End-of-life Care in the Prison Environment (Supplement #7)









Source: Lori Waselchuk: "Grace Before Dying" For An Aging Prison Population: https://bit.ly/3QRHCJP

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Announcement

THE AGING PRISON POPULATION is a world-wide phenomenon, which has turned a spotlight on the quality of prison healthcare services. In particular, the issue of end-of-life care (EoLC) in prisons is gaining traction in the professional literature and increased attention in the lay press. However, keeping abreast of "current thinking" and up-to-date on the latest research is a formidable challenge.

The End-of-Life Care Behind Bars website (https://bit.ly/4bDZm3l) is a new resource, which is intended as an advocacy, teaching and research "tool" – to inform and advance a seismic shift in society's attitudes towards the incarcerated, and to effect change.

Click on 'Current Thinking" (https://bit.ly/4dJ4oO8) on the new website to download 'End-of-Life Care in the Prison Environment' – Supplements #1, #2 & #3 (July, September, November 2023) and #4, #5 # #6 (January, March, May 2024), and also the August 2022 Backgrounder on prison palliative and EoLC research and media coverage 2018-2022.

Aging Prison Populations

"Successful ageing" needs a future: Older incarcerated adults' views on ageing in prison

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Model of successful ageing for older adults in prison: https://bit.ly/4ahOpUf

Prison Healthcare Services



Dying behind bars: At least 220 people died in Ohio jails over 4 years

CINCINNATI ENQUIRER (U.S.) | Online – 1 June 2024 – A Cincinnati Enquirer, Columbus Dispatch and USA TODAY ... investigation found jail personnel ignored serious medical conditions and injuries, withheld life-saving medicine and equipment... State officials, inmate advocates and relatives of the dead say the death toll is the product of a justice system that asks Ohio's county jails to do work they are not properly staffed, prepared or funded to do. More than 75% of those who died ... had yet to be tried for the crime for which they were being held. Jails are expected to meet minimum standards and owe a "duty of care" to those in custody. But again and again, Ohio jails fall short of those basic expectations, according to inspection reports, investigative documents, lawsuits and interviews. Full text: https://bit.ly/4e1bNlx

Related:



'How are professional medical societies addressing mass incarceration and carceral health through official society policy statements and guidance?' American Journal of Respiratory & Critical Care Medicine (U.S.) | Online – 30 April 2024 – Incarcerated people often receive specialty and hospital care in the community. However, community clinicians receive little education or guidance to promote patient dignity while treating this vulnerable patient group. Abstract: https://bit.ly/3QOVMLN

'Hospitalization through the lens of incarceration,' *Journal of General Internal Medicine* (U.S.) | Online – 17 May 2024 – The effects of incarceration span specialties and each has an opportunity to champion care. The American Society of Addiction Medicine may make specific recommendations for those affected by the opioid crisis in carceral facilities, while the College of Chest Physicians could advise on communicable pulmonary diseases ... that disproportionately impact prisons. Full text: https://bit.ly/4aBANDh

'America's prison system is turning into a *de facto* nursing home,' VOX (U.S.) | Online – 6 May 2024 – Conditions in American prisons continue to be detrimental to people's health and often lead to accelerated aging. Prisoners, for example, are much more likely to exhibit signs of cognitive decline, including dementia, at an earlier age than the general population. One study found that a 59-year-old in prison has the same morbidity rate ... as a non-incarcerated 75-year-old. Full text: https://bit.ly/3Wp0vHP



'END-OF-LIFE CARE IN THE PRISON ENVIRONMENT' can also be download from the Palliative Care Network website – #1, #2 & #3 (July, September, November 2023) at https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3QGRyXC; #4 & #5 (January, March 2024) at: https://bit.ly/3RdegnL



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Investment and wide-ranging efforts are needed to improve healthcare for First Nations people in prisons

CROAKEY HEALTH MEDIA (**Australia**) | Online – 30 May 2024 – Funding Aboriginal and Torres Strait Islander health services to play a much bigger role in prison healthcare, and the provision of healing programs are critical for First Nations people in prisons, who too often receive sub-standard, poorly coordinated and culturally unsafe healthcare from mainstream services... Indigenous prison health experts also highlighted the need to challenge and rewrite harmful public and policy narratives that contribute to shocking levels of overincarceration for Aboriginal and Torres Strait Islander people and the need to transform services that inflict harm and punishment rather than delivering therapeutic care to those who have experienced racism, violence and trauma. **Full text:** https://bit.ly/3XaJ122

