

# End-of-life Care in the Prison Environment (Supplement #1)



Photo Source: Prison Terminal

## Contents

Aging Prisons Populations .....	p.1	Care Planning .....	p.5
End-of-Life Care in Prisons .....	p.2	Grief & Bereavement .....	p.5
Prison Healthcare Services .....	p.4	Medical Assistance in Dying .....	p.5
Compassionate Release .....	p.4	Selected Resources .....	p.6

**T**HIS SUPPLEMENT LISTS SELECTED ARTICLES, REPORTS., ETC., published in the literature and in the news media since the last 'Backgrounder' 1 August 2022, which can be downloaded from the Palliative Care Network website at <https://bit.ly/3JkYGVg>. Also included in this supplement is a listing of selected resources. Articles of particular interest are "flagged" with the icon to the left.....



## Aging Prison Populations

### **Aging inside the system with dignity**

*CORRECTIONAL NEWS* | Online – 31 May 2023 – According to the 2012 American Civil Liberties Union ... seven years from now in 2030, there will be around 400,000 geriatric-age inmates within the criminal justice system. Geriatric populations are typically considered age 50 and older. As reported by The Sentencing Project, just under half of those serving sentences for life without parole are also age 50 and older with one in four being over 60 years of age. In 2020, The Sentencing Project surveyed departments of corrections from all 50 states, which revealed that more than 55,000 Americans are

incarcerated in state and federal prisons with no chance of parole. This reflects a 66% rise in people serving life without parole since 2003.

**Full text:** <https://bit.ly/3N54vbb>

***Black, Incarcerated, and Dying: Reflections on Racism and Inequities in Health Care***

Audio reading posted on the *Annals of Internal Medicine* website July 2022: <https://bit.ly/3VNLP2L>

**Related:****Dying with dignity**

*INSIDE TIME* (U.K.) | Online – 31 May 2023 – Death can be hard to talk about. But we shouldn't shy away from it. All of us should receive personalised end-of-life care (EoLC) with dignity and respect. This is no less true for people in prison. In 2020, a report from the Independent Advisory Panel on Deaths in Custody<sup>1</sup> ... looked at how natural deaths in prison might be prevented and, where that's not possible, how EoLC can be managed with dignity and compassion. **Full text:** <https://bit.ly/3C5Plwf>

1. 'Avoidable natural deaths in prison: Putting things right': <https://bit.ly/3JzUwao>

**The multiple punishment of being an older adult coping with health problems in prison**

*THE GERONTOLOGIST* | Online – 21 March 2023 – Studies have examined the vulnerabilities and the extent of health problems experienced by the older adult population in prison. Reports about the subjective experiences of incarcerated older adults who are coping with health problems are scarce. This is alarming since older adults comprise the fastest-growing demographic in the prison systems of the U.S. and Europe. **Abstract:** <https://bit.ly/3U1BgZ2>

**When a prison sentence becomes a death sentence**

NATIONAL PUBLIC RADIO (U.S.) | Online – 27 April 2023 – After spending 38 years in the Alabama prison system ... Larry Jordan feels lucky to live long enough to regain his freedom. The decorated Vietnam War veteran survived prostate cancer and hepatitis C behind bars when a judge granted him early release last year. At least 6,182 people died in state and federal prisons in 2020, a 46% jump from the previous year, according to the UCLA Law Behind Bars Data Project. <https://bit.ly/3NSt5wL>

**What does it mean to be an older person in prison?**

NUFFIELD TRUST (U.K.) | Online – 20 April 2023 – Older people in prison have significant healthcare needs, but prisons are not equipped to address these... The health and justice framework for integration 2022-2025 sets out commitments for integrated care systems on access to healthcare, including at the end of life for people in prison. The Prisons Strategy White Paper<sup>1</sup> noted the need to build new prisons that are accessible and for training on conditions such as dementia. <https://bit.ly/40l2HhS>

1. 'Prisons Strategy White Paper,' Ministry of Justice, December 2021: <https://bit.ly/3N2CVVW>

