

A photograph of a large, multi-story brick building with a covered walkway, set in a landscaped garden with a path and various flowers. The image is framed with rounded corners and a blue border.

The route to success
in end of life care – achieving
quality in prisons and for
prisoners

A practical guide to implementing high quality
end of life care in prisons

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As of March 2010, 85,184 people were being held in prisons in England and Wales, with around a further 9,400 held in Scottish and Northern Irish prisons. This figure does not include those in immigration detention and removal centres. (Data from the Ministry of Justice, the Scottish Government and the Northern Ireland Prison Service)



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It is generally acknowledged that many prisoners have complex needs, mental health problems and/or learning disabilities. Often, this will also be compounded by complicated family relationships, poor education and, for some, revolving admissions to the criminal justice system.

The demand for prison spaces could increase to nearly 95,000 by 2017 (*Prison population projections 2011-2017 England and Wales*, Ministry of Justice, 2011). As a result, and due also to changes in sentencing practices, it is expected that the number of older prisoners will grow. A 2008 report by HM chief inspector of prisons recommended a national strategy for older prisoners which would provide guidance on age-related issues, including end of life care services (*Older prisoners in England and Wales: a follow-up to the 2004 thematic review*, HM Inspectorate of Prisons).

The Prisons and Probation Ombudsman for England and Wales *Annual Report 2008-2009* similarly noted that "As the average age of the prison population increases ... , it seems reasonable to assume that the trend in natural cause deaths will be upwards." In 2008-2009 there were 181 deaths in custody, with 159 of these occurring in prison. Of the deaths in prison, 96 (60%) were from natural causes. The most common natural causes of death were heart attacks and cancer, and the average age of the deceased was 52 for men and 44 for women (ibid). A proportion of these deaths would have been anticipated and it is reasonable to assume that some of those in prison could have benefited from improvements in planning for their end of life care *An evaluation of current end of life care provision in prisons in Lancashire and Cumbria*, Payne et al, International Observatory on End of Life Care, Division of Health Research, Lancaster University, 2009

Therefore it is with this in mind that Carrie Cannings, Equality Group NOMS notes: "No-one wants to have to deal with an



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end of life situation in prison, but with our aging population, it is likely that most prison staff will be faced with the need to manage or be involved in one at some point. It is important to remember that no-one should be worried that they have to deal with the situation on their own. The key to successfully managing end of life in prison is working together as a team: officers, governors, healthcare staff and external and third sector organisations. Each part contributes on those areas that fall within their expertise, and supports the other team members during what is a difficult time for all. And remember we have resources such as Employee Support that can provide a professional service to staff who may be finding the experience difficult."

The aim of this publication is to provide a practical guide to support both prison and health and social care professionals in delivering high quality end of life care to prisoners. The guide aims to complement Department of Health (DH) and HM Prison Service guidance and seeks to showcase good practice examples from across the health and prison communities in their work to support prisoners at their end of life.

People approaching the end of their life need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is also critical to allowing prisoners who become unwell a dignified death and to offering families support in bereavement. This care should be of the same high quality regardless of diagnosis and of whether the care is carried out at home, in hospital, in the community or in any other setting, including prison.

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death.

Each section outlines the relevant steps of the pathway, questions to ask about the individual's care and the practitioner's and prison officer's role in that care. Additional guidance can be found within the Department of Health's *End of life care strategy: quality markers and measures for end of life care* (2009). See appendix 2 for a full list of quality markers.

We also include case studies highlighting best practice. Forthcoming NICE standards currently being devised will also be relevant to the delivery of end of life care in all settings.

It is hoped that the guide will help practitioners and staff working within prison health services to make connections across service boundaries to:

- Identify prisoners approaching the end of life phase
- Review care planning
- Help to review practice
- Support communication, team working and learning
- Improve and measure quality.

Core principles for delivery of end of life care

- *Treat individuals with dignity and respect*
- *Identify and respect people's preferences*
- *Provide information and support to families and carers*
- *Recognise and respect an individual's spiritual and religious needs*
- *Provide effective pain and symptom management*
- *Provide care after death*
- *Ensure care is patient-centred and integrated*
- *Provide a safe comfortable environment for care.*

Background: end of life care within prisons

In 2006, prisoner health became the responsibility of the NHS. Prison healthcare staff are now employed by primary care trusts (PCTs) and standards of care are greatly improved. Further to *The Bradley report* in 2009, which made a number of recommendations about diverting offenders with mental health problems or learning difficulties into other, more appropriate, services (*The Bradley report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system*, DH), a cross-Government programme is now underway to improve health outcomes for all people in touch with the criminal justice system. The mutual needs of custody and care remain at the heart of the service and can be especially complex when it comes to delivering end of life care within the prison setting.

At the same time as the transfer of prison health responsibility has happened, the profile of end of life care in the wider health and social care field has increased. In 2004, the NHS launched its National End of Life Care Programme (NEoLCP) in England, with the central aim of improving end of life care for all, regardless of diagnosis or care setting.

The National End of Life Care Programme has been working in partnership with the Department of Health's offender health team to support the development of guidance intended to promote a high standard of care for all prisoners regardless of diagnosis at the end of life, by improving the quality of care offered and enhancing the dignity and choice for serving prisoners approaching the end of life.



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The programme also promotes the use of three end of life care tools designed to increase choice, improve standards of care and facilitate communication between professionals, patients and families. These are: the [Gold Standards Framework \(GSF\)](#), the [Liverpool Care Pathway for the Dying Patient \(LCP\)](#) and the [Preferred Priorities for Care](#) document. (www.endoflifecareforadults.nhs.uk)

Meanwhile, in 2008, the Department of Health's *End of life care strategy* set out a blueprint for change and improvement in end of life care in England over the next 10 years. Its aim, it said, was "to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money."

In the preceding year, the DH issued guidance on care for older prisoners which also references the importance of end of life care (*A pathway to care for older offenders: a toolkit for good practice*, 2007). This stressed the importance of having robust palliative care policies in place in all prisons. These publications reflect the fact that end of life care is increasingly being seen as a priority for both the Department of Health and HM Prison Service. It was also identified in the Prisons and Probation Ombudsman *Annual Report 2008-2009* (see also *Review of older prisoners' provisions*, P Rich, North East Offender Health Commissioning Unit, 2009).

However, as this resource guide seeks to show, there is still much that could be achieved to share current good practice and ensure all prisoners receive good end of life care.

"Each prison addresses bereavement issues differently according to: the type of sentence committed; date of bereavement; manner of death; relationship of the prisoner to the deceased; level of security risk ... category of prison ... and particular culture of the prison in relation to death." (*"This is not just about death – it's about how we deal with the rest of our lives": coping with bereavement in prison*, M Wilson, Prison Service Journal, Jul 2010)

The future of the NHS

The government has set out its intentions for the future of commissioning in the NHS in the white paper *Equity and excellence: liberating the NHS* (DH, 2010) and the supporting consultation document *Liberating the NHS: commissioning for patients* (DH, 2010). These state that the NHS Commissioning Board will assume future responsibility for the commissioning of prison health services in England, working closely with clinical commissioning consortia. This guidance should be read in the context of these forthcoming changes.