Related:

'Addressing a human rights crisis: Healthcare for prisoners in Australia.' JOURNAL OF LAW & MED-ICINE, 2024;31(1):42-69. People are sent to prison as punishment and not to experience additional punishment. Nevertheless, this principle is habitually violated in Australia: prisoners frequently receive healthcare that is inferior to healthcare that is available in the general community. This article proposes law reforms to address this human rights crisis. Abstract (via PubMed): https://bit.ly/3K7VDj2

'Health care for Victoria's prisoners: Honing government obligations,' *Public Law Review*, 2024;34(4): 343-373 (Australia). This article argues that it is difficult to hold government to account for improving prison healthcare within the current legal framework. The article, therefore, proposes law reforms that would hone the Government's obligations to meet prisoners' healthcare needs and strengthen means of ensuring that it fulfils them. Abstract: https://bit.ly/3V3yAMu

Health optimization of older people in prison

HEALTHCARE MANAGEMENT FORUM (Canada) | Online – 28 May 2024 – This article examines the leadership challenges of prison healthcare, specifically focusing on the ageing inmate population. It highlights the distinct health burdens faced by this demographic, including higher disease prevalence and an accelerated ageing process. The concept of prison activities of daily living is central to addressing these challenges, emphasizing the need to tailor health assessments and care plans to the unique prisoner-environment interactions. This article advocates for inclusive person-centred care. It suggests that involving older prisoners in their care planning, aligned with the "ageing in the right place" principle, can significantly improve their quality of life. Full text: https://bit.ly/3X0wVJ4



Respect for bioethical principles and human rights in prisons: A systematic review on the state of the art

BMC MEDICAL ETHICS (Italy) | Online – 22 May 2024 – Respect for human rights and bioethical principles in prisons is a crucial aspect of society and is proportional to the well-being of the general population. These ethical principles have been lacking in prisons and prisoners are victims of abuse with strong repercussions on their physical and mental health. Prisoners ... find it difficult to access care, and have an increased risk of suicide and disability. Furthermore, they are often used as improper organ donors and have constrained autonomy that also compromises their willingness to have end-of-life treatments. In conclusion, prison staff (doctors, nurses, warders, managers) must undergo continuous refresher courses to ensure compliance with ethical principles and human rights in prisons. Full text: https://bit.ly/4au9afp



TO KEEP ABREAST OF CURRENT THINKING in hospice and palliative care check out 'Literature Search' posted each month on the website of the International Association for Hospice & Palliative Care: https://bit.ly/3WWxUYC



Healthcare governance in prisons in England: Prisoners' experiences of changes over time

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CRITICAL PUBLIC HEALTH (U.K.) | Online – 8 May 2024 – Healthcare provision in English prisons has seen several reorganisations, notably in 2006 and 2013, with the stated intentions of improving healthcare provision in prisons. This article focuses on prisoners' reported experiences over the periods of changes in healthcare governance, with the aim of identifying whether there are improvements from their perspectives. Despite the reorganisations of healthcare governance, the trends from 2003 to 2019 are of increasing health needs of prisoners and decreasing initial access, ongoing access, and quality of healthcare provision. There is little indication of any improvements experienced by prisoners from the 2006 or 2013 reorganisations. Full text: https://bit.ly/4acOZ5y

Related:

'Hopeless healthcare.' *Inside Time* (**U.K.**) | Online – 30 April 2024 – Being in prison should not affect your access to effective and positive healthcare and treatment; equal to that which you would receive in the community. You are entitled to, and indeed assured, according to policy, that you will receive the same treatments and medication, within reason, as you would receive from your local GP if you were not in prison. Not all prison healthcare is poor, neglectful, or lacking. **Full text:** https://bit.ly/3QzRs3c

