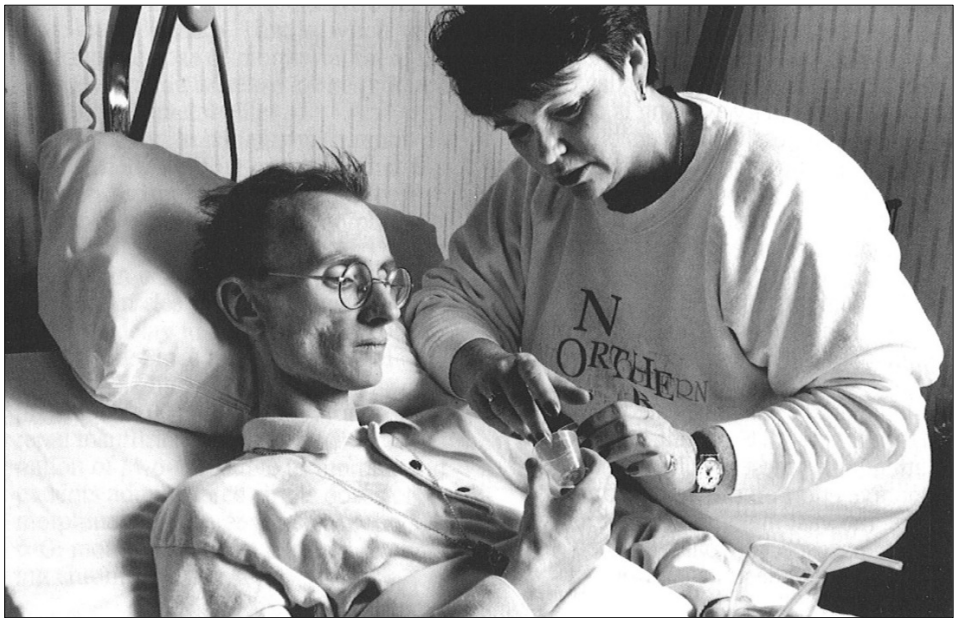
Engaging the Hospice Community in End-of-Life Care in Prisons (Part 2)

By Barry R. Ashpole

PART 1 OFFERED A BROAD OVERVIEW of the potential role community hospices can play to improve end-of-life care (EoLC) for a particularly vulnerable and underserved population. As has been widely acknowledged, prisons and correctional facilities are caught between the proverbial "rock and a hard place," between issues of security and public safety and the civil rights of the prison inmates to healthcare comparable to what is available to the populace-at-large. [1] Part 2 takes a closer look at specific initiatives by some community hospices to support prison inmates towards the end of life.



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PRIOR TO CONDUCTING RESEARCH FOR ITS 2020 REPORT, 'Dying Behind Bars: How can we better support people in prison at the end-of-life,' Hospice UK had only anecdotal evidence of the important work that some hospices were engaged in to support prison inmates at the end of life. The scope of this support had not been established at a national level. After conducting a survey of hospice services across England, researchers found that 25 hospices – representing approximately 15% of hospices in the country – are indeed providing this care and support, working with 34 different prisons. The support provided ranges from on-demand specialist palliative care (PC) advice to directly caring for inmates within prisons. Some hospices have been conducting this work for more than 15 years, while others are at the beginning stages of establishing working relationships with local prisons. [2]

Gilbert and colleagues at Bristol University examined three models of care delivery for people in prison, notably in high-income countries: 1) Embedded hospice model, typified by an interdisciplinary team and volunteer caregivers providing care on-site; 2) Outsourcing care model, in which end-of-life care (EoLC) is provided outside the prison; and 3) Collaborative community model, which involves prisons engaging with other healthcare facilities or practitioners to assist prison inmates. Specifically, prison teams actively pursued multidisciplinary collaboration with local PC specialists. Staff from community palliative services, alongside prison healthcare professionals, offered care to people in prison through "in-reach" services. Some prisons had their own EoLC programs, with a growing number of inmates trained as "buddies" to support fellow inmates. Central to this model is the idea that individuals in prison with serious illnesses should ideally receive care within or close to their "home" institution, ensuring comfort and familiarity for the person in prison coping with serious illness. [3]

