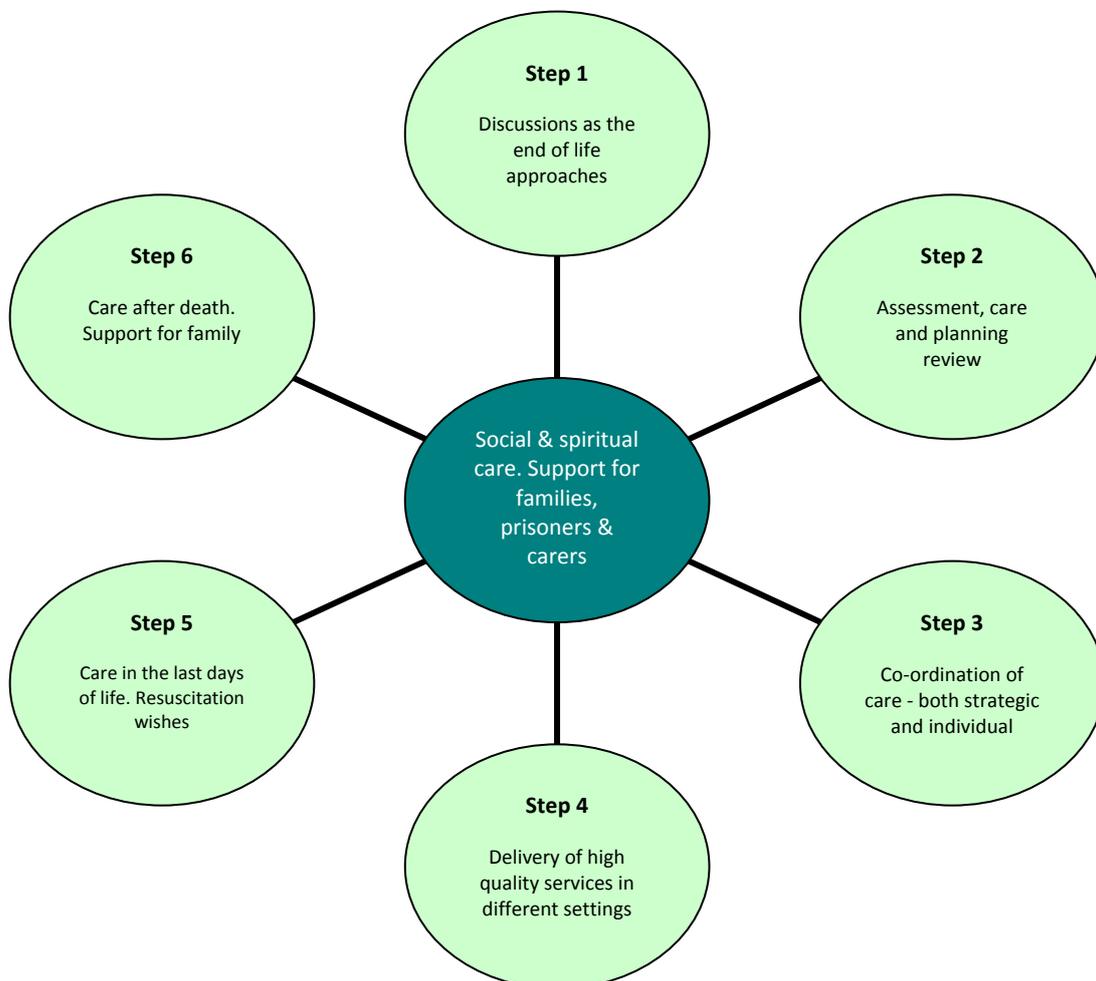
Prison Service Instruction 64/2011¹⁴ was issued in February 2012. It contains a number of chapters which refer to end of life care issues such as family liaison and advance directives, as well as a specific chapter on the 'Management of prisoners who are terminally or seriously ill'.

From April 2013, responsibility for end of life care services in prisons in England will fall to the NHS Commissioning Board, which will assume

responsibility for commissioning public health services for people in prison in England. To facilitate this, the Department of Health has ring fenced funding for the NHS Commissioning Board to commission certain public health services.

The ageing population both in the community and in prisons has brought the provision of social care to the fore recently, and led the Government to produce the White Paper: 'Caring for our future: reforming care and support'. The White Paper outlines the framework for social care delivery in the community, as well as recognising social care needs in a prison setting. This is the first time that it has been explicitly stated and recognised by the Government that the social care needs of prisoners have, in the past, been neglected due to the lack of clarity about where responsibility lies. This is supported by Her Majesty's Chief Inspector of Prisons' (HMIP) 2012 annual report¹⁵ which reported that few prisons had developed health services for dealing with the social care needs of older prisoners.

Figure 1: Representation of the prisoner end of life care pathway (NEoLP 2011)



Local policies and initiatives

In the absence of a national policy and before the introduction of the NHS guidelines in 2011, some prisons developed their own local policies and introduced a number of initiatives for older people. For example, HMP Downview, a women's prison, created a detailed policy for older offenders which is based on survey data as well as Department of Health and Prison Service policy. HMP Stafford provides a number of clinics specifically for older prisoners, such as twice weekly physiotherapy, an anxiety clinic and a prison-specific screening tool. The prison also provides a regular day club for retired prisoners.

Age UK has helped to set up older prisoner forums in prisons since 2008¹⁶. The forums are run by prisoners themselves and overseen by prison staff. The forums were set up in HMPs Channings Wood, Leyhill, Dartmoor, Hull and Gartree. Other forums are being developed at local prisons (e.g. HMPs Exeter and Bristol).

There are other prisons that have developed new facilities and adapted their existing facilities to cater for the care needs of terminally ill and ageing prisoners. HMP Isle of Wight (Albany) holds a considerable number of older prisoners. The prison took part in the King's Fund Enhancing the Healing Environment Project¹⁷ and, as part of the project, two bedrooms for end of life and respite care were purpose-built. Prisoners also helped to create an eco-friendly garden in the prison grounds.

HMP Whatton in Nottinghamshire has an older than average population with 60 per cent of prisoners over the age of 40 and a high rate of cancer. The prison has a senior nurse with specific responsibility to lead on palliative care and significant improvements have been made to the accommodation for terminally ill prisoners and their visitors. A grant from the NHS Offender Health Division through the King's Fund (Enhancing Healing Project) has financed a purpose-built end of life care suite attached to the healthcare centre. A room is also provided on a residential wing where families can visit their terminally ill relative if they are too ill to attend the visits hall.

Macmillan Cancer Support and the North East Offender Commissioning Unit with the support of

County Durham and Darlington Foundation Trust have been working with prisons¹⁸ in the North East region to develop the Macmillan Adopted Prison Standards (MAPS). MAPS is a set of 28 measurable standards and associated tools for delivering best practice end of life care in prison. The project has been running since 2010 and has secured funding until 2014. So far, 90 staff (prison and healthcare) have gained accredited training in palliative care. Each prison also has at least one palliative care champion. Prisoner information packs and a DVD have been developed to support on-going training. In conjunction with Teeside University, a prison diploma in palliative care has been developed. A palliative care register has been set up in every North East prison. When a prisoner is placed on the palliative care register (at the first point of a terminal diagnosis) this prompts a multi-disciplinary team meeting made up of nurses, operational staff and a family liaison officer to ensure a holistic end of life care pathway is put in place.