'Patients diagnosed with cancer in prison more likely to die from the disease, research shows,' *MedicalXpress* (U.K.) | Online – 30 April 2024 – Patients with cancer face several barriers to diagnosis in prison and once diagnosed, they receive significantly less treatment and lower planned care costs, and report worse experiences of care. ^{1,2,3} Researchers analyzed cancer data ... and conducted interviews with cancer patients in prisons, as well as with prison and healthcare professionals. **Full text:** https://bit.ly/44uf4fl

- 'Cancer in prison: Barriers and enablers to diagnosis and treatment,' eClinicalMedicine, 19 April 2024. Full text: https://bit.ly/3y3ThyY
- 2. 'Cancer incidence, treatment, and survival in the prison population compared with the general population in England...,' *The Lancet Oncology*, 2024;25(5):553-562. **Full text:** https://bit.ly/3UIAaTE
- 'Does the cost of cancer care for people in prison differ from those in the general population? Analysis of matched English cancer registry and hospital records,' eClinicalMedicine, 29 April 2024. Full text: https://bit.ly/4bl0DMI

'Supporting older, frail, and vulnerable adult prisoners through peer care: Observations, reflections, and recommendations based on a U.K./U.S. researcher exchange visit,' *JOURNAL OF CORREC-TIONAL HEALTH* | Online – 29 April 2024 – The researchers identified several differences and similarities in peer caregiving between U.K. and U.S. sites and detail six recommendations related to policy and practice concerning both sides of the Atlantic. Access full text at: https://bit.ly/4buryWs

Addressing challenges in the management of long-term conditions in prisons

PRIMARY HEALTH CARE (Northern Ireland) | Online – 4 April 2024 – The prison population is disproportionately affected by risk factors for long-term conditions, has greater healthcare needs than the general population and is, overall, increasing and ageing. There are multiple challenges to the management of long-term conditions in prisons, including a disjointed healthcare system, a focus on security, a lack of health promotion, limited scope for prisoners to self-manage their conditions and limited budgets, staffing and training. This article describes the challenges in the management of long-term conditions in prisons and discusses how these can be addressed through a more joined-up approach, better health promotion, and prisoner engagement and improved staff training. **Abstract:** https://bit.ly/4dKqHCK



End-of-Life Care in Prisons

"I'm somebody that nobody thought I could be."

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CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION | Online – 4 June 2024

- The concept of ... "prison hospice" is being adopted by a relatively small number of institutions in several countries. These initiatives are consistent with the philosophy and practice of hospice and palliative care: improving the quality of end-of-life



care for the incarcerated and recognizing the potential capacity of correctional facilities to help rebuild – not destroy – souls. As one prison hospice volunteer has remarked: "I'm somebody that nobody thought I could be." Where volunteer inmates have been trained to care for those living with a terminal illness, prison hospice (has also served to work against the sense that the incarcerated are of little or of having no value. Full text: https://bit.ly/4e5Y1EF

Webinar



Palliative care in prisons

ALL IRELAND INSTITUTE OF HOSPICE & PALLIATIVE CARE | Online - Accessed 14 May 2024 - Prof. Audrey Roulston, Senior Lecturer at Queen's University Belfast, Northern Ireland, is the presenter in this webinar. Dr. Roulston was lead author of an important study that concluded that prison hospice and end-of-life care are commonly under-resourced, with high levels of unmet need. 1 To meet the unmet social care needs of prisoners, who anticipate dying in prison, and their relatives, the authors tabled nine recommendations, for example: all staff need training on how to promote social justice and human rights; and, early release schemes should be reviewed and offered where prison hospice care is under-resourced or unavailable.

Filming Death: End-of-Life Documentary Cinema

EDINBURGH UNIVERSITY PRESS (**U.K.**) | Online – Accessed 17 May 2024 – For the dying subjects, participation in end-of-life documentaries where the narration is based on their life stories provides a venue to build their personal and public legacies. The filming of 'Prison Terminal: The Last Days of Private Jack Hall' (2013) serves as a possibility to reconcile his troubled identity and ask for social redemption in front of the public. **Contents Page:** https://bit.ly/4bnfVkz

N.B. Scroll down to Section II, click on pdf icon, scroll down to pp.137-141; 'Prison Terminal...' website: https://bit.ly/2LTYv7M