Each prison environment should consider whether the following processes or policies have been addressed to support good end of life care:

- Are prisoners and their environment safe? This overrides all other principles of care. Staff must be accountable for the safe custody of the prisoner and that of the whole prison environment
- What are the particular security requirements within that prison for individuals, visitors, and medical staff coming in with prescribed medication and for assessment and review purposes?
- What access is there to required end of life care/symptom control medications? Also, what is the policy on using morphine/syringe drivers in custody?
- Have assessments included the prisoner/patient's physical condition as well as likelihood of violence?
- What are the policies relating to dignity and privacy for the individual/the environment management strategy/the use of the open door policy?
- Does a prison officer always have to be present during visits/medical treatment and death?
- What is the agreed communication process?
- What is the process for considering whether release is appropriate on compassionate grounds as per PSO 6300: Release on temporary licence (HM Prison Service, 2005)?
- What is in place to provide for the needs of the family/carers? Also, how will these be identified and recorded?
- Are there measures to aid communication with those for whom English is not their

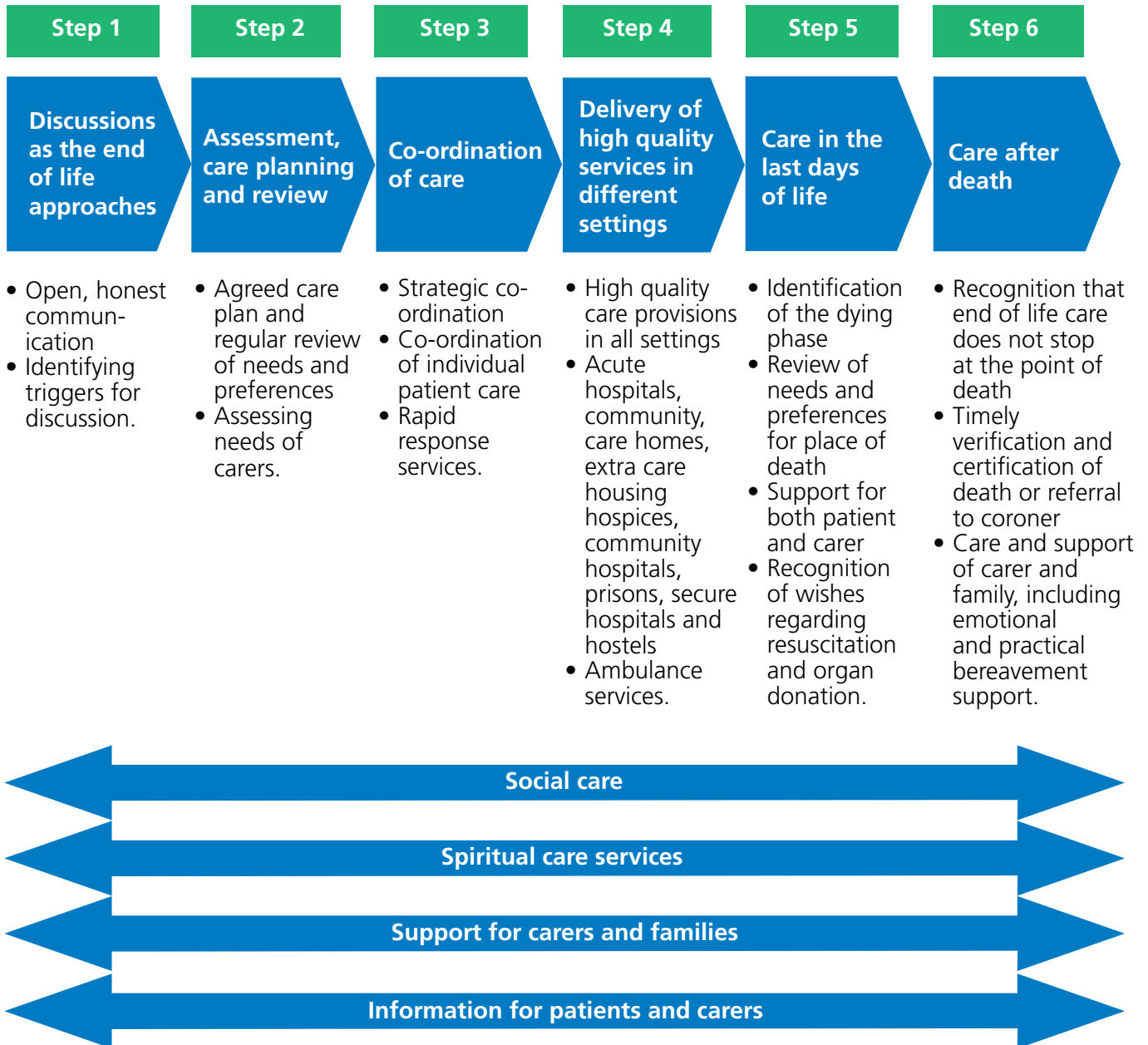
first language, those who have speech and language difficulties and those whose understanding may be compromised due to cognitive impairment or a learning difficulty?

- Is there access to appropriate training, education and support for prison staff?



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End of life care pathway



Step 1

Discussions as the end of life approaches

*"I think the prison service may have felt a bit frightened by what they had to deal with, especially the officers, not knowing what was going to happen with a terminally ill patient." Palliative care nurse**

Enabling people to die in comfort and with dignity is a core function of the NHS. One of the key challenges is knowing how and when to begin a discussion with a prisoner – and relatives – about what they would wish for as

they near the end of life. Agreement needs to be reached on when discussions should occur, who should initiate them and what skills and competences staff require to take on this role.



Photo courtesy of iD.8 Photography *Quote courtesy of Payne et al, 2009

Questions

- Have you identified a key worker or a way in which the discussions should start?
- How can you identify those in your care who are approaching the end of life?
- Have you noted triggers which indicate it is an appropriate time for a discussion? Have you considered who might support such a discussion?
- What would help those discussions if the prisoner has learning disabilities, sensory needs or if English is not their first language?
- Is the environment safe and comfortable and does it offer privacy?

Your role

- Recognise when symptoms have increased or condition has deteriorated
- Ask yourself the question, "Would I be surprised if this person were to die in the next 6-12 months?"
- Take account of recent changes in circumstances such as the death of a spouse or a change in family circumstances outside the prison environment
- Make sure those who need to be are on an end of life supportive care register
- Select an appropriate time to begin the discussion process
- Have open and honest discussions about prognosis and possible realistic future care options
- Provide any relevant information required, whether that is about the individual's condition, financial situation if appropriate, or anything else.

Top tips

- Recognise that greater attention and support may be required for those prisoners who struggle to communicate their needs due to dementia, learning difficulties or other health problems
- Death and dying should not be hidden from other prisoners, relatives and carers. Building a trusting relationship will help facilitate conversations that may include end of life care
- As a caregiver and/or a prison officer it is important to recognise how your own attitude to death and dying may influence the care you provide and your ability to talk openly
- Consider how to integrate conversations into existing activities and/or assessments (eg, substance use) or general key worker discussions
- Try to provide private spaces in which to break bad news or initiate end of life care discussions
- Ask your manager to find out what training is available, or contact your local palliative care team or hospice to enquire about support and education.



Photo courtesy of iD.8 Photography

Case study HMP Isle of Wight (Albany)

A new eco-friendly garden within the grounds of Albany prison on the Isle of Wight is already making a difference to the lives of terminally ill prisoners.

The garden, which has been transformed from an area of tarmac over the last year, is part of a King's Fund [Enhancing the Healing Environment](#) project that will also create two purpose-built bedrooms where prisoners can be moved for respite care and at the end of life.

Both rooms will adjoin the main 18 x 16 metre garden, which has a multi-coloured geodesic dome at the centre as well as sculpted plant beds, an olive tree and seating. Prisoners themselves were responsible for much of the garden's design and decoration.