A working group from the North East Health Commissioning Unit is currently working with HMPs Frankland and Holme House to assess the feasibility of using a suitably trained registered nurse to verify an expected death in prison rather than calling a doctor or the emergency services to verify the death, as currently happens.

2.3 Age and end of life care: now and what the future holds

Although the prison population has risen dramatically in recent years, this has not been the same across all age groups. The proportions of all the age groups under 40 years have fallen, while all the age groups over 40 have increased (Table 1). People aged 60 and over are the fastest growing age group in the prison system (Figure 2). and currently make up four per cent of the total population. Between 2002 and 2012, the number of sentenced prisoners aged 60 and over

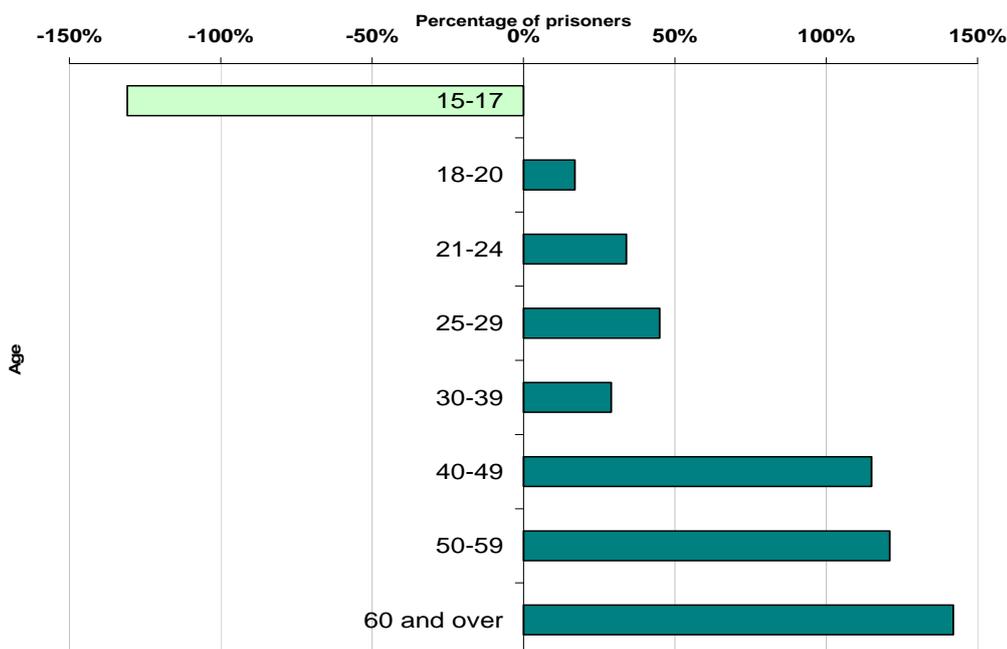
increased by 142 per cent from 1,376 to 3,333. The actual number of 15-17 year olds in prison has fallen by 903 in the same time period and is the only age group to do so.

As the prison population ages, the number of deaths from chronic disease or simply old age is expected to rise. There is likely to be a corresponding increase in the number of cases where prisoners would benefit from planned end of life care.

Table 1: Prison population by age 2002¹⁹ and 2012²⁰

Age	2002		2012	
	Number of prisoners	Percentage of total	Number of prisoners	Percentage of total
15-17	2,083	4%	1,180	1%
18-20	6,154	11%	7,219	8%
21-24	10,373	18%	13,882	16%
25-29	10,869	19%	15,780	18%
30-39	16,437	29%	23,310	27%
40-49	7,058	12%	15,173	18%
50-59	2,955	5%	6,580	8%
60 and over	1,376	2%	3,333	4%
Total	57,306	100%	86,457	100%

Figure 2: Percentage change in the age of the prison population between 2002²¹ and 2012²²



Various factors are contributing to the faster rise in the number of older prisoners. Conviction for 'historic' offences (often sexual offences) which were committed sometimes decades ago has impacted on the age of prisoners when they first enter custody. Legislative changes have introduced longer custodial sentences, such as the introduction of mandatory life sentences for those convicted of a second serious sexual assault, and harsher sentencing policies for drug trafficking offences. In addition, those who were sentenced to indeterminate sentences (the proposed abolition of Imprisonment for Public Protection sentences will not be applied retrospectively) are not released until they can show they no longer pose a risk to others. These three factors mean that prisoners are older than previously when they first enter prison and/or are growing old in prison. This upward trend is likely to continue at an accelerated rate if the prison population increases to 95,000 by 2018 as projected²³. The increase in the number of older prisoners has been commented on by many practitioners and organisations, including the Prisons and Probation Ombudsman in his 2012 annual report²⁴.

HMIP carried out a thematic review²⁵ in 2004 of older prisoners and published a follow up report²⁶ four years later. The follow up report found that healthcare provision for older prisoners and those receiving palliative care had improved during the four years. However, it also found that two of the healthcare recommendations had not been implemented: for every health service centre to have a lead nurse or manager who has responsibility for older prisoners, and for staff working with older prisoners to receive training in how to recognise signs of mental health problems. The follow up report repeated the recommendation (from 2004) for prisons to have a policy for identifying and meeting the needs of older prisoners, with a designated lead from the prison staff.

The 2008 HMIP report added a new recommendation: for prisons to ensure that the social care needs of the ageing prison population are identified and fully met. Social care has been identified as an area which is often neglected in prison. The 2008 follow up report found that the provision for social care was still largely seen as a healthcare issue rather than one for the prison as a whole. The introduction of the White Paper

on social care provision will hopefully address this neglect by the Prison Service and prisons will in future meet the social care needs of their prison population with a more holistic approach.

The National Offender Management Service (NOMS) rejected a recommendation made by HMIP in both reports to implement a national strategy for older and less able prisoners. NOMS did not accept that it was appropriate to manage prisoners on the basis of age, but instead insisted that this should be on the basis of individual need. This does not chime with Government policy which, in 2005, launched a national strategy for an ageing population²⁷. The strategy recognised the need to set out a coherent framework to ensure that all policies address the issues faced by older people.

Despite this, survey data from HMIP²⁸ collected in prisons across the country in 2011-12 showed that prisoners aged 50 and over were the group most positive about their access to health services. Over two thirds found it easy to see the nurse and just under half found it easy to see a doctor. They are most likely to have reported that the quality of care they had received in prison was good or very good. They were also the group most likely to be taking some form of medication and be allowed to keep possession of it in their own cell.

3. End of life care in PPO investigations

3.1 Introduction

From January 2007 to October 2012 the PPO investigated 647 natural cause deaths in prison. These are deaths which are caused by an illness, for example lung cancer, heart disease or a respiratory disease such as pneumonia. This report focuses on those prisoners whose death was foreseeable due to the terminal and incurable nature of their illness and, for whom formal end of life care could have been appropriate. There were 214 prisoners in this sample whose death was foreseeable.

The sample data is based on 214 data collection forms which were completed by the PPO investigators during their investigations. The forms are split into 17 sections and cover most aspects of prison life. The investigator has access to the deceased prisoner's medical records, prison records (including security information reports) and can request any information they may need. They are also able to ask for an interview with any member of staff - both discipline and medical, and with serving prisoners, if they feel it will aid their investigation. The data collection forms allow some standardisation of the information collected during the investigations to enable cases to be compared, but not all information is available or recorded in all cases.