**N.B.** See 'Living (and dying) as an older person in prison: Understanding the biggest healthcare challenges for an ageing prisoner population,' Nuffield Trust, April 2023. **Download at:** <https://bit.ly/3HiWhsJ>

[End-of-Life Care in Prisons](#)**Caring for each other: End of life behind bars**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE NEWSLETTER – June 2023 – The quality of end-of-life care behind bars is emerging as a universal public health issue, one which is receiving increased attention in the literature as well as in the news media, with reports of a number of initiatives, notably in the U.S., in what is commonly termed "prison hospice." Where volunteer inmates have been trained to care for those living with a terminally illness, prison hospice has also served to work against that sense that prisoners often have of being devalued or having no value. Prison hospice, therefore, can clearly serve two critically important purposes, both consistent with the philosophy and the practice of hospice and palliative care. **Full text:** <https://bit.ly/3P0CxyM>



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## Edgar Barens shares how prison hospices are changing lives



HEART OF HOSPICE (U.S.) | Online – 17 February 2023 – Academy Award-nominated documentary, 'Prison Terminal,' has screened in more than 60 prisons and at more than 80 colleges, universities, and community centers. Edgar takes great satisfaction in his ability to tackle large-scale problems within the American criminal justice system and present them on a very personal level so that the destructive impact of a dysfunctional correctional system can be made more palpable to the viewer. 'Prison Terminal' chronicled the journey of inmate Jack Hall and his inmate brothers who were part of Jack's care team up to and through his death. Edgar witnessed incredible acts of kindness and compassion during his time with Jack and his hospice team. **Download podcast at:** <https://bit.ly/43dlHjZ>

**N.B.** 'Prison Terminal: The Last Days of Private Jack Hall' website: <http://bit.ly/2LTYv7M>



## Transforming the way prisoners die

COMMONWEAL (U.S.) | Online – 30 September 2022 – With the graying of the prison population, the need for more compassionate and effective end-of-life care (EoLC) is acute. No human being, not even those behind prison walls, deserves to die alone without comfort and appropriate care, much less alone in a prison cell or shackled to a hospital bed and left to die. Humane Prisons Hospice Project's model of training prisoners in compassionate EoLC and grief companionship is transformational – not only for the prisoner receiving the care, but also for the prison correctional staff who witness this incredible act of humanity, and for the trained prison caregiver, who may for the first time in their life have the opportunity to extend compassion, empathy, and grace to another human. **Full text:** <http://bit.ly/3M1Kp1E>

## Prison inmates deserve access to high-quality palliative care: A call to action to support terminally ill incarcerated people

CANADIAN NURSE | Online – 18 July 2022 – Currently, palliative care for inmates in Canada is largely left to Correctional Service Canada, which was never designed or equipped to provide such care. Within prison walls, inmates' end of life is fraught with fears for personal safety, increased suffering due to unmanaged pain, and feelings of isolation. Just as the number of aging and dying individuals in correctional settings is on the rise ... so is the need to address their health concerns and protect the sanctity of dignifying death. At the same time, a lack of qualified personnel who are trained to provide specialized care within the correctional setting acts as a compounding barrier to the delivery of palliative services and the recognition of holistic needs of terminally ill inmates. **Full text:** <http://bit.ly/3G4LUYU>

## A thematic analysis of hospital medical records of patients with advanced illness experiencing incarceration in the last 3 months of life

PALLIATIVE MEDICINE | Online – 7 December 2022 – The constraining prison culture is not, for the most part, conducive to the provision of palliative care for people in prison. This study aimed to explore patterns of palliative and end-of-life care (EoLC) provision for hospitalised prison patients. Institutional influences of security and control challenged the provision of equitable EoLC for people experiencing incarceration. Further research is required to inform, and incorporate, best approaches to identifying patient wishes and advance planning into care within, or despite, the constraints of incarceration. Policy reform and a coordinated, best practice approach to the management of EoLC for people experiencing incarceration is needed. **Abstract (w. references):** <https://bit.ly/3n9WEP7>