The aim, says healthcare manager Mick Hunton, is to create a space to talk and contemplate within the limits of security, and it seems to be working. "The patients find it really relaxing. They can have one-to-one chats with their friends, staff, family, chaplains, visiting specialists or Macmillan nurses about their condition, feelings, fears and worries. We're trying to give them the sense of greater freedom and privacy in a secure environment."

It also offers patients a psychological boost. "If they do get down a bit and want a break there's been nowhere for them to go in the past. This gives them that option. Their friends can visit and spend time in the unit as well."

The garden opened in August and the entire project was completed by the end of



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2010, enabling many more prisoners to spend their last days in prison if they wish. Previously most died in the nearby hospital or hospice simply because the prison did not offer suitable facilities.

Mick has no doubt an attractive environment can make a huge difference. "We moved from a Victorian building to this purpose built unit a year ago and staff morale shot up straight away. I was amazed within a week of coming here the difference it made to everybody."

Contact: mick.hunton@iow.nhs.uk or information@eolc.nhs.uk

Step 2

Assessment, care planning and review

*“Another thing that has been particularly challenging and difficult for me in the prison is that it takes longer for them to get the medication in when there is a change of prescription. So when I go in and advise that a drug needs to be changed or increased on a Wednesday, that might not happen until the Saturday. It takes them that long to get the drugs, whereas I am used in the community to advising it and starting it the same day.” Macmillan nurse**

Early assessment of an individual’s needs is vital to establish their preferences and choices and identify any areas of unmet need. Too often an individual’s needs and those of their family and carers are not adequately assessed. Holistic assessment needs to cover physical,

psychological, social, spiritual, cultural and, where appropriate, environmental and financial needs. This can be more complicated for those within the prison system, especially if they have learning difficulties or mental health needs.



*Photo courtesy of iD.8 Photography *Quote courtesy of Payne et al, 2009*

Questions

- Has a holistic needs assessment been carried out?
- Can you initiate the advance care planning process?
- Have the needs of the carer been considered?
- How do prison regulations impact on the outcome of the assessment?

Your role

- Undertake a holistic needs assessment when the end of life phase has been identified (see *Holistic common assessment of supportive and palliative care needs for adults requiring end of life care*, NEoLCP, 2010)
- Apply DisDAT (Disability Distress Assessment Tool) process
- Listen to the individual and carer and understand what is important to them and record this
- Introduce advance care planning as a continuous process as early on as possible
- Assess the individual's ability to make decisions. If in doubt, assume capacity in the first instance and seek appropriate methods in the case of prisoners who have learning difficulties or for whom English is not their first language. Make sure the Mental Capacity Act (2005) process is used where there are doubts about capacity
- Identify an individual's wishes and preferences about future care
- Record any advance decisions to refuse treatment in appropriate documentation
- Review care plan and regularly reassess if a long-term condition is deteriorating
- Communicate information appropriately (with permission) to relevant people both inside and outside of the prison
- Identify the main carer or professional support worker - also taking into account any close relationships that have formed whilst in prison
- Respond appropriately to requests for a carer's assessment.

Top tips

- If a prisoner makes an advance decision to refuse life-sustaining treatment it must be in writing, signed by that person (or representative) and witnessed
- Holding an open meeting with prisoners and relatives/significant others can be a way of raising awareness about the possibility of expressing personal wishes and preferences
- Assess the prison environment. If someone is deteriorating, consider how that environment may need to be modified – for instance, in terms of privacy, wash facilities and stairs
- Assessment may need to be undertaken in stages to avoid tiring the patient
- Complete a key contact sheet pro forma - that is, a form held with the prisoner's file providing easy access to relevant information - and keep in a readily accessible place
- Ensure you hold information about community services that have been involved with the prisoner and that they are contacted where appropriate



Photo courtesy of iD.8 Photography

Case study

Paul, a younger prisoner needing end of life care

Paul (not his real name) was 39 years old and was sentenced early in 2009. Shortly afterwards he was diagnosed with lung cancer and referred to an oncologist for chemotherapy.

After undergoing chemotherapy he spent time recovering at the inpatient unit at a different prison but was keen to return to the familiar surroundings of his own prison. Despite treatment, the tumour quickly doubled in size; Paul subsequently had palliative radiotherapy but his prognosis was poor (6-12 months).

Paul's care was well managed by the prison healthcare team but his care choices were necessarily limited because he was in prison. He named his home as his preferred place and did not want to return to the prison where he had two difficult post-chemotherapy stays. However, his application for compassionate release was turned down and refused again at appeal because he was expected to survive more than three months.

The oncologist tailored Paul's chemotherapy doses to the prison environment, he had a daily nurse review and the same GP visited him every week to monitor his medication. Other aspects of his care included:

- Daily medication collected from the healthcare unit and kept in a safe in his cell
- The community Macmillan nurse visited regularly. Paul could also phone her directly with any medical concerns



Photo courtesy of iD.8 Photography

- Family liaison ensured he was supported by his family, who had open visits and were allowed to bring him extra food and clothes
- The prison kitchens met his dietary needs, providing soft foods as required
- The prison chaplain, his personal officer and his peer group also continued to provide emotional support.

Paul died at the end of November 2009. Although his appeal for compassionate release had been refused, his prison governor granted him release on temporary licence leave and he died at home.

Case study from *An evaluation of current end of life care provision in prisons in Lancashire and Cumbria*, Payne et al, International Observatory on End of Life Care, Division of Health Research, Lancaster University, 2009

Step 3

Co-ordination of care

"We have got a really good link, we have a really good service, the hospice offers a lot of support – we have been really lucky, we have built up a good network with them." Member of prison healthcare staff*

Once a care plan has been agreed it is essential that all the services the individual prisoner needs are effectively co-ordinated. This should cover primary, community and acute health providers, the local hospice, prison transport

services and social care. A lack of co-ordination can mean a prisoner's needs and preferences are not met. Prisoners should always give permission for information to be shared with other services.



Photo courtesy of iD.8 Photography *Quote courtesy of Payne et al, 2009

Questions

- Is there a communication system in place to keep all members of the multi-disciplinary team fully informed and which includes all services involved in and outside the prison? This is particularly important if mental health or learning disability teams have been involved
- Has a professional key contact been identified from the community services?
- Can the community services respond rapidly and appropriately to changes in circumstances?
- Is there a process to list key contacts for emergencies or changes to circumstances?

Your role

- Identify individuals on an end of life supportive care register (if applicable in your area)
- Ensure communications systems are in place with all relevant community services
- Appoint a key worker within the prison to act as the link between services
- Provide, where possible, access to 24/7 advice, care and support
- Provide timely access to relevant equipment
- Inform out-of-hours services (in the prison) of anticipated care needs
- Inform outside emergency services of anticipated care needs
- Ensure you know who your key contacts are across the provider services/voluntary/social care sectors.

Top tips

- Find out which pharmacies your local hospice uses. These are more likely to offer out-of-hours delivery of drugs to your institution
- Building strong relationships with other services (for instance, GPs, palliative care teams and social care) can help you provide the prisoner with good end of life care
- Remember: good communication systems need to work in both directions
- Phone calls between a dying patient and health professionals or relatives can maintain contact and resolve some issues without the need for a visit
- Consider identifying champions – from prison or hospice – to lead the work and build links between prisons and the wider healthcare world.



