

# Engaging the Hospice Community in End-of-Life Care in Prisons (Part 1)

By Barry R. Ashpole

**C**OMMUNITY HOSPICES CAN BE AN INVALUABLE RESOURCE for prison healthcare services. As has been demonstrated, notably in the U.K., community hospices “bring to the table” experience and expertise in the education, training and support of custodial staff and also of inmates. The challenges in providing quality end-of-life (EoL) care, however, are formidable.

A recent scoping review in the U.K., focussed on high-income countries, identified three models of palliative care (PC) for people in prison: ‘Embedded Hospice,’ ‘Outsourcing Care,’ and the ‘Community Collaboration’ model. Establishing collaborative relationships, however, between prisons and community PC providers relies on “a complex process of relationship building, staff preparation, effective communication, and clear oversight,” where the balance between care and custody requires understanding both contexts and a willingness to adapt policies accordingly. Good practice in the ‘Community Collaboration’ model depends on motivated staff and grass-roots initiatives, where prison or community PC providers actively seek working relationships. However, in the U.K. only 53% of prisons have any PC policies, 17% lack policies and 30% are unaware of their policy status, which could compromise staff’s incentive to implement pre-emptive planning by establishing relationships with relevant community services. <sup>1</sup>

Compared with prison-based hospices, little is known about the role played by community-based hospices in providing PC to people in prison. The support provided by hospices to prisons extends beyond direct care, and many hospices 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. For the many countries who have not adopted prison-based hospices, effective collaboration between prisons and community hospices on a national level will be required to meet the needs of the growing number of people in prison who require PC. <sup>2</sup>

Results from a 2020 survey of Hospice UK’s membership show that 24 hospices work with 21 prisons across England. From providing on-demand advice to prison clinicians, to directly caring for patients on the prison estate and in hospice inpatient units, the breadth of work conducted is far-reaching. From Hospice UK’s analysis of the deaths in English prisons due to natural causes between October 2018 and October 2019, 61% were foreseeable. These cases all explicitly mentioned the prisoners had required EoL care. In over a quarter of these cases, hospices were, to varying degrees, involved in the prisoners’ EoL care. Whilst there is substantial existing hospice involvement in prisons in England, there is also potential to increase it, and ultimately, improve EoLC care that prisoners receive. <sup>3</sup> [For additional information scroll down to ‘Resources.’]

## Survey findings:

Of the respondents (84%) working with prisons:

**65%**  
are providing  
on-demand end of life  
care advice to prisons



**62%**  
are providing  
direct clinical care  
to people in prisons



**54%**  
are providing end of  
life care teaching and  
training to prison staff



A partnership between EoL charity Marie Curie and one of the highest populations of older, long-term prisoners in Scotland presented with specific challenges. Barriers, for example, included identification of prisoners with PC needs, lack of 24/7 healthcare, timely access to medication, the prison environment and regime, staff confidence and competence, and some high risk offenders would not be eligible for compassionate release. From a clinical perspective, approach-

es taken included hospice clinical nurse specialist attendance at monthly prison healthcare meetings, and individualized review and plans for each prisoner with PC needs. <sup>4</sup>

Two cases in Canada demonstrate how difficult it is for an incarcerated terminally ill patient to be allowed to die in the community. In the first case, an elderly patient was dying of cancer in a medium security institution and Correctional Service of Canada (CSC) staff put his case forward to the Parole Board to be granted release to a hospice within the community. The response from the Parole Board was that it wanted to see the offender managed in a minimum security institution before granting him release to the hospice. He was eventually released to the community, but died 2 hours after release. In the second case, CSC staff supported the transfer of a terminally ill patient (minimum security) to a hospice facility within the community, and brought the case forward to the Parole Board. There was concern that the patient may not have much time left and that they may lose the spot they had secured with the hospice so the institution tried to push the Parole Board to make a decision quickly. The Board responded that should it not be able to make a decision quickly, CSC could use a medical escorted temporary absence (ETA) to accommodate the offender in the community hospice. A medical ETA requires uniformed guards to be present with the offender at all times. Quite appropriately, the hospice was not supportive of these conditions. <sup>5</sup>

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 incarcerated to healthcare comparable to what is available to the populace-at-large. <sup>6</sup> As has been clearly demonstrated, there’s a real opportunity for community hospices to engage with prisons and correctional services to affect a seismic shift on the quality of EoL care for one of Society’s most underserved and most vulnerable populations.

#### Call for feedback

‘END-OF-LIFE CARE BEHIND BARS: Engaging the Hospice Community...’ Part 2 will focus on specific initiatives that demonstrate the valuable resource that community hospices can be to local prisons. Share your experiences by contacting the author at: <https://bit.ly/4cdWVFD>

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#### References

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3. Supporting prisoners at the end of life, Hospice UK (2020). <https://bit.ly/4bE9RU9>

4. Kemp R, Milton L, Michie G, *et al.* Palliative care for prisoners: A partnership approach, *BMJ Supportive & Palliative Care*, 2018;8:A25-A26. <https://bit.ly/40t4e95>
5. Aging & Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody, Office of the Correctional Investigator (2019). <https://bit.ly/3y7wltD>
6. Ashpole BR. Compassionate Release: Call for humility and more leniency, End-of-Life Care Behind Bars.com (October 2024). **Full text:** <https://bit.ly/4fuzXuU>

## Resources

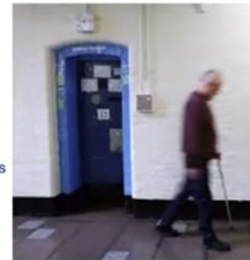
HOSPICE UK WEBINAR: Speakers representing prison management, frontline healthcare staff and voluntary sector partners discuss how to promote compassionate and end-of-life care for people in prison. **Download at:** <https://bit.ly/4fgfzy1>

HOSPICE UK NATIONAL CONFERENCE 2022 session about end-of-life care in prisons. **Download at:** <https://bit.ly/3O6DzYA>

THE EXTENSION OF COMMUNITY HEALTHCARE OUTCOMES (ECHO) Project forms a key part of Hospice UK's current strategy, facilitating meetings for practitioners interested in learning about palliative and end-of-life care in prisons. **Prisons ECHO Network:** <https://bit.ly/3YMHTBd>

### Challenges of palliative care in prison

- Late diagnosis
- Access to treatment
- Access to Medicines
- Contact with family
- Unsuitable environment
- Skills/ knowledge of workforce
- Access for visiting professionals




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BARRY R. ASHPOLE is an educator and communications consultant living in Ontario, Canada. Now semi-retired, he has been involved in palliative and end-of-life care since 1985. He established the End-of-Life Care Behind Bars website (<https://bit.ly/4dU4gmi>), an advocacy, teaching and research “tool” – to inform and, hopefully, affect a seismic shift in society’s attitudes towards the health and well-being of the incarcerated. Regular postings include annotated listings of current articles, reports, and so on, culled from the professional literature, the news media and other sources.

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