3.2 Demographic make up of the sample

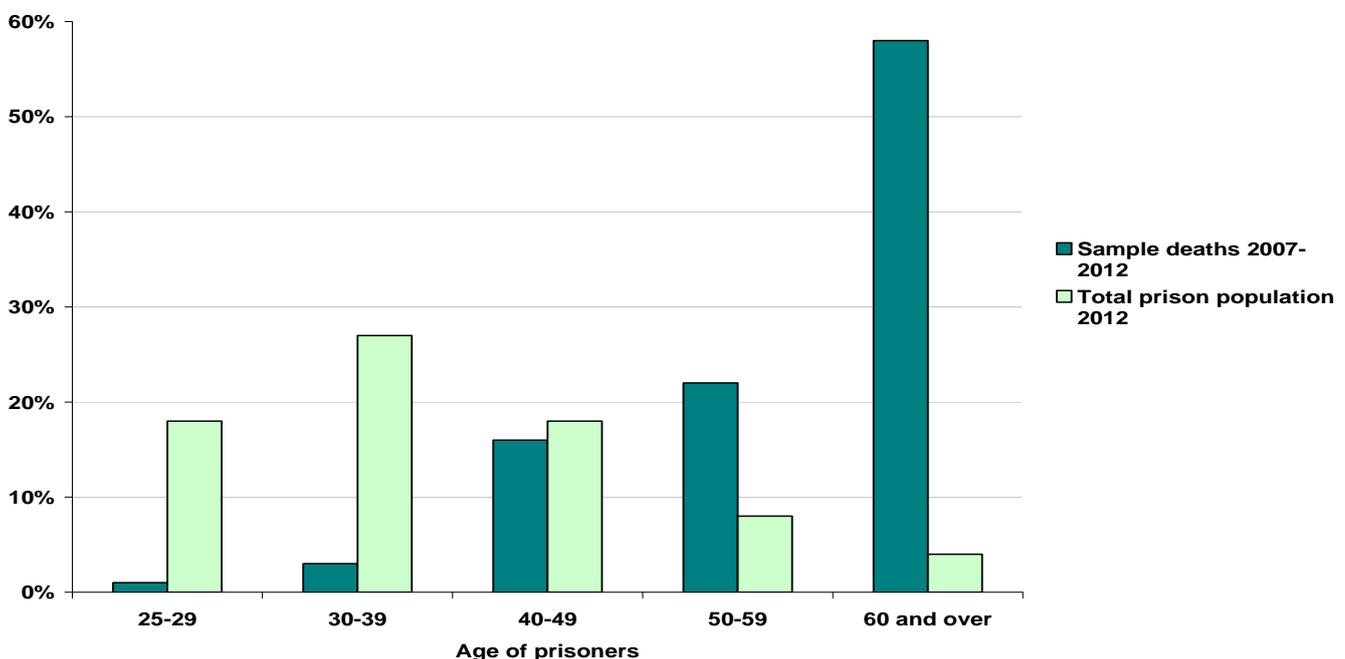
The sample shows some differences to the prison population as a whole²⁹.

The vast majority of the sample was male (97%) and only six were female; reflecting the fact that 95 per cent of the total prison population is male. There was a disproportionate number of deaths of white prisoners, with almost 90 per cent of the sample being white, even though black and minority ethnic prisoners represent a quarter of the total prison population.

One in ten of the sample was a foreign national prisoner. This is roughly the same as the total prison population where foreign nationals account for 13 per cent of the total prison population.

Older prisoners (aged 60 and over) made up the majority of those who died of a terminal or incurable illness (Figure 3). The vast majority of the sample was aged 50 and over (80%). When the age groups were broken down, those aged 65-74 made up over a quarter (30%). There were 11 prisoners aged 80 or over at the time of their death; the two oldest prisoners were aged 88 years old when they died.

Figure 3: Disproportionality of age of sample compared to prison population in 2012³⁰



Nearly a third of the sample had a disability; the same proportion as in the general prison population. Of those in the sample who had a disability, around half had a disability related to their mobility. Other disabilities recorded included problems with sight and hearing.

3.3 Primary cause of death

The sample is based on cases where death was reasonably foreseeable. This includes both those who had a terminal diagnosis and those who had multiple conditions which individually may not have been terminal, but which in combination meant that the prisoner was unlikely to live much longer.

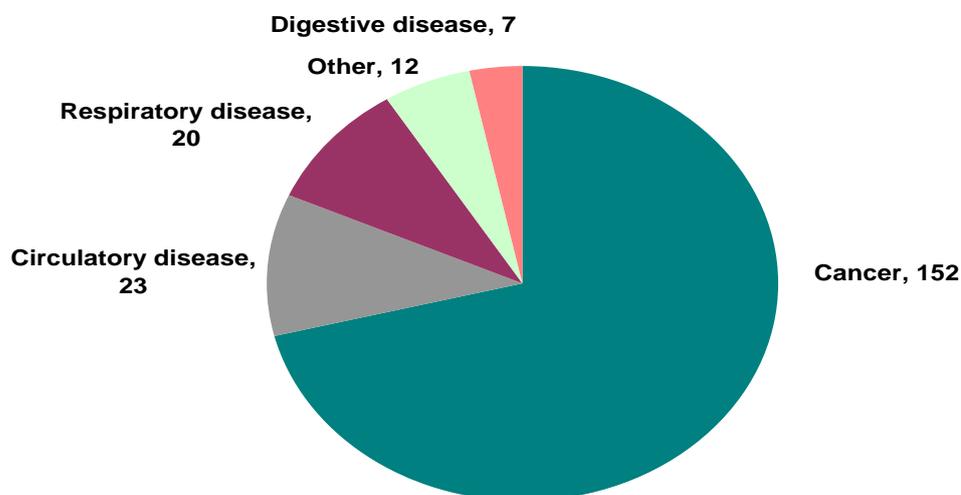
The PPO categorises the types of deaths investigated according to the World Health Organisation Standard International Classification of Diseases (ICD 10)³¹. In cases where multiple conditions contributed to the death, only the primary cause of death as indicated by the death certificate is reported here. The cause of death in the majority of cases in the sample (71%) was cancer (Figure 4). The primary cause of death was circulatory disease in 11 per cent of all deaths and respiratory disease in nine per cent. Other infectious diseases, diseases of the nervous system and digestive diseases accounted for nine per cent of all deaths in the sample.

Neoplasms (chapter II: blocks c00-d44³²) cover all types of cancer, including leukaemia and unspecified cancers. As in the community, cancer is the most common cause of death in the sample. The most common type of cancer found in the sample (and the wider community) was lung cancer, which accounted for one in three (56) of the prisoners who died of cancer.

Circulatory diseases (chapter IX: blocks 100-199³³) cover a range of conditions, all relating to the supply of blood to and from the heart, brain and the rest of the circulatory system. Deaths can range from those due to cerebrovascular diseases (block 160-69) such as from cerebrovascular accident (a stroke) to pulmonary diseases that affect blood supply to the lungs (block 126-28). The most common forms of causes of death from a circulatory disease are those from ischaemic heart diseases, which often result in a heart attack. The primary cause of death in twenty three cases in the sample was heart disease. Ten in the sample died from a stroke or another type of circulatory disease.