## [Prison Healthcare Services](#)

### **Motivation and training needs of prison healthcare professionals: Findings from a qualitative study**

*BMC PSYCHOLOGY* | Online – 20 May 2023 – Healthcare in prison is a challenging task. The conditions of imprisonment create distinct difficulties for those providing healthcare in this setting. These particular circumstances have led to a shortage of quality professionals, working for the health of imprisoned people. The aim of this study is to elaborate reasons for healthcare professionals to work in a prison environment. The main research question is: why do healthcare workers choose to work in prisons? This study identifies training needs in various fields ... [and] ... points out the need for more specific training programs for healthcare workers in prison and provides suggestions to ameliorate the recruitment and education for future prison healthcare workers. **Full text:** <https://bit.ly/45h1wDL>

Page | 4

#### **Related:**

#### **Caring for the convicted: The challenges of nursing on the inside**

*NURSING IN PRACTICE* | Online – 3 October 2022 – At the start of September, there were 81,245 people serving out prison sentences in the U.K. According to the latest report from the Prison Reform Trust this number is expected to increase by a further 18,000 by 2026. An increase in older prisoners means nurses are likely to manage larger and more complex workloads. This is the case for Deanna Mezen, an advanced clinical practice nurse and palliative care expert... **Full text:** <http://bit.ly/3Kn6w16>

#### **The perceptions of healthcare professionals on the provision of palliative and end-of-life care in prisons**

*ANNALS OF ONCOLOGY*, 2022;33(7):S1359. The health of incarcerated individuals is worse than the general population. They are at greater risk of developing life-limiting and chronic conditions, which require palliative and end-of-life care (EoLC). Understanding healthcare professionals' perceptions of challenges and practicalities around providing palliative and EoLC in prisons is key to advance the state of services. **Abstract (of conference paper):** <https://bit.ly/3nzeoUo>

## [Compassionate Release](#)



### **Terminal illness and compassionate release: Lessons for the International Criminal Court from the United Nations tribunals and national jurisdiction**

*JOURNAL OF INTERNATIONAL CRIMINAL JUSTICE* | Online – 2 April 2023 – The practice of granting compassionate release is not new in international criminal law. Persons convicted by the Nuremberg Tribunal and imprisoned in Spandau Prison, Berlin, were granted early release following a diagnosis of terminal illness. Compassionate release is “an ethical and just response to managing terminal illness” in custodial contexts. Despite this, neither the UN Tribunals nor the ICC’s legal framework contain an explicit right or procedure to grant compassionate release to terminally ill prisoners. This lacuna has created legal obstacles for seriously ill prisoners who had not served the required amount of time to be considered for typical early release. **Full text:** <https://bit.ly/3ZHtuVI>

#### **Related:**

#### **Relieving the Crisis of Dying in Prison: Medical Release Reform**

THE OREGON JUSTICE RESOURCE CENTER (U.S.) | Online – March 2023 – In-custody deaths are cruel and inhumane experiences for the individuals affected and their loved ones, they are taxing and traumatic for the staff and volunteers tasked with providing end-of-life care and services, and they require extensive financial costs to taxpayers that could be mitigated by allowing those in custody to seek care and comfort outside of prison during their final days. **Download at:** <https://bit.ly/3V6xvSx>

## [Care Planning](#)

### **Illinois officials obtained do-not-resuscitate orders from prisoners who were not of sound mind**

NATIONAL PUBLIC RADIO (U.S.) | Online – 3 April 2023 – Alan Mills, executive director of the Uptown People’s Law Center and a lawyer on the lawsuit over healthcare, said the aging and ailing population is fallout from the tough-on-crime era of the 1990s, which put more people behind bars for longer periods of time. But he says the department is not equipped to care for this population or provide end-of-life counseling. “We don’t have anybody who sits down with somebody who’s beginning to deteriorate in health and say: ‘Okay, this is what’s going to happen to you. This is what we can do. How much of this do you want? How much of this don’t you want?’ And make an overall plan for the last couple of years of somebody’s life. <http://bit.ly/3m7F4v2>