Download at: https://bit.ly/3K0eGvr

1. 'Deaths in prison custody: A scoping review of the experiences of staff and bereaved relatives,' *British Journal of Social Work*, 2021;51(1):223-245. **Full text:** https://bit.ly/3UWnw3A

Case Study

Psychological distress among caregivers for patients experiencing end of life while incarcerated

JOURNAL OF PAIN & SYMPTOM MANAGEMENT (U.S.) | Online – 18 April 2024 – Throughout admission, the patient repeatedly voiced her experiences of psychological pain and distress. The interdisciplinary care team experienced moral distress given perceived conflict in maintaining ethical conduct, patient rights, and patient dignity while abiding by rules and regulations set by corrections department. Compassionate release was discussed by the hospice team given the patient's metastatic disease and prognosis with initial pushback from patient's correctional team given several arrest warrants in various counties throughout the state. The patient was ultimately granted compassionate release while still admitted to inpatient hospice. Abstract: https://bit.ly/3wW9sxZ

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Grief & Bereavement

Teaching prisoners lead grief support groups

PSYCHOTHERAPY.NET (U.S.) | Online - Accessed 30 May 2024 - Most people are unaware that many prisons in the U.S. have hospice programs. What makes them unique is that they utilize select inmate Page | 6 volunteers to serve as caretakers for the dying. The prisoners go through extensive vetting with the hospice staff, current volunteers, and the prison wardens. Once chosen, they become a part of the care team along with the doctors, nurses, and clergy. Most recently, four psychiatry residents from Tulane Medical School were part of a new program that trained 31 caregiver-inmates at four different prisons in Louisiana to facilitate in-house grief groups. The goal was to teach a select group of incarcerated individuals to lead grief support groups for their peers. Full text: https://bit.ly/3X2XLAb

Breaking barriers: New bereavement protocols for incarcerated individuals

JUSTICE DEFENDERS (Kenya) | Online - 21 May 2024 - A judge in Kenya recently ruled that incarcerated individuals and pre-trial detainees have the right to attend the burials of close family members unless there are compelling reasons to deny such permission. In his judgment, he emphasised that this right is anchored in the principle of human dignity. However, the court noted that this right is not absolute and must consider factors such as previous escape attempts or a propensity for violence by the prisoner. This landmark ruling in Kenya ensures that thousands of incarcerated individuals will now benefit from established bereavement protocols, allowing them the chance to bury their loved ones. The petition's outcome significantly uplifts the welfare of pre-trial detainees and prisoners... Full text: https://bit.ly/3yW6k5C

Care Planning & Serious Illness Conversations



Advance care planning: Perspectives of people living in prison

JOURNAL OF HOSPICE & PALLIATIVE NURS-ING (U.S.) | Online - 29 April 2025 - Key themes regarding advance care planning (ACP) were identified: components of ACP, initiation and continuation of ACP, barriers to implementing ACP, and facilitators to implementing ACP. Participants noted several key components related to the name, structure, and content of ACP programs. Insights about who should initiate the conversation, when to continue the conversation, and how to deliver education about ACP were obtained. Findings contribute to identifying best practices for infusing ACP into prisons. Best practices will inform the development of a toolkit of contextually relevant, person-centered approaches to ACP that are tailored to meet the unique needs of people who are incarcerated.

Abstract: https://bit.ly/3UF5liM

End-of-life ethical considerations for children of parents who are incarcerated

JOURNAL OF PAIN & SYMPTOM MANAGEMENT (U.S.), 2024;67(5):e659. This case highlights the importance of including incarcerated parents in medical decision making and end-of-life care for their children and well as touches on the potential for additionally complex grief for the incarcerated parent whose child dies. Accommodations are often made for dying inmates but unfortunately, in the case profiled here, not made for the parent of a dying child. More advocacy work may be needed to promote such accommodations. Conference abstract: https://bit.ly/3yjcSeu

Compassionate Release

Revisiting compassionate release: The sentencing commission's compassionate changes to the 2023 Compassionate Release Policy Statement