Respiratory diseases (chapter X: blocks j00-j99³⁴) cover a range of conditions, from influenza and pneumonia to respiratory infections and lung disease. The primary cause of death in twenty cases in the sample was a respiratory disease.

Figure 4: Primary cause of foreseeable death 2007-12 (N=214)



3.4 Type of establishment

A very small number of female prisoners died of a terminal illness, reflecting the fact that women represent a very small proportion of the prison population.

A disproportionate percentage of prisoners, compared to the prison population as a whole, were in a high security prison when they died (19% compared to 7%). Prisoners in the high security estate are likely to have longer sentences than those in the rest of the prison estate, being either lifers or others convicted of serious offences and regarded as a significant risk to the public. As a consequence, the high security estate holds a higher proportion of prisoners aged 50 years and over compared to the rest of the prison estate. Prisoners aged 50 years and over make up 20 per cent of the total high security population compared to only 12 per cent of the rest of the prison population. As these prisoners are in the establishments for a longer period of time than those in the remainder of the estate, one would expect there to be a higher occurrence of prisoners dying of terminal illness and old age in these locations.

Prisoners held in the high security estate pose the greatest risk to the public, and pose the greatest risk if they escaped, so are given the highest security categorisations (category A or B). Categorisation is taken into consideration when assessing the prisoner for compassionate release or release on temporary licence (ROTL). Category A prisoners will automatically be excluded from applying for ROTL.

3.5 Location of death

The majority of prisoners died in hospital (54%), more than a quarter died in prison (30%) and only 15 per cent died in a hospice. Of those who died in prison, the vast majority died in the healthcare centre (73%) and 17 prisoners died in their normal cell location. This broadly reflects what happens in the community for patients with cancer; the home death rate is low (23%), the hospital death rate is high (55%) and a small percentage of people die in a hospice (12%) or a nursing home (10%)³⁵. People in the community who die in hospital as opposed to at home are more likely to be socio-economically disadvantaged, elderly, have no carers or have a long-standing illness.

Some prisoners do not want to be moved in the last stages of their life, and prefer to stay on the wing where they are surrounded by their friends, staff they know, and in an environment they are familiar with. There were examples of good practice in the sample where a small number of prisons had adapted prisoners' cells on the wing to accommodate their palliative care needs. Other prisons had established palliative care beds in their healthcare centres which were specifically designed for the care of prisoners at the end of life.

In the majority of cases where the data was collected, when special care needs had been identified for the prisoner, these had been accommodated by the prison (65%)³⁶. These included the prison providing a special bed or mattress, fitting an alarm cord and moving the prisoner to the ground floor to enable easier access to facilities. This highlights that it is not imperative for a prison to have a specialist end of life care wing/unit or cell to provide high quality palliative care. Prisons can provide a high level of care by ensuring their staff are well trained in palliative care, they have strong ties with their local hospital and hospice so they can access expert advice if needed. However, they will require the resources to adapt existing cells to cater for the care needs of prisoners at the end of their life.

Of those prisoners who died in prison, it was recorded in at least 53 per cent of investigations that the prisoner's cell was open at all times to allow healthcare staff easy access to care for the prisoner. This is important in helping deliver an end of life care plan which follows one of the core functions of the NHS - allowing people to die in comfort and with dignity³⁷.

3.6 Themes

3.6.1 Palliative care plan

It was recorded in the majority of cases in the sample (69%) that the prisoner had a palliative care plan. Of those 147 cases, nearly all of the prisoners (91%) were involved in their care plan. In this type of approach to end of life care, planning and review are the first two stages in the six stage end of life care pathway set out in the National End of Life Care Programme guide for prisons. The first two stages are important steps to take for both the prison and prisoner in

setting out what the prisoner's needs and wishes might be for the coming months or days and how best to manage them.

The third step of the end of life care pathway is to ensure co-ordination of care between the individuals and services that will be responsible for delivering and supporting the care plan. Co-ordination is important in any setting, but the prison estate provides extra challenges to care planning, such as making changes to a cell so a wheelchair can fit. Therefore, it is important that prisons are in regular contact with hospital or hospice staff to keep up to date with a prisoner's condition if they have been admitted. Prison staff should ensure that they are prepared for the prisoner's return from the hospital/hospice. Prison staff should co-ordinate transport and security arrangements for hospital visits and future referrals. The PPO had concerns in 16 per cent of cases about communication between the prison and hospital or hospice staff. There were also cases where test results were delayed, prisoners missed appointments due to misinformation, paperwork was lost between the hospital and prison and hospitals did not inform the prison of the severity of a prisoner's condition.

Step four of the end of life care pathway is the delivery of high quality services in different settings. For prisoners, this can apply to delivery of services in the healthcare centre, in the

prisoner's cell or in a hospital or hospice. Seventy five per cent of prisoners had appropriate equipment available to them in order to implement the care plan in a prison setting. In 11 cases, it was recorded that appropriate equipment was not provided to facilitate the prisoner's palliative care plan. This was mainly due to inadequacies in healthcare centres, lack of protocols to deliver end of life care and lack of equipment to deliver the Liverpool Care Pathway.

In the majority of cases (85%), the care provided was found by the investigation, which includes a clinical review by a medical practitioner, to be equivalent to the level of care the prisoner could have expected to receive in the community.

Recognition of the wishes of the prisoner about resuscitation in the event of a cardiac or respiratory arrest is included in step five of the end of life care pathway. Nearly half (99) prisoners had specified a 'Do Not Resuscitate' order to be in place and in the majority of cases (89), staff were confident they would be able to respect the prisoner's wishes and implement the order.

Step six of the care plan is care after death and the recognition that the care plan does not stop at the point of death. The care and support of relatives is covered in more detail in relation to family liaison later in this report.

Case Study A: Absence of palliative care plan (Local Prison)

Mr A was recalled to prison following a breach of his licence conditions. At the time of his death he was 72 years old and had poor mobility, walked with a stick and had difficulty breathing. At his first reception health-care screening, Mr A was admitted to the inpatient healthcare unit. A care plan was put in place to monitor Mr A daily until his heart condition was stabilised. (He had previously had a stroke and had a history of chronic obstructive pulmonary disease (COPD) – an umbrella term used to describe chronic bronchitis, emphysema or both).

Mr A was admitted to hospital for shortness of breath and was diagnosed with infective COPD. The hospital gave the prison a list of recommendations for his care on discharge which included a bed board and an extra pillow. When he returned to the prison, Mr A was moved to a single cell as he had an oxygen machine which was in constant use. He was offered the help of two prisoner orderlies to assist with tasks such as cleaning his cell and collecting his meals. The discharge summary from the hospital stated that as Mr A's condition was terminal, the hospital's palliative care team could help manage Mr A's end stage COPD. No evidence was found that a referral was made for Mr A to the palliative care team.

Ten days later, Mr A was taken back to hospital in an ambulance with extreme difficulty breathing. Mr A's condition deteriorated and hospital staff attempted to resuscitate him. Unfortunately this was unsuccessful and Mr A died twenty minutes later.

Case Study B: Good practice palliative care plan (High Security Prison)

Mr B was serving an 11 year prison sentence and was 81 years old when he died. At the time of his arrival in prison, Mr B suffered from Type 2 diabetes, angina, lung disease, chronic kidney disease and coronary heart disease. Mr B was slightly deaf and used a hearing aid. Mr B had only one fully functioning kidney and over two years before his death, he was fitted with a permanent catheter.

