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Learning lessons bulletin

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Dementia

This Learning Lessons Bulletin explores the experience of prisoners with dementia, and the challenges facing prisons in providing them with appropriate care and support.

I have written and commented extensively on the consequences of a rapidly ageing prison population from my mournful perspective investigating all deaths in custody. This bulletin extends this insight to another relatively new area of concern with which prisons are now grappling: dementia. Dementia is a potentially life-limiting condition affecting both physical and mental capacity, although most people with dementia die of other complications such as pneumonia or a stroke.

In my investigations, I have frequently been struck by how ill-prepared prisons were to deal with this new challenge, essentially because they were designed to meet the needs of younger people and not chronic age-related conditions. Things are beginning to move in the right direction in some prisons, with examples of good practice, but there is still a long way to go. While there have been relatively few investigations which have specifically highlighted issues relating to dementia, it is inevitable that this will be a growing issue as the population of elderly prisoners is projected to continue to increase.

I hope that the lessons outlined in this bulletin, derived from a number of my fatal incident investigations, will help the Prison Service to develop further its provision for this especially vulnerable group. The bulletin also confirms my view that the Prison Service badly needs a properly resourced national strategy for its rapidly growing population of older prisoners, to guide its staff in their management of age-related conditions such as dementia.

Nigel Newcomen CBE
Prisons and Probation Ombudsman

Background

Those aged over 60 are the fastest-growing segment of the prison population, increasing 125% between 2004 and 2014. Those aged over 50 are the second-fastest-growing segment, increasing by 104% in the same timeframe, while the overall prison population increased by just 15%. The Ministry of Justice project the population in prison aged over 60 to increase from 4,100 in 2015 to 5,500 in 2020[1]. Two of the main drivers for this demographic shift are longer sentences, and more late in life prosecutions for historic sex offences.

The ageing of the prison population shows no signs of abating, leading to an increase in deaths from natural causes in prisons and increasing social care needs of elderly and infirm prisoners. This has been recognised in the Care Act 2014, parts of which came into force in April 2015. The Act makes local authorities responsible for assessing and meeting the eligible social care needs of adult prisoners, although prisons will need to make referrals first. The aim is to bring the delivery of social care in prisons in line with the care of those in the community.

Dementia is a condition associated with the ageing population. A range of services are available in the community for dementia, including regular GP reviews, referral to specialists when necessary, local authority help with social care, support to help plan for the future and access to charitable organisations. That is not to say that dementia care in the community is always perfect. Care needs to be personalised, and improvements in dementia care are needed not just in prisons, but in hospitals too[2].

The government has recognised the need for improvement, and in 2012 the Prime Minister launched a national challenge to fight dementia. This detailed a programme of action to boost dementia research and deliver improvements in health and care. In 2015, this was extended, with plans set out for continuing improvements through to 2020[3]. Earlier this year, the Department of Health issued an Implementation Plan which set out actions to ensure that the commitments made in the 2020 Dementia Challenge are effectively delivered[4].

Dementia is a consequence of damaged brain tissue and covers a range of different conditions that mainly affect older people, with fewer than 5% of cases being 'early onset' (before the age of 65 years)[5]. Alzheimer's disease is the most common form of dementia, accounting for around 62% of cases; it destroys nerves and brain cells, disrupting transmitters which carry messages in the brain, particularly those responsible for storing memories.

Vascular dementia accounts for around 17% of cases and results from reduced blood flow to the brain as a result of narrowing and blockage of the small blood vessels in the brain, from a major stroke or series of mini-strokes. Other forms of dementia can have many other causes, such as drinking excessive alcohol over a long period of time or chronic illness. Dementia can impair many functions including memory, decision-making, concentration, problem-solving, communication and motor skills, as well as leading to personality change.[6]

In 2014, academics from King's College London and the London School of Economics estimated that there would be about 850,000 people in the UK with dementia by 2015 . The number of prisoners affected is unknown, although the Mental Health Foundation estimated it at approximately 5% of prisoners over 55 years old.[8] If this is the case, there are likely to be several hundred prisoners with dementia.

