End-of-life Care in the Prison Environment (Supplement #2)



Photo Source: Prison Terminal

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THE LAST UPDATED BACKGROUNDER, 'End-of-Life Care in the Prison Environment,' was posted on the Palliative Care Network website in August 2022; access at <u>https://bit.ly/3JkYGVg</u>. Occasional "supplements" listing selected articles, reports, etc., published in the literature and in the news media will be posted on this website: #1 (July 2023) <u>https://bit.ly/3QGRyXC</u>; #2 (September 2023)...

Aging Prison Populations

The aging prison population: Causes, costs, and consequences

PRISON POLICY INITIATIVE (U.S.) | Online – 2 August 2023 – New data from the Census Bureau reveals that the U.S. median age rose to a high of 38.9 years: an increase of three and half years in the last 23 years. The U.S. prison population is aging, too, and at a much faster rate than the nation as a whole – and older adults represent a growing portion of people who are arrested and incarcerated each year. The aging of the prison population is the result of a series of disastrous policy decisions in policing, sentencing, and re-entry over roughly the last half-century. And while prisons and jails are unhealthy for people of all ages, older adults' interactions with these systems are particularly dangerous, if not outright deadly. **Full text:** https://bit.ly/3KRw6eE

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Aging and dying in prison: An investigation into the experiences of older individuals in federal custody

OFFICE OF THE CORRECTIONAL INVESTIGATOR (Canada) | Online – Accessed 24 July 2023 – Prisons were never intended to be nursing homes, hospices, or long-term care facilities. Yet increasingly in Canada, they are being required to fulfill those functions. The proportion of older individuals in federal custody (those 50 years of age and older) is growing. They now account for 25% of the federal prison population (3,534 individuals 50+; 3,432 men and 102 women of a total prison population of 14,004). This demographic has increased by 50% over the last decade alone. Rising correctional healthcare costs, palliative care, and higher incidence of chronic disease reflect, at least in part, the impacts of a population that is aging behind bars. **Download report at:** https://bit.ly/3Y1td0h

Prison Healthcare Services

Volunteering in prisons: A systematic review and narrative synthesis

PUBLIC HEALTH, 2023;220(July):155-164. Prison volunteers may be an under-utilised resource, especially as effective volunteer programmes within prisons may provide many forms of support to the prisoner, leading to better health outcomes in the long-term. This article describes the motivations of prison volunteers, the benefits gained from volunteering experiences, highlighting the importance of the role. Commonly reported challenges of the volunteer experience point to areas of improvement for volunteer programmes, including needing formal induction, being more closely integrated with the paid prison staff, and having opportunities for ongoing supervision. The volunteer role needs to be promoted and appropriately supported... **Full text:** https://bit.ly/46MpqYH

Health care in U.S. correctional facilities - a limited and threatened constitutional right

NEW ENGLAND JOURNAL OF MEDICINE, 2023;388:847-852. The U.S. Constitution does not guarantee a right to health care. Yet since 1976, the Supreme Court has held that deliberate indifference to the serious medical needs of incarcerated people ... violates the Eighth Amendment's prohibition against cruel and unusual punishment. What this right means in practice, however, is far from settled, given that the standards for "deliberate indifference" and "serious medical need" are subject to judicial interpretation. Lacking quality standards, robust monitoring, and funding from public medical insurance programs, correctional administrators must provide health care for incarcerated people with limited guidance and often scarce resources. **Full text:** <u>https://bit.ly/3Lck13Y</u>

End-of-Life Care in Prisons

Death in prison through a philosophical equity-informed lens

PALLIATIVE & SUPPORTIVE CARE | Online – 6 September 2023 – Despite international recognition of the importance of palliative care as a shared universal right, a health equity gap exists between Canada's general and carceral populations. Incarcerated people face unparalleled health inequities before, during, and post-incarceration. While the nursing discipline made advances in recognizing the detrimental effects of social determinants on health, the specifics of inequalities faced by terminally ill prisoners remain hidden from the public view. In addition, the public and healthcare providers often impart judgment on prisoners and regard such individuals as unworthy of equitable healthcare. The authors explore death in prison from a social justice perspective. Full text: https://bit.ly/44Lnn4K



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"It's where we're at right now"