Page | 5

#### **Related:**

#### **Medical orders for life-sustaining treatment in correctional settings**

*JOURNAL OF CORRECTIONAL HEALTH CARE* | Online – 1 August 2022 – Decisions regarding end-of-life care ... are important because medical interventions can prolong life expectancies despite the chronic or terminal nature of an illness, yet at the cost of pain and suffering and with no promise for recovery. People who are incarcerated are less likely to be offered or participate in advance care planning or to document treatment preferences and might not have a surrogate if one is needed. **Full text:** <https://bit.ly/3AAOpil>

## [Grief & Bereavement](#)

### **Depression among incarcerated persons following the death of a loved one: Does social support mitigate grief?**

*DEATH STUDIES* | Online – 17 March 2023 – The death of a loved one generates adverse and potentially damaging consequences for surviving family members and friends. The challenges of bereavement can be especially severe when experienced by incarcerated persons who must cope with and grieve the death while incarcerated. Yet, limited research evaluates bereavement among incarcerated persons and whether factors such as social support buffer against health-related consequences. Using data from the LoneStar Project – a study of 802 incarcerated men in Texas – the authors examine depressive symptoms among currently incarcerated persons with differential exposure to a loved one’s death (i.e., immediate family, friends, extended family). **Abstract:** <https://bit.ly/3zihn6p>

## [Medical Assistance in Dying](#)

### **Ethical considerations regarding mental disorder and medical assistance in dying (MAiD) in the prison population**

*MEDICINE, SCIENCE & LAW* | Online – 26 December 2022 – Medical assistance in dying (MAiD) has rapidly advanced in Canada in recent years including its use within prison populations. There are considerable challenges when treating inmates with mental health needs. Although there can be little argument that there should be equivalence in access to MAiD for prisoners with terminal conditions, the expansion of MAiD include “mental disorders as the sole underlying medical condition” MDSUMC calls for careful appraisal. In applying MDSUMC to prisoners, there is a high risk of misinterpreting loss of hope caused by situational hardships and insufficient therapeutic opportunities in prisons with psychiatric conditions that may otherwise be remediable. **Full text:** <https://bit.ly/3z2RIDY>

## Selected Resources

AUSTRALIA | Palliative Care in Prisons Project (University of Technology Sydney): <https://bit.ly/32GrcOy>

AUSTRALIA | University of Melbourne: <https://bit.ly/3eqeVh9>

CANADA | Office of the Correctional Investigator: <https://bit.ly/3Y1td0h>

EUROPE | European Association for Palliative Care Task Force: Mapping Palliative Care for People in Prisons: <https://bit.ly/3NRvjg6>

EUROPE (Belgium) | End-of-Life Care Research Group (University of Ghent): <https://bit.ly/3OuX23v>

EUROPE (Switzerland) | Prison Research Group (University of Bern): <https://bit.ly/42gerD2>

U.K. | International Observatory on End-of-Life Care (Lancaster University): <https://bit.ly/3AlpfWa>

U.K. | Palliative & End-of-Life Care Research Group, University of Bristol: <https://bit.ly/3KxsuyR>

U.K. | Penal Reform International: <https://bit.ly/3leePJ4>

U.S. | Hospirus Health Hospice Prison Program: <http://bit.ly/3TXY9w8>

U.S. | Humane Prison Hospice Project: <http://bit.ly/2VLRkTK>

U.S. | Louisiana-Mississippi Hospice & Palliative Care Organization: <http://bit.ly/3Ko9DWQ>

U.S. | National Prison Hospice Association: <http://bit.ly/43g4MvO>

U.S. | Prison Fellowship: <https://bit.ly/3AdWQkQ>

U.S. | Prison Policy Initiative <https://bit.ly/425vyb0>

U.S. | University of Minnesota (School of Nursing): <http://bit.ly/41IGbGi>

U.S. | The Visiting Room Project, Louisiana State Penitentiary <http://bit.ly/3MaNpsv>

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**Biosketch:** <https://bit.ly/3XMTRs4>