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Case study

HMP Durham prison cluster

The North Durham community palliative care team has worked in partnership with staff in HMP Durham prisons cluster over the last six years to ensure dying prisoners' wishes are respected wherever possible.

Collaborative working has resulted in:

- Identification of link nurses in each prison
- Access to palliative care education
- Three-monthly palliative care clinical review meetings.

The palliative care team works closely with designated link nurses in the four Durham prisons and liaises with the prison authorities to facilitate improved visitation rights and prompt applications for compassionate release or discharge on licence. Joint work is continuing to develop a resuscitation policy for prisoners approaching the end of life when death is expected.

The team has been directly involved with the clinical care of 24 prisoners. Over half achieved their preferred place of care at the end of life and the others have accepted a compromise. The partnership approach enabled one prisoner with an incurable cancer to remain in his preferred place of care on the wing with other inmates for as long as possible before transferring to the prison healthcare wing for closer medical supervision and one-to-one nursing support. Finally, at the very end of life, he was transferred to a local hospice where he died.

A service improvement pilot project funded by Macmillan Cancer Support and aimed at improving the standards in cancer, palliative and end of life care in prison began earlier

this year (2011). It has already started to deliver palliative care distance learning education and syringe pump training, identified prison health and discipline champions and developed a prisoner working group.

Contact: Dr Lindsay Crack, consultant in palliative medicine, lindsay.crack@stcuthbertshospice.com Gill Scott, Macmillan prison project lead, g.scott3@nhs.net



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Step 4

Delivery of high quality care in prisons

"We have had a few people that have gone to [the hospice] for short stays. We have got a policy in place where the governor has excused handcuffs and officers have gone in civvy clothing so it doesn't unsettle other patients. We have had that happen on a few occasions. The symptoms have been controlled and they come back to us." Member of prison healthcare staff*

Prisoners, their families and carers may need access to a complex combination of services across many different settings. They should be able to expect the same high level of care regardless of where they are. Prisoners should be treated with dignity and respect and given

as much choice as possible about the care they receive as they approach the end of their lives. This may mean they end their days in prison, in familiar surroundings and with those they know.



Photo courtesy of iD.8 Photography *Quote courtesy of Payne et al, 2009

Questions

- Has an operational policy for the management of end of life care been developed within the organisation?
- Can all staff access an appropriate on-going training programme for end of life care?
- Does the environment offer privacy and respect for the individual and their family?
- What systems are in place to monitor the quality of end of life care?

Your role

- Establish or be aware of the operational policy for implementing end of life care in your setting
- Ensure all staff are aware of and understand end of life care core principles and values
- Promote or participate in relevant end of life care training, including communication skills, assessment and care planning, advance care planning, symptom management and ensuring comfort and well-being
- Ensure due consideration is given to the environment in which end of life care and support is delivered – for example, access to a quiet room, to specialist equipment and to facilities for relatives
- Identify key quality measures within your organisation and the process for collecting and sharing evidence of service improvement/complaints
- Use prisoner/patient experience and carer feedback to support continuous service improvement.

Top tips

- Don't forget the role that other prisoners may be able to play in the planning and delivery of care, particularly those who have developed a close relationship with the person who is dying
- Staff training needs should include not only the physical aspects of care but also psychological and spiritual care
- Help prisoners to maintain the maximum level of independence, choice and control for as long as possible
- You could discuss with community matrons and community urgent care providers when it would be appropriate to contact them. Ask for information and contact numbers
- Consider keeping a small stock of medications on the prison unit for anticipatory prescribing purposes similar to Just in Case boxes (Motor Neurone Disease Association). Always bear in mind prison policies about medication storage
- Consider adapting end of life care tools such as the Gold Standards Framework (GSF) and Preferred Priorities for Care (PPC) specifically for use in the prison environment.

Case study

Marie Curie Cancer Care guidelines

Marie Curie Cancer Care and County Durham PCT have worked closely with staff from the Durham prisons cluster to develop local guidelines which enable high category prisoners to be transferred to the Marie Curie Hospice in Newcastle for end of life care in accordance with their wishes.

The guidelines include the security arrangements for transfer from the prison to the hospice, care and support for the prisoner in the hospice and arrangements following death.

Roles and responsibilities are clearly defined to enable staff to provide the best quality of care at the end of life while maintaining appropriate security in the hospice environment. Prisoners are considered to be patients first and prisoners second with an absolute right to the same standard of care as any other patient.

The prison service retains responsibility for maintaining security during transfer and throughout a prisoner's stay at the hospice. High category prisoners (A and B) are accompanied at all times by at least two prison officers.

The guidelines were drawn up by a working group that included key staff from the hospice, the prison healthcare service, the community palliative care team and the PCT, and involved considerable negotiation.

The hospice insisted, for example, that no-one in their care should be handcuffed and that prison officers should not wear



Photo courtesy of iD.8 Photography

uniforms while at the hospice and this was accepted. The prison service agreed to inform key hospice staff about any specific additional risk posed by the prisoner and to conduct a pre-and post-transfer risk assessment at the hospice.

Through liaison with the coroner and prison governors it has also been agreed that hospice doctors can certify deaths and nursing staff can undertake care after death. It is hoped the guidelines will be adopted elsewhere, enabling more dying prisoners to choose their preferred place of care.

Contact: information@eolc.nhs.uk

Step 5

Care in the last days of life

*"Normally when we start with an opiate we would go with 12-hourly dosings but in order to do that we had to get special permission for him to take the drug onto the wing and initially that caused a lot of angst. [So we had to think] around how we can do that differently, like looking at drugs that last for 24 hours rather than the 12." Macmillan nurse**

The point comes when an individual enters the dying phase. For some this may seem to happen suddenly and without warning but for many others it can be a gradual process. It is vital that those caring for them recognise they

are dying and take the appropriate action. How someone dies remains a lasting memory for their relatives and carers as well as the health, social care and prison staff involved.



Photo courtesy of iD.8 Photography *Quote courtesy of Payne et al, 2009

Questions

- Are the relevant prison staff and professionals aware of the changes which happen during the dying process?
- Are systems in place for involving families and relatives in discussions as death approaches?
- Is there a clear communication plan to keep relevant others informed as the prisoner becomes less well?
- Do the family have and know visiting rights and processes during this phase?
- Have any specific wishes or preferences been identified?
- Has the Liverpool Care Pathway (LCP) or equivalent pathway been implemented within your organisation?
- Do you have an open door policy for those at the end of life whereby cell doors are left open whenever possible and relatives have increased access?

Your role

- Be aware that using an end of life care pathway does not hasten or postpone death and that on occasions an individual's condition may improve and the pathway can then be discontinued
- Have open discussions with relatives and carers to ensure they know what to expect during the last days of life and can visit where appropriate
- Ensure, where possible, that an individual's wishes about their preferred place of care and any other stated preferences are met
- Follow a validated integrated care pathway for the last days of life such as the LCP
- Ensure anticipatory prescribing systems are in place in advance of need.

Top tips

- Consider adapting the LCP to incorporate security issues. Starting on the LCP can help to trigger a review of the prisoner's security status in relation to medication management and open door policies
- Where possible, plan to have someone - a member of staff or a volunteer - available to sit with the dying prisoner. This will provide them with comfort and reassurance
- Consider ways to support the relatives who the prisoner wishes to have present by providing, where possible, transport, assistance via the Assisted Prisons Visitors Unit (subject to eligibility criteria), and emotional support
- Support people with the same respect you would want for yourself or a member of your own family.