Mr B was admitted to hospital with a urinary infection and breathing difficulties. He was very ill and a subsequent chest X-ray showed he had a mass on his lung. Mr B did not want any further investigations or tests to assist diagnosis of the mass on his lung. Following Mr B's discharge from hospital, he discussed his decision to put in place a 'Do Not Resuscitate' order with a hospital doctor. The monitoring and care of Mr B after his discharge from hospital and decision not to have further treatment was supported by prison healthcare staff. After he was discharged from hospital, Mr B moved to the palliative care suite (a cell specially designed for the needs of end of life care prisoners) in the prison's healthcare centre.

Although Mr B did not have any further investigations into the mass on his lung, the (presumed) terminal nature of the tumour meant a palliative care plan was put in place and followed until his death. The care plan used two nationally recognised pathways; the Liverpool Care Pathway and the Gold Standards Framework. Other measures were taken to ensure Mr B was as comfortable as he could be in the last stages of his life. He was visited in prison by a Macmillan cancer palliative care nurse, and during the last few days of his life his cell door was left open and he had frequent visits from staff and fellow prisoners.

3.6.2 Restraints

The PPO has frequently identified the inappropriate use of restraints on prisoners who are at the end of their life as an area of concern³⁸, most recently in a Learning Lessons Bulletin³⁹. These concerns are again highlighted in the cases identified in this sample.

When prisoners have to travel outside of the prison to a hospital or hospice, a risk assessment is conducted to determine the nature and level of any security arrangements, including any restraints. This should consider the probable harm the prisoner poses to the public or to specific individuals in the event of an escape, alongside their motivation and ability – both physical and in terms of outside resources – to escape. In 20 cases out of 170 cases where restraints were considered, no risk assessment was carried out for the use of restraints.

Advice for prisons is outlined in the National Security Framework, (NSF) and in the 'Prisoner Escort and Bedwatch Function', a concordat between NOMS and the NHS. The concordat notes that (following a High Court ruling⁴⁰) using restraints on terminally or seriously ill patients should be considered inhumane except when justified by security considerations. It goes on to say:

"Levels of restraint used on prisoners must at all times be proportionate to the perceived security risks and be balanced by consideration of care and decency for the prisoner."

NOMS is currently developing the guidance into a new Prison Service Instruction.

In at least 28 cases, the PPO identified specific concerns about security and escort arrangements when the prisoner was in hospital or a hospice. The concerns mainly related to the excessive use of restraints compared to the level of risk posed by the prisoner. In one case, a prisoner was restrained while in a coma. In another case the prisoner died while still handcuffed to a prison officer. In case study B of this report, Mr B was restrained by an escort chain in hospital (a length of chain with a handcuff at each end attached to the prisoner and an officer). Although the restraints were eventually taken off, this was only when they had begun to restrict Mr B's circulation. There was no evidence that he was at risk of escaping and while he had committed serious offences, these had occurred over 30 years ago. The Ombudsman considered the presence of two prison officers was more than adequate to escort a very ill, 81 year old man in a wheelchair. In 16 cases in the sample, restraints were not removed until just 24 hours or less before the prisoner's death.

The Ombudsman identified that the level of restraint was inappropriate in at least 18 cases when the prisoner was under escort to a hospital or hospice, in at least 32 cases while in hospital or a hospice and in at least 21 cases when a prisoner was restrained during treatment.

As stated in the National Security Framework and the concordat, the level and use of restraints should be reviewed regularly. This was found to have been the practice in the majority of cases, but 30 prisoners out of the sample of 158 who were restrained at some point, did not have their level of restraint reviewed or adjusted.

There are examples where working arrangements have been made which have successfully balanced the palliative care needs of the prisoner with the level of risk they pose and

the restraints which are used. Marie Curie Cancer Care and County Durham PCT⁴¹ have worked closely with staff at the Durham prisons cluster to develop local guidelines which enable high security prisoners to be transferred to the hospice in Newcastle for end of life care, if they choose to be moved there. Hospice staff imposed a number of conditions on the Prison Service while the prisoners were in their care. Specifically prisoners were not to be handcuffed to prison officers while they were in the hospice. Also prison officers were to wear civilian clothes as opposed to their uniforms, so as not to draw attention to the prisoners or intimidate other hospice residents. This example shows that best quality end of life care can be provided to prisoners in a dignified and humane manner, while not compromising the security risk the individual may pose.

Case Study C: Use of restraints (Training Prison)

Mr C was sentenced to fifteen years imprisonment. He was 66 years old at the time of his death. Mr C informed prison staff when he arrived at the prison that he had been diagnosed with terminal cancer and given, at most, six months to live. He was immediately admitted to the prison's healthcare centre. Mr C attended a pre-existing hospital appointment at which his consultant informed him and the prison healthcare team that his condition had significantly deteriorated. His cancer had spread and he was unlikely to live more than a few weeks.

Mr C was very frail and had lost a lot of weight, weighing only five stone when he was in prison. A palliative care plan was put in place and the prison doctor was in contact with a local hospice to arrange an admission. Two months after Mr C arrived in prison his condition deteriorated further and he agreed to be transferred to the local hospice.

A risk assessment was completed when Mr C was escorted to the hospice from prison. This said he presented a medium risk to the public and of escape, but no explanation was given to support this assessment and the medical information section of the form was not completed. Two prison officers escorted Mr C and he was handcuffed to an officer. Two officers remained with Mr C at the hospice and he was cuffed (by escort chain) to an officer at all times - apart from when he needed to bathe. The weight of the chain on Mr C's frail skin caused him to bleed and bandages had to be applied to stop the chain from rubbing. The restraints were removed when Mr C's condition deteriorated. He died 36 hours later.

Mr C was a very sick man whose death was imminent. His physical capacity and the risk that he posed at the time do not appear to have been taken into account in the risk assessment. The Ombudsman was concerned that a recommendation had been made to the prison a year earlier about the use of restraints in a similar case, but did not appear to have affected the way Mr C's escort was handled.

Case Study D: Use of restraints (Local Prison)

Mr D was sentenced to three years imprisonment. At the time of his death he was 71 years old. Mr D was very underweight when he arrived at prison, he used a walking stick, had arthritis and had previously had a stroke. Despite this being noted by healthcare - to the extent that he was immediately given a place in the healthcare centre as an inpatient - no investigations or tests were carried out to establish the cause of his frail state nor was he fully examined by a doctor.

Mr D's weight loss was eventually addressed and he was monitored and put on a high calorie diet. Blood tests were ordered but not reviewed in a timely manner by the healthcare staff. When the results were reviewed, Mr D was admitted to hospital for an emergency blood transfusion and diagnosed with lung cancer. The delay in reviewing the blood results could have been life threatening. There were gaps in the recording of Mr D's medical history throughout his time in prison and the clinical reviewer suspected that Mr D had lung cancer when he first arrived at prison.

Mr D was restrained using an escort chain when he was taken to hospital. This was despite a risk assessment that he was a low risk to the public, he was not an escape risk and he had restricted mobility (he relied on crutches to walk). When Mr D's health deteriorated further, the palliative care team applied bandages to his wrists to minimise the effects of the escort chain as his skin was very thin. In hindsight, prison staff accepted that the restraints should have been removed at an earlier stage.