U.S. prison system struggling to keep up with growing need for palliative care

HOSPICE NEWS (U.S.) | Online - 10 August 2023 - Individuals in prison environments often have limited access to palliative care (PC) services, making these patients among the hardest to reach for providers. Labor pressures amid growing demand represent the largest barriers in terms of both limited staffing volumes and high workforce costs. Many incarcerated seniors who could benefit from PC do not receive adequate access or referrals to these services, according to Katherine Supiano, associate professor in the College of Nursing at the University of Utah. "We're facing a backdrop in which a lot of people with serious illness are disproportionately represented in our jails and prisons," Supiano told Palliative Care News. "And that is just unconscionable, but it's where we are at right now...." Full text: https://bit.ly/454mh5d

Related:

How many hospice programs exist in prisons

PRISON INSIGHT (U.S.) | Online - 16 June 2023 - Providing end-of-life care in a prison setting presents unique challenges... Correctional facilities may have limited resources, staff shortages, or inadequate training in palliative care. Furthermore, security concerns and logistical problems can make it difficult for family members, volunteers, or outside medical professionals to visit the dying inmate. There are also ethical considerations that must be taken into account when providing hospice care in a prison. Full text: https://bit.ly/300cs1P

Caring for people in prison with palliative and end-of-life care needs

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE, 2023;17(3):224-230. Few countries have integrated prison hospices. Palliative care (PC) needs may go unrecognised in prison. Older offenders may not trust the prison to care for them and may benefit from segregation. Peer carers can provide reliable symptom assessment. Family members are often absent when someone dies in prison. Palliative and end-of-life care in prisons requires a joined-up approach, and staff must understand the challenges of both this and custodial care in general. The relational network both inside and outside of the prison should be involved, and when possible and appropriate, we should consider alternatives to dying whilst incarcerated, such as compassionate release. Full text: https://bit.ly/44gQ6PG

The value of screening for a history of incarceration in the palliative care setting

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online - 26 June 2023 - Due to the aging of the U.S. population as a whole and limited opportunities for early release, the proportion of older people in prison continues to rise. Some correctional health systems have adopted geriatric and palliative care (PC) principles to better care for this aging population, many of whom die in prison. However, not everyone who grows old in prison will die behind bars. The authors explore existing literature that highlights the unique physical, cognitive, and psychosocial challenges that formerly incarcerated patients face. They argue that PC providers should screen for a history of incarceration to identify and address the needs of this patient population. Abstract (w. references): https://bit.ly/3r10Cvt

Nursing in Prison: Palliative and End-of-Life Care in Prison

SPRINGER | Online – 24 July 2023 – The main focus of this textbook is the provision of healthcare in the Prison Service of England and Wales, although examples are also be drawn from the U.S. and Australia. Healthcare within prison settings has changed remarkably to address the needs of the changing prison populations. This textbook provides an overview of the context of prison, prisoners, and healthcare, as well as the experiences of nurse specialists who work in this field, including adult, mental health, and learning disability nurses across primary care, mental health services, substance misuse and end-of-life care. Each chapter is written by experts within the field, including nurses who have worked or still working within the prison setting. Abstract to chapter: https://bit.ly/3DrY7Fq

Podcast

Hospice in prison: Part 1

GERIPAL | Online - 22 June 2023 - In the early 1990's, California Medical Facility (CMF) created one of the nation's first licensed hospice units inside a prison. This 17-bed unit serves inmates from all over the state who are approaching the end of their lives. A few are let out early on compassionate release. Many are there until they die. Participants in the podcast talk about the history of the hospice unit, includ-

ing how it was initially set up to care for young men dying of AIDS, but now cares for a very different demographic - the rapidly aging prison population. Participants also talk about the eligibility for the unit, what makes it run including the interdisciplinary team and the inmate peer workers, and the topic of compassionate release. Access podcast at: https://bit.ly/3gZ2Zz1

N.B. 'Hospice in Prison: Part 2' (Interview with volunteer pastoral care workers): https://bit.ly/445dWgZ

Lisa Deal updates progress underway with the Humane Prison Hospice Project

INMENLO | Online – 19 June 2023 – About 18 months ago, after working at San Quentin training groups of peer support volunteers with skills needed to support their **num** incarcerated peers nearing the end of life (EoL) – despite no prison hospice program

there - Humane was invited to work with a physician at the California Department of Corrections & Rehabilitation to develop a comprehensive, evidenced-based curriculum that could be used to train incarcerated people as compassionate EoL peer caregivers in prisons across the State. Humane's first program will launch at the California Medical Facility ... this month, with a second program launch planned in a women's prison in the fall of this year. Currently, there is no formal palliative care or hospice available for incarcerated women in the State. Full text: https://bit.ly/43OutWs