While relatively few of our fatal incident reports specifically mention dementia, this is not to say that deaths of people with dementia in prison are rare. Many of the older prisoners whose deaths we have investigated had some form of dementia, but our reports are unlikely to refer to their dementia unless it was relevant to the circumstances surrounding their death.

We have investigated some deaths where the prisoners already had dementia at the time they were sent to prison and others where dementia developed during their sentence. Although awareness of dementia is increasing within the Prison Service, few changes have been made to address the specific needs of people with dementia.

In 2013, the National Offender Management Service issued a guide for prison officers[9], to help them understand dementia and deal more effectively with prisoners who are affected. This bulletin aims to identify some learning from our investigations into deaths of prisoners with dementia, in order to help Prison Service staff deal more effectively with this group of prisoners. Most of the case studies used in this bulletin pre-date the Care Act, and it is to be hoped that the implementation of the new legislation will make a positive difference in prisons.

Dementia and decision-making

When someone has dementia they may, over time, lose the capacity to make decisions about their care and treatment and other important decisions affecting their lives. People being treated for dementia will usually have to make some decisions about their care during the course of their illness, including matters such as whether they want to be resuscitated if their heart or breathing stops and whether they consent to the sharing of confidential information. Prisoners must be regarded as having mental capacity to take such decisions and where clinicians consider they do not have capacity, as defined by the Mental Capacity Act 2005, they need to document their decisions. In such situations, family or friends can act as advocates, or, if there is no one else able to represent the person who is

independent of the service, independent mental capacity advocates can be used, as should have been the case for Mr A.

Case study A

Mr A was admitted to prison in 2009, at the age of 79. He was already suffering from diabetes, heart disease and dementia. His health deteriorated over time and, in 2013, he was admitted to a specialist unit in the prison for older prisoners with long term medical conditions. On admission, a care plan should have been completed involving an assessment of Mr A's mental capacity to see if he was capable of discussing his future care arrangements. No plan was completed and healthcare staff did not discuss with Mr A his preferences about his care and treatment, including whether he wanted to be resuscitated if his heart or breathing stopped.

An undated note in Mr A's medical records stated that he did not have the mental capacity to make an informed decision and should be referred to independent mental capacity advocates. Such advocates are used for people who lack the capacity to make important decisions, when there is no one else able to represent the person who is independent of the service. This referral was not made. When Mr A died, there was confusion about whether to try to resuscitate him, because no clear decision about his mental capacity or whether he should be resuscitated had been made. Resuscitation was attempted but was unsuccessful.

We concluded that a properly considered, comprehensive and recorded care plan would have better guided staff and addressed Mr A's needs and recommended that such a plan should be the standard expectation in similar cases in future.

> “When Mr A died, there was confusion about whether to try to resuscitate him”

Responsibilities and neglect

Prison Service Instruction (PSI) 15/2015, Adult Social Care, outlines the services prisons can expect from local authorities under the Care Act and the responsibilities of different agencies. The delivery of care and support in eligible cases is now the responsibility of the local authority and each prison should have a local lead for adult social care to liaise with the providers. Prisons must now work with the local authorities to develop care and support plans for each prisoner with eligible needs. In the past, before the Care Act was implemented, we found that communication failures caused delays and, sometimes, neglectful treatment, as was the case for Mr B.

Case study B

Mr B was 63 years old when he was sent to prison. He had several health problems, but in particular he had been diagnosed with vascular dementia, caused by a lack of blood to his brain, thought to have been caused by high blood pressure and previous strokes. A number of professionals assessed him to identify his care needs. He had a disability care plan, received appropriate medication and healthcare staff monitored him frequently. However, no one took overall responsibility to ensure that all his needs were met. Healthcare staff decided that the cause of his dementia was largely physical, and the mental health team did not assess him for almost a year.