Mr D was transferred to a hospice to receive chemotherapy and despite concerns raised by the hospice doctor the restraints remained in place. They were removed while he had chemotherapy and were then replaced. The restraints were removed four days before Mr D's death when he was seriously ill and not able to move without assistance.

The Ombudsman found that Mr D's condition was not given sufficient consideration during the risk assessment process. Mr D's serious ill health and his low level of risk did not justify the use of restraints while he was in a hospice, receiving chemotherapy and in the final stages of his life. Mr D received care which was deemed to be below the standard he could have expected in the community.

3.6.3 Early release

Early release on compassionate grounds

Prisoners who are diagnosed with a terminal illness can be considered for early release on compassionate grounds⁴². It is only granted in exceptional circumstances and prisoners are usually expected to have less than three months left to live. The released prisoner is not subject to licence conditions and returns to the community without restrictions or escort staff.

The principles that underlie the approach for early release on compassionate grounds are:

- The release of the prisoner will not put the safety of the public at risk.
- A decision to approve release would not normally be made on the basis of facts which the sentencing or appeal court was aware.
- There is some specific purpose to be served by early release.

The decision to release a prisoner on compassionate grounds is made by the Secretary of State for Justice taking into account information provided by Prison Service staff and medical opinions. A clear medical opinion on life expectancy is required. There are no set time limits but three months is considered to be an appropriate period of life expectancy. The Secretary of State for Justice also needs to be satisfied that there is no longer a risk of re-offending and that there are adequate arrangements for the prisoner's care and treatment outside prison. There is also a requirement that the early release of a prisoner will bring some significant benefit to the prisoner or their family.

Release on temporary licence

Release on temporary licence⁴³ (ROTL) is used to allow prisoners to be released from prison temporarily, but only for precisely defined and specific activities which cannot be provided in the prison. ROTL can be granted by the governor of the prison. Certain prisoners are automatically

excluded from ROTL: these include Category A prisoners, those identified as a risk of escape, those who have been convicted but are not yet sentenced and those on remand.

ROTL requires a satisfactory risk assessment and the availability of suitable accommodation for the prisoner's needs. The prisoner is not restrained by handcuffs, although escort officers can accompany the prisoner to provide support, manage risk and ensure that visits are managed safely. The governor must be satisfied that the release of any prisoner on ROTL would not attract reasonable public concern, in that the release would not be likely to undermine public confidence in the administration of justice.

ROTL can be granted at the same time as an application for early release on compassionate grounds is being processed.

Compassionate release and ROTL in the sample

ROTL was considered in 58 cases (27% of all cases in the sample). In half of those cases (30) it was granted. For eight prisoners, ROTL was still being considered at the time of their death. Case study E shows how ROTL can be used even for a short time to bring dignity to a prisoner's final stages of life. It can allow prisoners to have the freedom they would

normally be afforded if they were dying in the community – with their relatives having free access to visit them.

More prisoners in the sample were considered for compassionate release than for ROTL (36% compared to 27%), however the application process for compassionate release is more complex due to the permanent change in the prisoner's status. Of those considered for compassionate release (78), only a minority (13) were granted it, and twice as many were still awaiting an outcome at the time of their death (26). Proportionately more ROTL applications were granted than compassionate release (50% compared to 17%), as would be expected given the uncertainties that often surround an individual's predicted time of death.

Another difficulty identified by the Ombudsman was the length of time it took for an application to be processed, which could mean that the prisoner had died before a decision was reached. Case study F shows how delays in compassionate release applications could be avoided. There are also practical difficulties in granting compassionate release to prisoners with a terminal illness as there must be adequate arrangements made for prisoners to receive the level of care and support they require before they can be released. In addition it has to be clear that the prisoner is no longer a risk to the public.

Case Study E: Good practice for use of temporary release (Female prison)

Ms E was 53 years old at the time of her death and was serving a sentence of just under four years. Ms E was referred to hospital after complaining of swelling in her neck. She was assessed and further tests were ordered. Soon after she was re-admitted to hospital after complaining of severe upper abdominal pain, she remained in hospital for three weeks. Ms E was diagnosed with cancer and a care plan was put in place by the prison healthcare staff in conjunction with the hospital. On both visits to hospital, a risk assessment was carried out and Ms E was accompanied by two escorting officers, using an escort chain.

After Ms E's cancer diagnosis, the hospital consultant wrote to the prison governor stating that it was highly likely Ms E would require continued hospital care and asked the governor to consider easing the visiting and telephone restrictions that were in place. In light of the letter, a further risk assessment was completed and all the restraints were removed, although the escort officers remained. Visits were allowed subject to security searches.

Ms E continued to be treated in hospital and a further risk assessment was completed which reduced the level of escort to one officer. Three days later Ms E was released on temporary licence (ROTL). This meant that Ms E was temporarily released from custody during her stay in hospital, and no escort or restraints were required. A nurse from the prison visited Ms E to carry out a full assessment to ensure that her needs would be met and a care plan was put in place when she was discharged from hospital.

Case Study F: Poor use of compassionate release (Local prison)

Mr F was convicted of a serious offence and sentenced to nine years in prison. He was 65 years old at the time of his death and died of lung cancer in a hospice.

Mr F was referred for a chest X-ray a month after arriving in prison after complaining of chest pain. The X-ray showed that he had a mass in his left lung which was diagnosed as cancer. Mr F was told by the hospital doctor that his life expectancy was approximately 12 months. Mr F agreed to have the recommended chemotherapy and radiotherapy treatment.

Mr F was given ROTL under compassionate grounds to undergo the radiotherapy treatment at hospital. Mr F was unrestrained and accompanied by one prison officer. Prison records show that Mr F was granted a further ROTL three months later, when he attended an appointment with a hospital doctor.

The head of healthcare in the prison was advised by the hospice's palliative care nurse that Mr F's life expectancy had reduced to two or three months. The head of healthcare contacted the hospital doctor and asked them to provide a prognosis report for an early release on compassionate grounds application. The doctor said they were unable to provide an accurate assessment of Mr F's life expectancy until he had undergone a CT scan in a month's time.

The head of healthcare was reluctant to delay Mr F's application based on his two to three month life expectancy. The head of healthcare contacted a doctor at the hospice eight days later and asked if they would provide an accurate report on Mr F's prognosis. They agreed and the appointment was arranged for five days later. Mr F did not attend the appointment as the prison did not have enough staff to provide an escort. The appointment was rearranged for nine days later, but in the meantime Mr F's condition deteriorated and he was taken to the hospice.

The application for compassionate release on medical grounds was sent to the relevant operational services, but as it was over the Christmas holiday period, his application was not considered for six days.

On the day the application was considered, Mr F was unconscious and likely to die. The prison tried to get an urgent update on the application, but they did not receive a response. The prison eventually received the information they needed and Mr F was granted compassionate release three minutes before he died.

The Ombudsman was surprised that in an operational service there does not appear to have been cover to deal with such an application over the holiday period. Mr F had been released on ROTL unrestrained and accompanied by one prison officer previously, so there is no reason why he could not have attended the prison doctor's original appointment under the same conditions. The lack of available prison officers to escort him and the holiday period meant that the application for early release on compassionate grounds was unacceptably delayed.