CLEVELAND STATE LAW REVIEW (U.S.) | Online – Accessed 6 May 2024 – The Sentencing Reform age | 7 Act requires the Sentencing Commission ... to describe "extraordinary and compelling reasons" warranting compassionate release (CR). However, the Commission's failure to convene as a quorum for nearly four years precluded any policy statement updates. In that time, the COVID-19 pandemic and the Bureau of Prisons' internal issues further complicated the CR process. This Note analyzes the 2023 amendment to the compassionate release policy statement, its potential implications, and suggests additional steps to be taken through effective use of the policy statement Commentary to aid district courts in deciding what constitutes an extraordinary and compelling reason CR. Full text: https://bit.ly/3y77Npz

Related:

Expanding compassionate release: A solution to Louisiana's large and aging prison populace, 'LSU LAW JOURNAL FOR SOCIAL JUSTICE & POLICY (U.S.), 2024;4. There is no "one-size-fits-all" approach that would completely abate the "grey tsunami" in the prison system. Inevitably, some elderly offenders released through compassionate release programs will re-offend, some geriatric inmates will die in prison, and others will end up caught in bureaucratic red tape. **Full text:** https://bit.ly/3Uxq0nw

Assisted Dying Practices

Assisted death for prisoners and forensic patients: Complexity and controversy illustrated by four recent cases

BJPSYCH BULLETIN (Canada) | Online – 6 May 2024 – There has been debate about the extent to which prisoners should have access to medical assistance in dying (MAiD) among those countries where MAiD is permitted. The arguments in favour of allowing access have often been centred on self-determination and equivalence of care. Rule 24 of the United Nations Standard Minimum Rules for the Treatment of Prisoners ... articulates that prisoners should enjoy the same standard of healthcare as available in the community. The authors describe four cases that raise questions about the complexity of voluntariness when the person is incarcerated and the issues of wider demands of justice. All material in these case summaries is from public records. Full text: https://bit.ly/4b1D7EE

From the Archives

Palliative and end-of-life care in prisons: A mixedmethods rapid review of the literature from 2014-2018

BMJ OPEN (**U.K.**) | Online – 21 December 2022 – Many of the key findings of this review reinforce points made in the Wion and Loeb review, ¹ such as the value of inmate hospice volunteers and the physical barriers presented by the prison environment. Other findings which were relatively minor in the previous review have become major themes in the literature published since 2014, such as the importance of maintaining family relationships, and the potential grief burden of inmate hospice volunteers. Finally, this review adds the main finding that relationships both inside and outside of prison are of importance to prisoners at the end of life, and recommends that those involved in their care should support prisoners to maintain these relationships. **Full text:** https://bit.ly/2PTCRR2

'End-of-life care behind bars: A systematic review,' American Journal of Nursing (U.S.), 2016;116(3):24-36. Abstract: https://bit.ly/4bzMon8



Caring, sharing, preparing and declaring: How do hospices support prisons to provide palliative and end-of-life care?

PALLIATIVE MEDICINE, 2020;35(3):563-573 (U.K.).

The typology presented describes the ways that hospices in Scotland engage with prisons in Scotland.

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This typology is of international relevance, particularly to the many countries who have not established hospitality.

Does your hospice have any links with a local prison?

Has your hospice provided any advice or consultation to a local prison?

Has your hospice had any prisoners as inpatients over the last 24 months?

pices within their respective prison systems. The ongoing mapping exercise being conducted by the European Association for Palliative Care taskforce suggests that many countries are similar to Scotland in that they do not operate prison-based hospices. This study is one of the first to describe an alternative model, one which relies on close collaboration between multiple agencies and individuals to balance the palliative care needs of the person at the end of life with the necessary functions of a criminal justice system. Full text: https://bit.ly/3a1Ejv9

Balancing punishment and compassion for seriously ill prisoners

ANNALS OF INTERNATIONAL MEDICINE, 2022;155(2):122-126 (**U.S.**). Determining medical eligibility [for compassionate release] ... is a medical decision and falls within a physician's scope of practice. Moreover, many states are considering expanding medical eligibility to include physical incapacity and elderly prisoners, in addition to terminal diagnoses. Physicians and other medical professionals have an opportunity to use their unique expertise and knowledge of prognosis, geriatrics, cognitive and functional decline, and palliative medicine to ensure that medical criteria for compassionate release are appropriately evidence-based. Using this medical foundation, criminal justice professionals can balance the need for punishment with an eligible individual's appropriateness for release. **Full text:** https://bit.ly/3QRtBvS

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