Mr B did not always remember to take his medication as prescribed and his personal hygiene deteriorated. He was seen by a doctor when he complained of painful feet, and the doctor noted that this was due to poor hygiene. The doctor made a referral to a podiatrist, but there is no record of this ever happening. A healthcare manager at the prison told our investigator that Mr B would have had to make a written application to see a podiatrist himself, if he wanted to be treated. We found this to be neglectful for a man with his poor mental capacity.

At the end of life, prison managers decided that Mr B should be restrained by an escort chain in hospital, without a proper risk assessment that took into account his health and mobility. He was restrained for three days in hospital before the restraints were removed, two days before he died.

Caring for those with dementia

The prison estate was designed for young, fit men and not for its current ageing population. Often, small cells originally meant for one man now hold two. It is often not even possible to get a wheelchair into the cell and, in most prisons, the majority of cells are not at ground floor level. There is often a waiting list for any more accessible cells. Lack of appropriate space or facilities can make it difficult for prisons to provide care that would be equivalent to that in the community.

Good practice

HMP Whatton has a special cell which can be allocated to prisoners with either mobility impairments or dementia. It originally held four men and now houses a maximum of two (including a prisoner carer if necessary). The cell has been designed to support prisoners with dementia, with a large clock, clear signs and a door frame of a different colour to the door.

Some prisons promote the Dementia Friends scheme, to raise awareness for other prisoners and for staff. This is an Alzheimer's Society initiative designed to change people's perceptions of dementia.

Under the Care Act, where the prisoner meets the eligibility criteria for social care, local authorities are responsible for meeting those specific needs. Where prisoners do not meet the eligibility criteria for local authority care, the local authority should help with developing each support plan. This should set out what needs to be done to meet a prisoner's current needs, and help to prevent or delay the prisoner developing additional needs. However, responsibility for delivering the plan rests with the prison, although this responsibility may be joint with other agencies such as healthcare and voluntary sector services.

Prisoners are likely to need support in other ways, such as with collecting their food, cleaning their cell, and other day to day tasks. Much of the social care delivered in prisons is provided by other prisoners. Formal arrangements are often put in place where risk-assessed prisoners are employed to provide extra support to prisoners who need it, as in the case of Mr C.

Case study C

When Mr C first arrived in prison, aged 63, he had a number of complex health problems, including heart disease, hypertension and diabetes. He was prescribed medication and received hospital treatment on a number of occasions.

During his time in prison Mr C's physical health deteriorated. He had a number of falls, was subsequently advised not to leave his cell, and was given a wheelchair. Staff also began to raise concerns about his memory. They recognised that his speech was slow, he lost track of conversations and he struggled to remember to take his medication. He was later diagnosed with dementia.

As his health needs increased, Mr C was appropriately referred to hospital and local community services. An external social care provider visited the prison to assess Mr C's care needs, but he declined their help. However, Mr C received support from other prisoners. One of Mr C's friends and another prisoner both took short wheelchair pushing courses and became Mr C's "wheelchair buddies", taking him to areas of the prison he would not have been able to get on his own, including the healthcare centre and visits room. One of these prisoners subsequently took on a full caring role for Mr C. This involved collecting his meals, helping him to get dressed and to wash his clothes, and accompanying Mr C around the prison.

In the final months of his life, the support of his prisoner carer helped Mr C to carryout his daily tasks, with as much normality and dignity as possible. Mr C died from hypertensive heart disease, aged 73.

> "Much of the social care delivered in prisons is provided by other prisoners."

When used effectively, prisoner carers can provide essential support to prisoners with dementia or other vulnerabilities, helping to improve the quality of their day to day life, as well as helping the carer to develop a skill and make a positive contribution to their prison community. However, prisoner carers must be properly managed and their duties should be appropriate. It is important that assessments and safeguards (equivalent to those conducted in the community) are still put in place in addition to any support from prisoner carers.