3.6.4 Family involvement

Involving families in the end of life care process is a key part of an end of life pathway and should ideally happen at the earliest stage in a prisoner's terminal diagnosis. Strong support from families and friends can make an enormous difference to a prisoner's quality of life in its final stages. It is therefore important for prisons to keep accurate and up to date records of prisoners' next of kin. This was the case in the majority of cases in the sample (85%).

Not all family members are in contact with their relatives when they go to prison and the prison

will need to ascertain whether the family would like to be involved, taking into account the prisoner's wishes. In a small number of cases, next of kin details were not up to date because the prisoner had chosen not to keep in contact and this was respected by the prison. Nevertheless, the prison should check with the prisoner as their condition changes whether they would like to inform their next of kin or another person. This is supported by the Prison Service Instruction (PSI) 64/2011⁴⁴ which states that prisons should encourage a prisoner with a terminal illness to engage with their families or a nominated person.

Family involvement could be improved in palliative care planning. There were 50 cases where the family was not involved in the palliative care plan of their relative. While some families, for various reasons, might choose not to have any contact with a family member who is serving a custodial sentence, those who are in contact should be able to be fully involved in the care plan if they choose to be. According to end of life care guidance, families should be involved at the very beginning of the care planning process and should be kept informed, as well as supported, throughout the different stages of the end of life care plan. In cases where the prisoner is terminally ill, PSI 64/2011 recommends that the prison appoint a member of staff to keep families informed of their relative's condition and offer them support. If a prisoner is hospitalised, it is recommended that the nominated member of staff meets the family to provide information,

including about the use of restraints, in order to lessen any distress this may cause them.

PPO investigations have repeatedly made recommendations to prisons to appoint a family liaison officer at the time that a terminal diagnosis is made as opposed to after death. Although the timing of the appointment of a family liaison officer is not specified in the PSI, it is good practice to ensure that trained staff are available to deal with end of life situations with sensitivity and empathy. Family liaison officers are usually the best people to organise extra visits and liaise with a hospital or hospice. They should also understand the importance of being non-judgemental and flexible to the needs of the prisoner and their family, as well as accounting for the prison's regime and security arrangements.

Case Study G: Lack of family liaison (Local Prison)

Mr G was remanded in custody, 38 years old and HIV positive. Mr G was in a confused and sick state when he was presented at court. He was not in a fit state to stand trial and was remanded in custody. When he arrived at prison, Mr G was taken straight to the healthcare centre. When asked by prison staff, Mr G did not provide any next of kin details. Mr G told healthcare staff that he was HIV positive and was suffering from stomach problems which he had done for a number of years. A treatment plan was put in place for Mr G but, later that day, his condition deteriorated and he was taken to hospital.

Mr G stayed in hospital for blood tests and then returned to prison. The hospital notes made no reference to Mr G's HIV, so the prison doctor telephoned a second hospital to secure Mr G a bed. Mr G was taken to the second hospital and diagnosed with meningitis. His condition deteriorated and the hospital nurse asked the prison officer to contact Mr G's next of kin. It is unclear when the officer contacted the prison to notify them of Mr G's change in condition and to start the search for his family. The police were contacted to assist in finding Mr G's next of kin, but the two addresses they provided were not his relatives.

The following day, the hospital again stressed to the prison that Mr G's family needed to be informed as he was in a very poor state. Unfortunately, they were not contacted and he died later that day. In the days after his death, the prison continued to search for Mr G's relatives, but again without any success. The governor appointed a prison nurse, who was not a trained family liaison officer or aware of the operational procedures for deaths in custody, to continue enquiries. The prison nurse eventually found details of a family member and telephoned them to inform them of the death. Regrettably, the nurse gave incorrect details of Mr G's death and the family member was telephoned again by the governor and given the correct information.

The prison had four trained family liaison officers at the time of Mr G's death who all would have been aware of the contingency plans for a death in custody and trained to deal with these types of situations. Providing incorrect information to the family members would have only added to their distress and could have been avoided.

Case Study H: Good family liaison (Local Prison)

Mr H was serving an eight year sentence, his first time in custody. Mr H was 73 years old at the time of his death. Mr H was in poor health when he arrived at prison and had been prescribed various medications. Mr H had an ulcer on his leg, and routinely attended healthcare to have the dressing on it changed. He was offered counselling by the mental health nurse on his induction, and was seen by a counsellor for a couple of months to help him come to terms with his circumstances.

He continued to have medical problems and was admitted to hospital for illnesses including problems breathing, swelling in his leg and low blood pressure. Mr H was moved to healthcare and often used a wheelchair to get around. He continued to experience health problems and was referred to hospital on a number of occasions for further tests.

Mr H was diagnosed with lung cancer. The prison doctor informed Mr H's brother and offered to answer any further questions he may have. Mr H went to hospital but was not fit enough to have surgery. He returned to prison and a Macmillan cancer nurse and a consultant in palliative care visited him and talked through his options of transferring to hospital, but it was decided that his symptoms could be best managed in prison. The hospital doctor discussed the possibility of hospice care with Mr H but he remained adamant that he wished to remain in prison, where he felt safe. Mr H's brother visited him (his transport was arranged by the prison) and the prison doctor talked to him about his brother's care.

Healthcare staff continued to monitor Mr H and when his condition deteriorated, they consulted the Macmillan nurse on ways in which they could make him more comfortable. Two district nurses visited Mr H in his final days and provided him a pressure mattress and syringe driver to administer fluids more easily. Following Mr H's death, his brother wrote to the prison to thank the staff for their kindness in caring for him and his brother.

4. Lessons to be learned

The eight case studies above demonstrate a number of learning points. This final section of the report summarises the themes that have emerged and the resulting implications for practice.

Prisons should implement an end of life care plan for every prisoner diagnosed with a terminal illness. The plan should follow the six step pathway as set out in the National End of Life Care Programme prison guide.

Two case studies highlight the importance of end of life care plans in ensuring a prisoner not only receives the correct treatment and support, but that friends and family can visit them in their final days and hours. The care plan is a holistic approach which should ensure that all aspects of the prisoner's wellbeing are included in the pathway. Having the plan in place also ensures that the final phase to death is recognised and that, within the constraints of their status, prisoners are able to die with dignity in the setting they choose.

Prisons could benefit from considering these further learning points in respect of their own establishment:

- Do your staff have palliative care training? Would they feel confident if a prisoner was to be diagnosed with a terminal illness and wanted to die in prison? Would your prison benefit from having a dedicated palliative care champion?
- How can you identify those in your care who are approaching the end of life? Would your prison benefit from a palliative care register?
- Are alternative arrangements available for prisoners who have mobility issues, sensory needs, learning disabilities or if English is not their first language? Would your prison be able to adapt an existing cell to cater for the needs of end of life care prisoners?

Prisons should ensure that sufficient weight is placed on a prisoner's current health and mobility when assessing the risk they pose to justify any use of restraints.

While the Prison Service's principal responsibility is the protection of the public, there is a balance to be struck in every case between decency and security. However as the case studies highlight, it seems that the correct balance is not consistently achieved. Too often an overly risk averse approach is taken when frail, immobile or even unconscious prisoners remain restrained when the presence of escorting officers is sufficient to minimise any risk of escape or harm to the public.