Photo courtesy of iD.8 Photography

Case study HMP Whatton, Nottinghamshire

Terminally ill inmates at Whatton prison in Nottinghamshire now have the option of spending their last days in prison because of a joint initiative between prison staff and Nottinghamshire Community Health.

HMP Whatton accommodates 840 category C male offenders. It has an ageing population with 60% over the age of 40 and a high rate of cancer.

Those with a terminal diagnosis are now cared for according to the GSF and will be placed on the LCP in their final days. They are able to make advance care plans and say if they do not want to be resuscitated. They can also receive visits from their family in privacy.

Senior practice nurse and palliative care lead Karen Shaw says the healthcare team had to overcome concerns from the prison authorities about introducing palliative care in a prison environment. Perhaps most difficult was getting agreement to house syringe drivers in the prison because of fears they could be misused. "If we hadn't been able to provide that then sadly the prisoners would have had to leave the prison to die. But in the end we resolved this."

Several patients have died peacefully, surrounded by their family and with their pain well controlled, since the new policy was introduced. This was made possible by allocating a room on the residential wing where families can visit terminally ill patients who are too ill to attend the visits hall.

Significant improvements have now been made to the accommodation for dying patients and their visitors. A grant from Offender Health through the King's Fund Enhancing the Healing Environment programme has financed a purpose-built end of life care suite attached to the health centre together with facilities for visiting families.

Contact: information@eolc.nhs.uk



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Step 6

Care after death

“The general view was that you don’t want to have a death in custody, even an expected death, as that means post mortems and police involvement. It was very alien to them and it took a lot of educating of staff to overcome.”
Senior practice nurse, Nottinghamshire

Good end of life care doesn’t stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to family wishes. The support and care provided

to carers and relatives will help them cope with their loss and is essential to achieving a ‘good death’. This is also important for staff, many of whom will have become involved with the prisoner.



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Questions

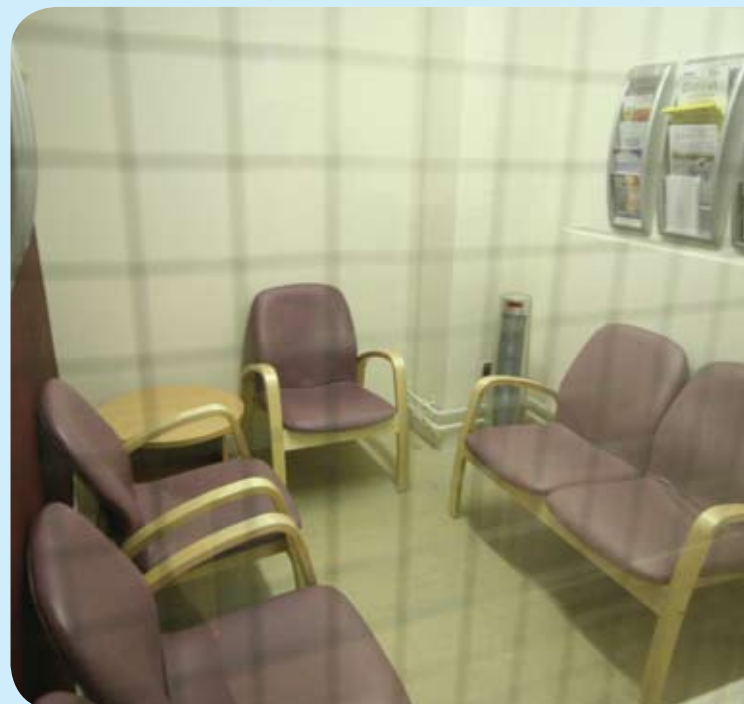
- Have the family been appropriately informed of the prisoner's death?
- Are they aware of what will happen next, processes and procedures?
- Have the other prisoners, relatives and carers/prison staff been provided with appropriate information?
- Are systems in place for offering bereavement support?
- Do mechanisms exist to support those, such as staff and other prisoners, who may be affected by a death?
- Have all involved community services been informed?
- What formal prison processes need to be adhered to?

Your role

- Respect individual faiths and beliefs and take steps to meet their requirements
- Be aware of verification and certification of death policies
- Provide appropriate information to relatives and carers about what to do after a death
- Offer information about bereavement support services if required
- Offer staff the opportunity for debriefing following a death
- Provide a comfortable environment in which staff can discuss or share their concerns.

Top tips

- Give other prisoners, relatives and staff the opportunity to acknowledge that a prisoner has died and allow them to pay their respects in their own way
- Recognise that a prisoner's death may be more significant to some than to others and they may require additional support
- Train volunteers to support dying patients and their families and offer support to bereaved people
- Send relatives a bereavement questionnaire (eg, [VOICES](#)) and provide frontline staff with feedback to support continuing improvement.



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Case study HMP Pentonville

Planning and forethought were the keys to ensuring that the care provided to a dying prisoner at HMP Pentonville, together with support to his family afterwards, was as compassionate and dignified as possible.

The prisoner had decided he wanted to die in prison partly because the nature of his crime meant moving to a hospice was not an option. Together with clinical nurse specialist colleagues, Carol Bullock, who is rehabilitation assistant with Islington's palliative care team, was called in to support him in his last weeks.

Following discussions with prison staff, Carol and her colleagues ensured the prisoner's family were able to make visits, even at night, and were there with him when he eventually died.

They also ensured the normal procedures for a death in custody – including sealing the cell and declaring it a crime scene – were set aside to allow the family to remain alone with the body before it was then taken to the local hospital mortuary.

Carol discussed in advance what was likely to happen with the prison wing manager, who then informed both CID and the coroner. As a result the prison was given permission to circumvent the normal guidelines.

"All the work was done beforehand", explains Carol. "It meant a priest gave the prisoner a small blessing at the end of his life and the family were able to sit with the body after he had died. The family were so grateful for the way everything was handled."

She pays tribute to the hard work and flexibility of prison staff. "You might say that I planted the seeds and watered them but they were the ones who did the work."

She also believes that what happened at Pentonville is transferable elsewhere. "If it can work there it can be blueprinted anywhere at all."

Contact: information@eolc.nhs.uk



Photo courtesy of iD.8 Photography

Other circumstances to consider

“Healthcare can’t be an add-on to security. It has to be realised that it is integral – and that includes psychological well-being. The trauma involved in something like this can create a far more difficult grieving process.” Modern matron

Staff will also need to consider how to employ these six steps with prisoners who have someone they are close to who is diagnosed with a life-limiting condition. This could be a

fellow prisoner or a family member outside the prison environment. This needs to be planned for as they move to the dying stage both within and outside prison.



Questions

- How does your prison manage those who are close to a prisoner who receives a terminal diagnosis? For example, a prognosis of less than six months?
- What processes are in place to support a prisoner whose family member receives a terminal diagnosis?
- How is support planned and implemented?
- What support is offered to the prisoner following a visit to someone who is sick and/or after the funeral?

Your role

- To identify relevant policies in your prison to support prisoners as the illnesses of loved ones or fellow prisoners evolve
- To have a clear communication plan for those affected by a prisoner's diagnosis
- To have a clear plan for managing information about a prisoner's loved one
- To agree who will be the key worker for the individual
- To agree when visits may be appropriate and co-ordinate what is required to enable this
- To ensure the individual knows what they are entitled to in terms of outside visits and contact
- To ensure funeral visits are arranged in a timely fashion
- To enable bereavement support for those who need it.