On occasions, investigations have found evidence of informal caring arrangements made by prisoners themselves, or prisons over-relying on prisoner carers. Prison Service Instruction 17/ 2015, Prisoners Assisting Other Prisoners, provides guidance about the appropriate use of prisoners as carers. Prisons should not rely on prisoner carers to provide assistance that is the statutory responsibility of another service, such as health or social care services. The arrangement must be appropriate for both the carer and the person receiving care, the care provider must be given appropriate training, and necessary safeguards need to be put in place

Restraints

Elderly and infirm prisoners often need to travel to and from hospital for appointments and treatment. When a prisoner leaves the prison, a risk assessment is conducted to decide whether the use of restraints is appropriate. The Prison Service has a responsibility to protect the public, and the decision should be based on the prisoner's motivation and ability to escape, and the harm they would pose if they were successful at doing so. The decision should take into account the actual risk the prisoner presents at that time, taking into account their current health and mobility.

The inappropriate use of restrains is a recurring issue in our investigations. Despite making numerous recommendations about restraints, and publishing a learning lessons bulletin on the topic, we continue to find too many cases where restraints have been used inappropriately on infirm and terminally ill prisoners, including those with dementia.

Case study D

Mr D was aged 72 when he first arrived in prison. At the time he suffered from diabetes, rheumatoid arthritis and poor vision. During his time in prison his general health gradually deteriorated. He developed heart disease and kidney disease, and he suffered increasing memory loss, which led to a diagnosis of moderate dementia. His mobility also deteriorated, and he was assigned a disability carer who helped him to move around his cell and carry out daily activities.

One day, Mr D appeared noticeably unwell and confused. He seemed to be dehydrated and was unable to stand up, so was sent to hospital. An escort risk assessment was carried out which indicated that he was a low risk to the public. A nurse completed the healthcare part of the assessment. She said that there were no medical objections to the use of restraints, but pointed out that Mr D used crutches or a wheelchair, at best was only able to take a few steps, and was in a very confused state of mind. In spite of this, an operational manager recommended that Mr D should be restrained, and another manager approved the use of restraints. He was escorted to hospital by two officers, and attached to one of them with an escort chain. This is a long length of chain with a handcuff at each end, one of which is attached to the prisoner and the other to the officer.

Mr D was diagnosed with pneumonia and remained in hospital for two days. Throughout this time he continued to be attached to an officer by an escort chain. He began to have serious breathing difficulties, at which point one of the escorting officers called the prison and asked for a review of the need for restraints. The prison made no immediate change. Minutes later Mr D became unresponsive and the officer removed the escort chain. He was pronounced dead shortly afterwards.

The Prison Service has a fundamental responsibility to protect the public, but this must be balanced with humanity. Mr D's initial assessment indicated that he was low risk of escape and that his mobility was poor. Furthermore, he had dementia and was very confused, which would have made it hard for him to comprehend what was going on and why he was restrained. It is therefore difficult to understand why managers concluded that an escort chain was necessary in the first place, and why they did not approve its removal when an officer called the prison to ask for permission to do so. It is unacceptable that a very ill, immobile and confused old man should be chained to an officer until he died.

> “It is unacceptable that a very ill, immobile and confused old man should be chained to an officer until he died”

Family contact

Prisoners with dementia often have difficulties doing things for themselves. In addition to day to day tasks like collecting their meals, they may also have difficulty keeping in touch with their family – including remembering to phone or coping with the process involved in doing this in prison. It is rarely possible for prisoners to receive incoming calls from their families. Prisons have an obligation to help prisoners to maintain family ties, and need to ensure that there are procedures to support this. Family contact is important for a prisoner's wellbeing, and where possible, a prisoner's family should be included in discussions about their care and treatment.