N.B. End of Life University (San Diego, CA) Podcast: Humane Prison Hospice Project with Lisa Deal RN and Fernando Murillo: https://bit.ly/3Z5yCng



The importance of developing palliative care quality indicators for the prison setting: Why now, and next steps

BMC PALLIATIVE CARE | Online - 8 June 2023 - Differences between community and prison palliative populations demographics and diagnoses, and the lack of evidence-based clinical guidelines for the prison setting mean that future development of prison palliative care (PC) indicator sets will likely require a combination of adoption of community indicators and consensus-based adaptation or development of prisonspecific PC indicators. Greater national and international collaboration would minimise duplication of effort in developing prison PC indicator sets, as is recommended in the community. However, there are no clear parameters describing how to determine which existing communitybased indicators are suitable for the prison environment... Full text: https://bit.ly/43sOmCg



N.B. Commentary on BMC Palliative Care article on University of Technology Palliative Care in Prisons Project website: https://bit.ly/44yccgi



PRISON HOSPICE PROJECT

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Compassionate Release

Dying and disabled Illinois prisoners kept behind bars, despite new medical release law

INJUSTICE WATCH | Online – 30 August 2023 – The Joe Coleman Medical Release Act was expected to have freed hundreds of terminally ill and medically incapacitated prisoners in Illinois by now. Under the act ... Illinois prisoners can request early release if they're terminally ill and expected to die within 18 months or if they're medically incapacitated and need help with more than one activity of daily living... But a year-and-a-half since the Coleman Act went into effect, an investigation by Injustice Watch and WBEZ [Radio] found far fewer prisoners have been released under the law than expected, as the medical release process has become mired in the charged politics of criminal justice reform in the post-George Floyd era. Full text: https://bit.ly/3Pnls0C

<u>Textbook</u>

Dying in Prison: The Carceral Geography of Death and Dying in Prison Custody

SPRINGER | Online – 11 May 2023 – This chapter explores the locations in which deaths from natural causes occur within the prison custody and demonstrates how the spatial contexts of these deaths in custody differ from those of other deaths and shape the possibilities for care. Particular attention is paid to four locations: the prison wing, the prison healthcare centre; the palliative care suite and hospitals or hospices to which the dying prisoner may be transferred. Research findings show the expectations of staff and prisoners associated with the carceral geography of dying and the meanings they read into the location of a prisoner. Finally, the "myth" of compassionate release to die at home is examined. **Abstract of chapter:** https://bit.ly/3slGcy1

A stepwise guide for healthcare professionals requesting compassionate release for patients who are incarcerated

INTERNATIONAL JOURNAL OF PRISON HEALTH | Online – 28 April 2023 – Compassionate release is a process that allows for the early release or parole of some incarcerated people of advanced age, with life-limiting illness, complex medical care needs or significant functional decline. Despite the expansion of State and Federal compassionate release programs, this mechanism for release remains underutilized. Health-care professionals are central to the process of recommending compassionate release, but few resources exist to support these efforts. This study describes the role of the healthcare professional in requesting compassionate release and offers guidance to help them navigate the process of preparing a medical declaration or request for compassionate release. **Full text:** https://bit.ly/3DWIdDa

Medical Assistance in Dying

A terminally ill federal inmate wants to be released so he can die outside of prison. He's been refused, so he's applying for MAiD

CTV NEWS (Canada) | Online – 24 July 2023 – After more than four decades in a federal prison, Ed Speidel is fighting for a compassionate release so he can die outside, in a halfway house, rather than in his jail cell. But after being rejected for parole and refused an appeal, he now fears he will die a painful death, struggling to breathe behind bars. "My biggest fear is dying in jail. I don't want to die in jail," said Speidel in a phone interview with CTV News from an office in the Matsqui Institution, a medium-security prison in Abbotsford, British Columbia. The 62-year-old suffers from end-stage chronic obstructive pulmonary disorder along with chronic pain and rheumatoid arthritis. Tests show his lungs have only 19 per cent function compared to healthy adults. **Full text:** https://bit.ly/44UOLxl



Please report any broken links.

Selected Resources

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

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

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

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

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

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

U.K. | Nursing in Prison (Springer Publishing): <u>https://bit.ly/30Q77KV</u>

N.B. Textbook: 'Palliative & End-of-Life Care in Prison' Chapter pp.187-210.

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

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

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

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

U.S. | National Prison Hospice Association: <u>http://bit.ly/43q4MvO</u>

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

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

U.S. | Prison Terminal https://bit.ly/2LTYv7M

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

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

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Biosketch: https://bit.ly/3XMTRs4