Top tips

- Consider the process used to date – which parts work well?
- Gain feedback from prisoners as they go through the process and towards end of life care and establish what worked well for them in terms of support and space they required after a visit
- Ascertain what aspects maybe particularly difficult to manage and what could help with this
- Gain feedback from relatives who have had a family member in prison about what could have helped?
- Consider what support would be needed and devise a plan to meet this.
- Ask the individual what they need.



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Case study

Visiting a dying relative

The following case study illustrates what can happen when insufficient thought and flexibility is involved in planning an end of life care event. There is usually only one chance to get this right – how can we contribute?

More thought needs to be given to the treatment of prisoners who have a relative dying in the community, says Heather Joy, modern matron for adults services and modernisation with Hull City Health Care Partnership.

Until recently, Heather was a member of the palliative care team working with a prison in the north. She relates the story of a man, in prison for a very short sentence, whose son was in a serious accident and taken to intensive care.

The prison authorities allowed the father to visit his son in hospital – although he remained in handcuffs – but 48 hours later the hospital called to say that tests showed the son was brain dead.

However, prison rules only allowed prisoners a single visit on compassionate grounds so the father was not allowed to be with his son when the ventilator was turned off.

The prisoner was extremely angry and upset and had to be placed on suicide watch for the following two days. He was also given full access to his personal officer and at a later stage was able to talk to a prison listener about his experiences.

This helped to resolve some of his immediate distress. “In the end he almost came to accept it but it was an awful time for him and many of the staff”, says Heather.

She feels the prison system needs to be more flexible when dealing with end of life care issues like this. “There definitely can’t be a one-size-fits-all approach, it needs to be far more holistic”, she says.

“I know prison orders and instructions guide security staff. But unless there is far closer working between health care departments and the prison I don’t think this is going to move on.”

Contact: information@eolc.nhs.uk



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In the current economic climate and with changes planned to how health care will be commissioned in the future, this is a highly appropriate time to consider how good quality end of life care is commissioned and delivered within the prison environment. The NHS Commissioning Board and clinical commissioning consortia will need to know and understand what good end of life care should look like in a prison environment. There is good practice out there and now is the time to share this to ensure each prison and their healthcare commissioner develops a model that works well for them in their locality.

It will also be vital to offer staff support at a time when they should be facing anxieties of their own.

The tensions between the need to provide care and the need to maintain security will always be there in a prison environment. But staff must never lose sight of the prisoner's needs and individuality. Preserving a prisoner's dignity and choice is never more important than at the end of life.

This applies to a range of issues. When managing visits to a terminally ill prisoner, for example, staff need to ask themselves:

- How can I facilitate visits from family, friends and fellow prisoners in the most humane way?
- Does the cell door need to be locked at all times?

Similar considerations apply to the death of a prisoner in custody. *PSO 2710: Follow up to deaths in custody* (HM Prison Service, 2007) sets out specific requirements relating to a death in custody which all staff have to follow, often in conjunction with particular local policies. In some circumstances it may be appropriate to treat the death of someone with a terminal illness as an expected death and so

avoid unnecessary and reduce often upsetting bureaucracy.

In no circumstances should the guidance be applied in a mechanistic way but rather in a manner that demonstrates that death is normal and shows the human face of death, even in prison. This will include dealing with the deceased, family, prison staff, health and social care staff and other prisoners. It will also cover the necessary legal processes that must be followed. The care planning must ensure that care, support and any further emotional and practical bereavement support continue as required.

Other issues that staff will need to address in the immediate aftermath of a death are:

- Contacting next of kin
- Coroner's inquest and certification
- Dealing with the prisoner's property and valuables
- Providing bereavement support.

Above all, prison and healthcare staff need to remember that the overall aim of end of life care is, in the words of the *End of life care strategy* (DH, 2008), to "enhance choice, quality, equality and value for money". This care should be made available "wherever the person may be", as appropriate to the need to balance security considerations.



Photo courtesy of iD.8 Photography

Case study

Hope for the future

As the prison population ages, end of life care has become an increasing preoccupation within Manchester high security prison and that is why it will be opening a specialist unit specifically for that purpose later this year.

The £40,000 suite, which has been primarily funded as part of the King's Fund Enhancing the Healing Environment programme, was created by knocking two cells into one but will have a domestic atmosphere complete with artwork, larger windows and doors and all the necessary equipment. It will also be possible for relatives to visit in private.

Nursing manager Karen Kenny suggests that the new unit will mean that for the first time, staff at the prison will be able to offer inmates the choice of ending their days within the prison rather than in an outside hospital or hospice.

For the past four years Karen has been responsible for the health of all prisoners over the age of 55 (currently numbering around 70) and over that time she has seen their health care needs increase significantly. There have been three deaths in that time, only one of which occurred in the prison – and this was due to the fact the individual died very suddenly.

But she believes she will be able to offer prisoners real choice in the future. For instance, she is currently caring for a prisoner with cancer who has already indicated he would like to stay within prison to the end. She believes the prison's links with the community palliative care team, combined with its in-house facilities,



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should now make this possible. "Of course he would like to be released but he accepts that he will die in prison and that we will make it as comfortable and pain-free as possible."

She admits that the prison's care after death still leaves something to be desired, mainly because any death in custody triggers a coroner's inquest where the body has to be removed. But the prison does have liaison officers trained in bereavement care who try to support relatives in the immediate aftermath of a death.

Karen and the officers visited the family of the last prisoner who died in custody and built up a good relationship. "They wanted to see the cell where he had spent his last few weeks and I think they were quite reassured by what they saw. But in these circumstances there is only so much that we can do."

Contact: information@eolc.nhs.uk

Review of relevant documents

Reports and policy documents

Policy context and background

End of life care in prisons has been affected in recent years by specific policy initiatives. These include the responsibility for prison healthcare being transferred (from 2004) to the NHS, and, in 2008, the publication of the Department of Health's national end of life care strategy.

The *End of life care strategy* (DH, 2008) sets out a ten year plan for implementing end of life care (EoLC) in all settings. Its contents explicitly extend to prisons and secure hospitals and, in a section dedicated to care in these environments, it states "To support improved end of life care for prisoners, the Department of Health and the Prison Service are working together to ensure that the principles, as set out in this strategy, are applied to prisoners."

See:

- *Review of older prisoners' provisions*, P Rich, North East Offender Health Commissioning Unit, 2009
- *An evaluation of current end of life care provision in prisons in Lancashire and Cumbria*, Payne et al, International Observatory on End of Life Care, Division of Health Research, Lancaster University, 2009
- *Care or custody? An evaluation of palliative care in prisons in North West England*, Turner et al, Palliative Medicine, Jan 2011

Chronological review of policy development

March 2001: National service framework for older people (DH)

A ten year programme of action and reform to address the needs of older people, with standards applied whether an older person is being cared for at home, in a residential setting, or in a hospital.

The NSF standards identified specific actions in relation to the eight standards focusing on:

- rooting out age discrimination
- providing person centred care
- promoting older people's health and independence.

April 2001 PSI 21/2001: National service framework for older people (HMPS)

PSI 21/2001 drew the NSF for older people to the attention of governing governors within HM Prison Service. The PSI required a copy of the NSF to be retained within the health care centre and that the PSI be brought to the attention of the establishment's senior probation officer, senior officers responsible for the supervision of resettlement services, and personal officers involved in sentence planning.