Case study E

Mr E was remanded to prison at the age of 88, already suffering from dementia as well as other chronic health problems. Although he had been able to write and use the telephone when he first arrived in the prison, his condition deteriorated quickly and he quickly became unable to do either without help. When Mr E's family phoned the prison to check how he was, no effort was made to get him to the phone and he was unable to speak to them. The prison made no arrangements to help him keep in contact with his family. On one occasion, his family came to visit him but Mr E was not able to get to the visits hall because the lift was not working and he could not use the stairs due to his disabilities. There had been no communication between healthcare staff and prison staff to work around this problem in advance, so Mr E's family were unable to see him that day. Visits were subsequently organised in the healthcare centre, but Mr E's family had been distressed about the lack of contact with him before this.

Endnotes

1 Ministry of Justice (2015) Prison population projections 2015-2021 England and Wales. Available online: *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480031/prison-population-projections-2015-2021.pdf*

2 Alzheimer's Society (2016) Fix Dementia Care: Hospitals. Available online: *www.alzheimers.org.uk/fixdementiacare*

3 Department of Health (2015) Prime Minster's Challenge on Dementia 2020. Available online: *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf*

4 Department of Health (2016) Prime Minster's Challenge on Dementia 2020: Implementation Plan. Available online: *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf*

5 Alzheimer's Society (2014) Dementia UK update. Available online: *https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323*

6 Mental Health Foundation (2013) Losing track of time: Dementia and the ageing prison population: treatment challenges and examples of good practice. Available online: *https://www.mentalhealth.org.uk/publications/losing-track-time*

7 Alzheimer's Society (2014) Dementia UK update. Available online: *https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323*

8 Mental Health Foundation (2013) Losing track of time: Dementia and the ageing prison population: treatment challenges and examples of good practice. Available online: *https://www.mentalhealth.org.uk/publications/losing-track-time*

9 National Offender Management Service (2013) Hidden Disabilities: Dementia (Essential Guide for Prison Officers)

10 Mental Capacity Act 2005. Available online at: *http://www.legislation.gov.uk/ukpga/2005/9/contents*

11 Prisons and Probation Ombudsman (2013) Learning lessons bulletin: Restraints. Available online: *http://www.ppo.gov.uk/?p=3718*

Lessons to be learned

Lesson 1
Support should be given to those with dementia to help them make informed decisions about their care. Where they lack capacity there should be appropriate assessments and documented decisions. Prisoners with dementia should have access to independent advocates where there are no other independent people, such as families or friends, to represent their interests.

Lesson 2
All prisons should have a local lead for adult social care, to liaise with partners involved in the care of older prisoners and to coordinate the individual care of prisoners with dementia, so that their needs are not overlooked.

Lesson 3
Prisons should share best practice and consider innovative ways of coping with the increasing number of prisoners with dementia and their associated mental and physical impairments.

Lesson 4
Prisoner carers must be given appropriate training and necessary safeguards need to be put in place, to ensure that caring arrangements are appropriate for both the carer and the person receiving care.

Lesson 5
When a prisoner is taken to hospital, a risk assessment should fully take into account their health, including their mobility and any conditions affecting their mental capacity, such as dementia. The decision about the use of restraints should be based on the actual risk the prisoner presents at the time, and should be frequently reviewed.

Lesson 6
Prisons should make reasonable adjustments to help prisoners with dementia and their families keep in touch. Where possible, families should be included in discussions and decisions about their relative's care.

The Prisons and Probation Ombudsman investigates complaints from prisoners, young people in secure training centres, those on probation and those held in immigration removal centres. The Ombudsman also investigates deaths that occur in prison, secure training centres, immigration detention or among the residents of probation approved premises. These bulletins aim to encourage a greater focus on learning lessons from collective analysis of our investigations, in order to contribute to improvements in the services we investigate, potentially helping to prevent avoidable deaths and encouraging the resolution of issues that might otherwise lead to future complaints.

PPO's vision:

To carry out independent investigations to make custody and community supervision safer and fairer.

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