The concordat between the Prison Service and the NHS explicitly states that the level of restraint used on prisoners must at all times be proportionate to the risk they pose and balanced by the decency for the prisoner and the care they need to receive. The level of restraint should be reviewed according to changes in the prisoner's condition, rather than just when routine risk assessments are due.

The following learning points may be helpful to prisons when considering their own practice:

- Are staff in your establishment aware of the NHS and Prison Service concordat on the use of restraints? Do they feel confident in its application?
- Are your risk assessments carried out in response to medical concerns? Are they done in a timely manner to respond to the (often rapid) change in a prisoner's medical condition?

Prisons should ensure that where appropriate, applications for early release on compassionate grounds are completed at the earliest possible opportunity.

The process for early release on compassionate grounds for prisoners who meet the requirements should begin as soon as possible. Prompt applications will give the prisoner the strongest chance of having their application approved before they die, enabling them to die with dignity in the community and without the need for prison staff to be present. In order for a timely application to be made, prison staff should work closely with medical and probation staff, both in the prison and in the community, to ensure that appropriate reports are prepared to support the application. The need for expedition is

highlighted in case study F where the prisoner was not released until minutes before his death.

Prisons should ensure that families are involved (where appropriate and where they choose to be) in the palliative care planning.

Case studies G and H highlight the need to keep family members involved in every key stage in the prisoner's end of life process, starting from the diagnosis and continuing throughout treatment until and after death. End of life care does not stop at the point of death. Prison staff should follow good practice for the care and viewing of the body as well as being responsive to family wishes for the funeral and returning the prisoner's property.

Prisons should work with the family and keep them involved by appointing a family liaison officer. It is recommended that a prison family liaison officer should, where possible, be appointed at the time of diagnosis (rather than after the prisoner's death) and be the key contact for the family during the prisoner's final months and days. As highlighted in case study G, it can be distressing for a family to find out that a relative has died in prison and they were delayed in being told, or given incorrect details about the death. If more effort is put into establishing the next of kin before the prisoner dies, then these situations can be avoided.

4.1 Concluding remarks and moving forward

There is scope for learning lessons about end of life care in prison from this brief study. By and large prisons do all they can to ensure that prisoners die in a dignified and humane way with the care and support they require. However, this is by no means always the case and there are particular lessons to be learned about care planning, applications for compassionate release, the involvement of family and the use of restraints on prisoners who are terminally ill and at the end of their life. This learning needs to be shared across the Prison Service.

References

- 1 HM Prison Service (2006) *Prison Service Order 3050: Continuity of healthcare for prisoners*. London: Ministry of Justice.
- 2 Macmillan Cancer Support (2012) *Dying with Cancer: A booklet for prisoners*
- 3 Kerbs.J. (2000) 'The older prisoner: Social Psychological and Medical considerations' in *Elders Crime and the Criminal Justice System: Myth perceptions and Reality in the 21st Century*. MB Rotham et al. New York: Springer.
- 4 Liverpool Care Pathway (n.d) Available at: <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway> [Accessed on 27/02/2013]
- 5 Gold Standards Framework (n.d) Available at: www.goldStandardssframework.org.uk [Accessed on 27/02/2013].
- 6 The independent review is chaired by Baroness Julia Neuberger and will report to Department of Health Ministers and the NHS Commissioning Board by the summer of 2013.
- 7 Department of Health (2008) *End of life care strategy - promoting high quality care for adults at the end of life*. London: Department of Health.
- 8 National End of Life Care Programme (2011) *The route to success in the end of life care - achieving quality in prisons and for prisoners*. London: NHS
- 9 HM Prison Service (2003) *Prison Service Order 3100: clinical governance - quality in prison healthcare*. London: Ministry of Justice.
- 10 HM Prison Service (2004) *Prison Service Performance Standard Manual 22: Health Services for Prisoners*. London: Ministry of Justice
- 11 Department of Health (2007) *A pathway to care for older offenders: a toolkit for good practice*. London: Department of Health.
- 12 op. cit. (8)
- 13 National PPC Review Team (2007) *Preferred Priorities for Care*. London: Department of Health.
- 14 HM Prison Service (2012) *Prison Service Instruction 64/2011*. London: Ministry of Justice.
- 15 HM Inspectorate of Prisons (2012) *Annual Report 2011-12*. London: The Stationery Office.
- 16 Le Mesurier, N. (2011) *Supporting older people in prison: ideas for practice*. London: Age UK.
- 17 Waller, S. and Finn, H. (2011) *Environments for care at the end of life The King's Fund's enhancing the healing environment programme 2008-2010*. London: The King's Fund.
- 18 HMPs Frankland, Durham, Low Newton, Deerbolt, Holme House, Acklington and Kirklevington.
- 19 Home Office (2003) *Prison Statistics England and Wales 2002*. Norwich: TSO.
- 20 Ministry of Justice (2012) *Table 1.5 Population in prison by prison by sex, establishment and nationality status, 30 September 2012, England and Wales*. London: Ministry of Justice.
- 21 op. cit. (19)
- 22 op. cit. (20)
- 23 Ministry of Justice (2012) *Prison Population Projections 2012-2018 England and Wales*. London: Ministry of Justice.

- 24 Prisons and Probation Ombudsman (2012) *Annual Report 2011-2012*. London: Prisons and Probation Ombudsman.
- 25 HM Inspectorate of Prisons (2004) *No problems - old and quiet: Older prisoners in England and Wales*. London: HM Inspectorate of Prisons.
- 26 HM Inspectorate of Prisons (2008) *Older prisoners in England and Wales: a follow-up to the 2004 thematic review by HM Chief Inspector of Prisons*. London: HM Inspectorate of Prisons.
- 27 Department for Work and Pensions (2005) *Opportunity Age: Meeting the challenges of ageing in the 21st century*. London: Department for Work and Pensions.
- 28 HMIP (2012) *Prisoner Survey responses: Age breakdown across all functional types*. Unpublished.
- 29 op. cit (20)
- 30 op. cit. (20)
- 31 World Health Organisation Standard International Classification of Diseases (2010). Available at: <http://apps.who.int/classifications/icd10/browse/2010/en>. [Accessed on 27/02/2013].
- 32 op. cit. (31)
- 33 op. cit (31)
- 34 op. cit (31)
- 35 Thomas, K. (n.d) *Community palliative care*. Available at: <http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/ABC%20Palliative%20Care.pdf> [Accessed 12 December 2012].
- 36 Care needs data collected for 152 of 214 cases.
- 37 op.cit. (7)
- 38 op.cit. (22)
- 39 PPO (2013) *Learning Lessons Bulletin Restraints*. London: PPO.
- 40 *R (on the application of Graham) v Secretary of State for Justice* [2007] All ER (D) 383 (Nov).
- 41 NHS (2011) *The route to success in end of life care - achieving quality in prisons and for prisoners*.
- 42 HM Prison Service (2005) *Prison Service Order 6000: Parole release and recall*. London: Ministry of Justice.
- 43 HM Prison Service (2005) *Prison Service Order 6300: Release on temporary licence*. London: Ministry of Justice.
- 44 op. cit. (14)

**For further information on this paper and other PPO research
please contact:**

**Sarah Colover, Research Officer
Prisons and Probation Ombudsman
Ashley House
2 Monck Street
London
SW1P 2BQ**

**e sarah.colover@ppo.gsi.gov.uk
t 020 7035 2039**

© Crown copyright 2013

www.ppo.gov.uk