The PSI identified the specific reference to older people in prison in the NSF and emphasised the need for:

- An integrated system of care
- Single needs based assessment
- Resettlement planning to involve partner organisations including social care and health
- Liaison with social services: district of residence issues
- Development of partnerships with local health and social services to ensure older prisoners with health and social care needs get full access to services.

**2004: “No problems – old and quiet”:
older prisoners in England and Wales (HM
Inspectorate of Prisons)**

In 2004, HM chief inspector of prisons published a thematic review of the treatment and conditions of the growing number of older prisoners in England and Wales.

This report highlighted the lack of progress in the development of partnerships between the NHS and the prison service to meet the health and social care needs of older prisoners.

The report also noted that while the *Disability Discrimination Act 1995* had applied to prisons since October 2004 and required them to take all reasonable steps to ensure that prisoners with disabilities can access services, few prisons were reaching the standards required by the legislation and guidance. HM Prison Service subsequently issued orders setting out the steps prisons should take, including *PSO 2855: Prisoners with disabilities*, HMPS, 2008 and *PSI 32/2011: Ensuring equality*, HMPS 2011.

April 2005: Disability Discrimination Act 2005 (DDA)

The 2005 DDA Extended the requirements of the *Disability Discrimination Act 1995* placing a duty upon public bodies, including prisons, to review the impact of all policies, to promote equality of opportunity, to eliminate harassment and to promote positive attitudes to people with disabilities.

Jan 2006: Our health our care our say: a new direction for community services (DH, 2006)

Health and social care services are moving towards personalisation in response to this white paper.

April 2008: PSO 2855: Prisoners with disabilities

PSO 2855 detailed the overarching policy for the handling of disabled offenders in custody. The PSO also includes recommendations to encourage the development of good

practice towards prisoners with disabilities, and guidance on areas that establishments may wish to consider when drawing up their establishment action plan. (See also *PSI 32/2011: Ensuring equality*)

2008: Doing time: the experiences and needs of older people in prison (Prison Reform Trust)

This report was launched at Wandsworth prison and called for strengthened joined-up working between the prison and probation services and the Department of Health.

June 2008: Older prisoners in England and Wales: a follow-up to the 2004 thematic review, (HM Inspectorate of Prisons)

This was a follow-up report to the Inspectorate’s 2004 thematic review of older prisoners in England and Wales (“*No problems – old and quiet*”: *older prisoners in England and Wales*). The 2004 report noted that the National Offender Management Service (NOMS) still had no national strategy for older prisoners, and their needs were too often not met.

It highlighted the lack of mandatory national and local standards, and the gap between the provision for older prisoners and the government’s national strategy for an ageing population.

The 2008 follow up report on older prisoners recommends a national strategy, supported by national and local standards, which “would provide central guidance to prisons on ... age-related issues [including] ... end of life services.”

December 2008: Secretary of state report on disability equality: health and care services (DH)

This report by the secretary of state for health identified that the medical and clinical care of older prisoners is age dependent mainly in relation to the management of their chronic conditions such as type 2 diabetes, some

cancers, and cardiovascular disease. Older prisoners are also likely to have greater health and social care needs due to the faster onset of age-related disabilities from living in a custodial setting. The continuity of their care is an essential element of its overall quality; this is challenged as people move into and between prisons, are managed across NHS and social care sectors, and are released to the community, and also in relation to ensuring care delivery at different times of the day.

April 2009: The Bradley report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system (DH)

This was the report of the independent review into the diversion of offenders with mental health problems or learning disabilities away from prison as appropriate. A national delivery plan building on *The Bradley report* was published later in the same year (*Improving health, supporting justice: the national delivery plan of the health and criminal justice programme board*, DH, 2009). The coalition government has subsequently accepted the direction set out in *The Bradley report* and are taking its recommendations forward via the cross-government Health and Criminal Justice Programme.

Prison Service Orders (PSOs) and Prison Service Instructions (PSIs)

PSOs and PSIs (Prison Service Instructions) are documents which outline the rules, regulations and guidelines by which prisons are run.

Prison Service Orders (PSOs)

These were issued until 31 July 2009. They were mandatory instructions with no expiry date and remained in force until cancelled. Existing PSOs will remain in force until replaced.

Prison Service Instructions (PSIs)

From 1 August 2009, all prison service operating instructions are published as PSIs. They have a fixed expiry date. Prior to 1

August 2009, PSIs were issued to convey short-term instructions or amendments to PSOs and had a maximum validity of 12 months.

The following PSOs are concerned with end of life care in prisons. These and all other PSOs which are currently in force are available at <http://www.justice.gov.uk/guidance/prison-probation-and-rehabilitation/psipso/psos.htm>

PSO 3100: Clinical governance – quality in prison healthcare (HMPS, 2003)

Although it makes no reference to end of life or palliative care, this PSO sets out requirements for governors to ensure that arrangements are being made for clinical governance in prison health care. Governors are not responsible for setting up the detailed arrangements for clinical governance – this falls to the clinical governance lead and health care team – but are accountable for ensuring that the agenda is taken forward. This PSO was published before the transfer of prison healthcare responsibilities to the NHS, and prior to the publication of the *End of life care strategy* (DH, 2008).

PSO 3050: Continuity of healthcare for prisoners (HMPS, 2006)

This PSO contains guidance to improve the continuity of healthcare received by prisoners. It includes guidance on reception, transfer and discharge of prisoners, with particular focus on those with ongoing health needs. It also sets out clinical management of outpatient escorts and NHS inpatient episodes.

PSO 2710: Follow up to deaths in custody (HMPS, 2007)

This PSO contains instructions on action to be taken following a death in custody. It covers the immediate actions required; notifications; family, staff and prisoner needs; legal issues and investigations. All deaths in prisons are subject to a police investigation; an investigation by the prisons and probation ombudsman; and a coroner's inquest before a jury.

PSO 6000: Parole release and recall (HMPS, 2005)

Sets out procedures for permanent early release on licence of all prisoners on compassionate grounds. Before supporting an application for early release the governor must consider whether the prisoner's needs can be met by temporary release, for example on compassionate licence. (See *PSO 6300* below.)

PSO 6300: Release on temporary licence (HMPS, 2005)

PSIs issued from 2010 onwards are available at <http://www.justice.gov.uk/guidance/prison-probation-and-rehabilitation/psipso/psis.htm>. The following PSI is also relevant to end of life care:

PSI 31/2008: Allocation of prisoners with disabilities (HMPS, 2008)

This PSI introduces a number of additional measures to ensure that prisoners with disabilities are allocated to appropriate accommodation as soon as possible after reception and on recategorisation.

This is not an exhaustive list of all PSOs and PSIs. A full list can be found at <http://www.justice.gov.uk/guidance/prison-probation-and-rehabilitation/psipso/index.htm>.

A search for further relevant policy and guidance documents brought little that relates directly to end of life care in prisons.