Demonstrations of the Collaborative Community Model

St. Luke's Hospice, in South West England, offers a unique case study endorsing the collaborative community model. In partnership with local prison authorities, the hospice faced a range of challenges: first and foremost how can things be done differently for prison inmates approaching the end of life; could the hospice increase the knowledge of the prison's healthcare staff, warders, the governor and all the support structure around them; by increasing their knowledge and understanding of EoLC, better equip prison staff to have discussions about EoLC, equip the healthcare team to be able to cope with more complexity, and look at where the prison could do things differently with maybe increasing the amount of care someone could have in their cell; and, could it actually mean that there are more options for inmates approaching the end of life? [3]

St. Luke's Hospice's partnership with Dartmoor prison, in the South West of England, has been in place for some twenty years. In the words of the hospice's specialist nurse Martin Thomas:

Both the prison's management and healthcare team have really engaged and have a fantastic can-do attitude. When we've been faced with challenges like setting up end of life and palliative nurse-led clinics they've said yes. Every first Wednesday of the month there's a nurse-led clinic where inmates can be booked in and seen by our nurse. If they're too frail he can visit them in their cells and work with the prison team to look at what their health and psychological needs are approaching the end of life, so that's fantastic. At both clinics advance care planning is discussed, so a big change is that there is dialogue now about prisoner's wishes. [4]

Over the years, the number of inmates at Dartmoor prison accessing end-of-life services increased seven-fold, care is patient-centered and integrated, and there is greater choice for inmates in the care they receive. Importantly, the prison's culture is now more compassionate. A "buddy system" is seeing inmates support each other by giving practical help to the less able, and they are also receiving training to become listeners. [5] (Scroll down to 'Resources' for additional information.)

It has been estimated that 30% of hospices in Scotland provide support to prisons. There are differences, however, in the degree of involvement. The support provided by some hospices extends beyond direct care. Many are also involved in sharing their expertise in relation to specialist PC. Others are developing services to meet the demand of this population with the assistance of prisons and those involved in custodial care. Those hospices actively involved in *caring* describe a complex process of relationship building, staff preparation, effective communication, and clear oversight of the transfer process, all of which are necessary to facilitate care delivery. [6]

A partnership between Scottish Prison Service, National Health Service Lothian and the charity Marie Curie is endeavoring to transform the experience of PC for prison inmates. For example, Marie Curie is working with one of Scotland's highest populations of older, long-term prison populations located in Edinburgh. Challenges include identification of inmates with PC needs, the lack of 24/7 healthcare, timely access to medication, the prison environment and regime, staff confidence and competence, and that some high-risk offenders may not be eligible for compassionate release, a critical issue.[7] Basically, compassionate release is a process that allows for the early release or parole due to advanced age, with a life-limiting illness, complex medical care needs or significant functional decline and deemed not a threat to public safety. This brings into play another consideration and perhaps an incentive to effect change. The care of incarcerated older adults, many of whom have high rates of chronic disease and disability, has generated rising prison healthcare costs and strained prison healthcare infrastructures. The many benefits seem obvious, yet compassionate release is rarely given. [8]

Grief & Bereavement Support

The prison environment, with its logistical and security concerns, can have a negative impact on the grieving process. Grief and bereavement support for both inmates and prison staff has been the focus of a number of initiatives, as demonstrated by three presentations at Hospice UK's national conference in November 2024.

The Strathcarron Hospice in Scotland developed "a community of practice," providing an opportunity for prison staff to increase their knowledge and confidence in discussions about loss and grief. A programme of learning was developed which could be replicated in other prisons to help staff support bereaved inmates as well as each other. [9]

St. Peter's Hospice, in South West England, partnered with three local prisons. Prison staff identified the need to improve palliative and EoLC and to learn how to develop bereavement support to imprisoned people, but also their families. Education sessions covered palliative and EoLC, last days of life, what a good death looks like in prison, advance care planning, and communication skills. Specific bereavement training enabled prison staff to provide informed, compassionate bereavement support to prison inmates, and also their families. [10]

St. Barnabas Hospice, in the East Midlands of England, worked with prison staff and prison mentors to design and launch bereavement support. A range of bereavement care options were made available both individually and in groups. The service clearly demonstrated that specialist bereavement support breaks the destructive experience of historical and newly experienced grief in prison and profoundly changes lives and futures. [11]

Community hospices face formidable challenges in establishing partnerships with local prisons, but as has been demonstrated the "returns on investment" can be – and are – positive and far-reaching.

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