Quality markers for end of life care

(End of life care strategy: quality markers and measures for end of life care, Department of Health, 2009)

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.
6. Have mechanisms in place to ensure that care for individuals is coordinated across organisational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

References and weblinks

Suicide and self-harm in prison service establishments in England and Wales, HM Inspectorate of Prisons, 1990

Older prisoners in England and Wales: a follow-up to the 2004 thematic review, HM Inspectorate of Prisons, 2008

Annual Report 2008-2009, Prisons and Probation Ombudsman for England and Wales, 2009

Review of older prisoners' provisions, P Rich, North East Offender Health Commissioning Unit, 2009

An evaluation of current end of life care provision in prisons in Lancashire and Cumbria, Payne et al, International Observatory on End of Life Care, Division of Health Research, Lancaster University, 2009

Care or custody? An evaluation of palliative care in prisons in North West England, Turner et al, Palliative Medicine, Jan 2011

Care and the prison officer: beyond 'turnkeys' and 'care bears', S Tait, Prison Service Journal, Nov 2008

"This is not just about death – it's about how we deal with the rest of our lives": coping with bereavement in prison, M Wilson, Prison Service Journal, Jul 2010

Common core competences and principles for health and social care workers working with adults at the end of life, NEoLCP/Skills for Health/Skills for Care/Department of Health, 2009

Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own, DH, 2008

Preferred Priorities for Care (PPC), National End of Life Care Programme (NEoLCP), 2007

Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff, NEoLCP, May 2011

Advance decisions to refuse treatment: a guide for health and social care professionals, NEoLCP/ National Council for Palliative Care, 2008

Mental Capacity Act (2005) code of practice, Department for Constitutional Affairs, 2007

Planning for your future care: a guide, NEdLCP/National Council for Palliative Care/University of Nottingham, 2009

Making a will (Directgov guidance on wills including links to Citizens Advice Bureau guide to making a will and Age UK fact sheet)

End of life care strategy: quality markers and measures for end of life care, DH, 2009

Out-of-hours toolkit, Macmillan Learn Zone (online learning resources for professionals)

Gold Standards Framework (GSF)

The Liverpool Care Pathway for the Dying Patient (LCP)

What to do after a death (Directgov guidance)

National end of life care strategy: promoting high quality care for all adults at the end of life, DH, 2008

No one knows: offenders with learning difficulties and learning disabilities: the prevalence and associated needs of offenders with learning difficulties and learning disabilities, N Loucks, Prison Reform Trust, 2007

People with learning disabilities as offenders or alleged offenders in the UK criminal justice system, G Murphy/I Clare, Journal of the Royal Society of Medicine, Apr 1998

Websites for further information

National End of Life Care Programme
<http://www.endoflifecareforadults.nhs.uk>

National Council for Palliative Care
www.ncpc.org.uk

Marie Curie Cancer Care
www.mariecurie.org.uk

Help the Hospices
www.helpthehospices.org.uk

The King's Fund
www.kingsfund.org.uk

Gold Standards Framework
<http://www.goldstandardsframework.nhs.uk>

Liverpool Care Pathway for the Dying Patient (LCP)
<http://www.liv.ac.uk/mcpil/liverpool-care-pathway>

Ministry of Justice prison and probation statistics and data for England and Wales
<http://www.justice.gov.uk/publications/statistics-and-data/prisons-and-probation/index.htm>

The Scottish Government prison population statistics
<http://scotland.gov.uk/Topics/Statistics/Browse/Crime-Justice/TrendPris>

The Northern Ireland Prison Service population statistics
<http://www.niprisonservice.gov.uk/module.cfm/opt/8/area/Population%20Report/page/population/>

Glossary of end of life care terminology

Advance care plan: This is the document which arises as a result of the advance care planning (ACP) process, which is described as “a process of discussion between an individual and their care provider irrespective of discipline. The difference between ACP and more general planning is that the process of ACP is to make clear a person’s wishes and will usually take place in the context of an anticipated deterioration of the individual’s condition” (*Advance care planning (Support sheet 3)*, NEdLCP, 2010). This document should be regularly reviewed and communicated to key persons involved in the individual’s end of life care.

Advance decision to refuse treatment (ADRT): Individuals cannot demand that they receive specific treatments but have the right to refuse them. An advance decision to refuse treatment (previously known as a living will or advance directive) is a decision you can make to refuse a specific medical treatment in whatever circumstances you specify. This can include the choice to refuse treatment even if doing so might put your life at risk. The advance decision to refuse treatment will not be used if you are able to make your own choices at the time that the treatment is needed and offered. The *Mental Capacity Act (2005)* lays out the ways in which these decisions must be communicated.

Do not attempt resuscitation (DNAR): A do not resuscitate document, often called a living will, is a binding legal document that states that resuscitation should not be carried out in any of the following circumstances:

- Where it would be considered medically ‘futile’. Eg, where someone has experienced a cardiac arrest and is likely to have another one irrespective of treatment. In this situation the person need not have a document but medical staff may have made

that decision in advance and documented this within the patient’s notes

- Where the person has an advance directive which states that they do not wish to be resuscitated in the particular situation which they are currently experiencing. Eg, they have advanced cancer or advanced dementia and a life-threatening infection
- Where someone entitled to make decisions on behalf of the patient by holding a health focused power of attorney for them decides that the patient would not wish to be resuscitated in the current situation.

Gold Standards Framework (GSF): The Gold Standards Framework is a systematic evidence-based approach to optimising the care for patients nearing the end of life delivered by general health and social care staff. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting.

GSF improves the quality, co-ordination and organisation of care in primary care, care homes and acute hospitals. This enables more patients to receive the type of care they want, in their preferred place, with greater cost efficiency through reduced hospitalisation.

Independent mental capacity advocate (IMCA): The *Mental Capacity Act (2005)* places a responsibility on local authorities to ensure that people who are assessed as lacking the mental capacity have access to an independent advocate when they are having decisions made about them relating to:

- Serious medical treatment (SMT)
- Changes of NHS accommodation for 28 days or more
- Change of local authority accommodation for more than 8 weeks.

People can also access IMCA support in accommodation reviews and safeguarding adults situations or when they have no family or friends to represent them.

IMCAs meet with the person and try to assist them in communicating and being as involved as possible in the decision making process. The IMCAs represent the wishes and feelings of the person and will consult with other people. IMCAs check that those working with the person adhere to the main principles of the *Mental Capacity Act* and act as a safeguard for the person's rights.

IMCAs provide the decision maker with a written pre-decision report, making recommendations, and will visit the person again after the decision has been made and provide a written post-decision report. IMCAs will challenge decisions if necessary.

The Liverpool Care Pathway (LCP): The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of life for the dying patient in the last hours and days of life. It is a means to transfer the best quality for care of the dying from the hospice movement into other clinical areas, so that wherever the person is dying there can be an equitable model of care. The LCP has been implemented into hospitals, care homes, individuals' own homes/ communities, and hospices. It is recommended as a best practice model, most recently by the Department of Health in the UK.

Person centred planning: Person centred planning is a process of life planning for individuals based on the principles of inclusion and the social model of disability. In person centred planning the process, as well as the product, is owned and controlled by the person (and sometimes their closest family and friends). As there are no prescribed forms, tick boxes or checklists, the resulting plan of support is totally individual. It creates a comprehensive portrait of who the person is and what they want to do with their life and brings together all of the people who are important to the person including family, friends, neighbours, support workers and other professionals involved in their lives.

Preferred Priorities for Care (PPC): This patient held document was designed to facilitate patient choice in relation to end of life issues. Through good communication and by documenting their choices, both patient and carers become empowered through the sharing of this information with all professionals involved in their care. The PPC document provides the opportunity to discuss difficult issues that may not otherwise be addressed (to the detriment of patient care). The explicit recording of patients/carers wishes can form the basis of care planning in multi-disciplinary teams and other services, minimising inappropriate admissions and interventions.

The PPC also records services available, services being accessed and reasons for changes in the care trajectory. PPC is a process which facilitates service review, further empowering professionals to negotiate service requirements on behalf of patients and becoming an integral part of service commissioning and design.

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Publication date: Oct 2011 Review date: Oct 2013