End-of-life Care in the Prison Environment (Supplement #13)



Source: 'Grace Before Dying': <u>https://bit.ly/3QRHCJP</u>

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Aging Prison Population

Who cares? A consultation on ageing and lost milestones in prison

PRISON REFORM TRUST (**U.K.**) | Online – 25 November 2024 – A key cross-cutting issue is the need to create a prison environment suited to older prisoners. Older prisoners should be in the care of people who understand them. Whilst attitude is not really something you can teach, training has merit. The current problem is that staff training covers how to deal with both the average and the unruly prisoner, but does not cover how to work with an ageing population with different mental and physical health requirements. This was summed up perfectly by an officer who said "I signed up to be a prison officer, not an old people's home attendant." There is a need for operational wing officers to be trained in identifying and meeting the needs of an older prisoner. **Download report at:** https://bit.ly/497Bzcj

Related:

'The construction of intolerable punishments: On the value of documenting the pains of old prisoners,' *Theoretical Criminology* (**U.K.**) | Online – 8 November 2024 – Geriatric inmates are more likely to experience dementia, impaired mobility, and loss of hearing and vision... Older inmates are usually in worse health than their counterparts outside prison because they develop health issues much earlier due to their previous lifestyle, socioeconomic factors, and the prison environment. **Full text:** <u>https://bit.ly/3Aw08mh</u>

'A Long Stretch: The challenge of maintaining relationships for people serving long prison sentences,' Prison Reform Trust (**U.K.**) | Online – 6 November 2024 – The Justice Committee has highlighted the distinct health and social care needs of older people due to the prevalence of health conditions, disability, decreased mobility and sensory impairment. ¹ These needs include palliative and end-of-life care (50% of those who die in prison are older people). **Download report (scroll down to p.24) at:** <u>https://bit.ly/40y80yh</u>

 'Ageing prison population,' House of Commons Justice Committee, July 2020. Download the report at: <u>https://bit.ly/40ANhtu</u>

Prison Health Services

Attitudes toward voluntary assisted dying for people in prison in Australia

DEATH STUDIES | Online - 29 November 2024 - End-of-life care options in Australia, recently Page | 2 including voluntary assisted dying (VAD), are available to people in prison. Little is known about how the public perceives this right. The authors aimed to identify the attitudes of the public by conducting a qualitative content analysis of comments across four Australian online news media outlets discussing the first case of a person in prison being granted VAD... Most comments were punitive, highlighting the opinion that VAD was escaping punishment and reflected a tension between the rights of the individual versus the perceived rights of the community. The authors highlight the risks these attitudes can pose in terms of providing end-of-life care to people in prisons. Abstract https://bit.ly/49iMtvF

Moral injury in correctional healthcare

JOURNAL OF CORRECTIONAL HEALTH CARE (U.S.) | Online – 8 November 2024 – This qualitative study ... offers insights into the prevalence and effects of moral injury in correctional healthcare while offering solutions to navigating moral injury. These findings contribute to a deeper understanding of the complex ethical and psychological dynamics within correctional healthcare settings and explore implications for practice, policy, and future research. Abstract (w. references): https://bit.ly/4ehOrxi

Resource: 'Assisted Dying Practices," International Association for Hospice & Palliative Care: <u>https://bit.ly/4cKSgLh</u>

Related:

'Life without parole and euthanasia: The future unintended consequences of current sentencing policies,' *Punishment & Society* (U.S.) | Online – 8 November 2024 – Canada and some European nations have authorized different forms of medically assisted death... These rights have been extended to the incarcerated... The authors provoke a discussion of the ethical and legal aspects of these two controversial policies by asking which is worse "life" or death. Abstract (w. references): https://bit.ly/3AyxCjT

United Nations Office on Drugs & Crime champions prison healthcare reforms

UNITED NATIONS INDIA (India) | Online – 29 November 2024 – Investing in prison healthcare is an investment in safety, and social progress. Effective prison healthcare not only improves the lives of inmates but also safeguards public health when they reintegrate into society. Recognizing this critical need, United Nations Office on Drugs & Crime ... hosted prison administrators, healthcare providers, and policymakers at a consultation to enhance prison healthcare... A highlight of the event was ... an interactive toolkit designed to educate prison staff on the United Nations' Nelson Mandela Rules (<u>https://bit.ly/3VePMOQ</u>) guiding healthcare in prisons. Participants engaged in a practical session featuring case studies and role-play exercises Full text: https://bit.ly/3Ou9XEL

Council of Europe supports discussion of best practice and standards of healthcare in prisons

COUNCIL OF EUROPE (**Republic of Moldova**) | Online – 25 November 2024 – National stakeholders in the Moldova were presented with a detailed analysis of prison healthcare models from various Council of Europe member states. The Analysis investigated the ways of optimising the governance, organisation, and management of healthcare in prisons and is a first step in supporting national stakeholders in getting a better understanding of the benefits and the challenges of transferring the responsibility for prison healthcare from the Ministry of Justice to the Ministry of Health. It will help coordinate the efforts of the Moldovan authorities to strengthen independence of medical professionals and align the standards of medical services in prisons with those in community at large... **Full text:** https://bit.ly/4eRuSw0

N.B. See 'Governance of Prison Healthcare: "People in prison exist in a twilight zone between criminal justice and health systems." <u>https://bit.ly/3Yu8xzL</u>

Healthcare provision in prisons: Continuity of care

HEALTH SERVICES SAFETY INVESTIGATIONS BODY (U.K.) | Online – 28 November 2024 – This investigation focuses on the continuity of care for patients in prison. In the context of this investigation, "continuity of care" means maintaining a patient's healthcare throughout the prison system regardless of their location. The investigation considered the movement of patients between prisons, to and from court, and on release. This is the second of a series of reports on the theme of healthcare provision in prison. These investigations were launched after discussions with 26 national organisations across the healthcare and justice systems, through which Health Services Safety Investigations Body gained knowledge of their concerns about healthcare in prisons. Download report at: https://bit.ly/418P21A

Related:

'Understanding and improving the quality of primary care for people in prison: A mixed-methods study,' *Health & Social Care Delivery Research* (U.K.) | Online – 11 November 2024 – The quality of prison healthcare is complex and multifactorial... Both people who had been in prison and staff highlighted how the organisational-level factors of understaffing and poor skill mix undermine healthcare delivery, which then becomes reactive and crisis-led. **Download at (click on pdf icon):** <u>https://bit.ly/3USRSUd</u>

Preliminary evaluation of a novel Aboriginal communitycontrolled prison health service for First Nations people

AUSTRALIAN & NEW ZEALAND JOURNAL OF PUBLIC HEALTH | Online – Healthcare in Australian prisons is provided by the Health or Justice Department or is contracted to a private provider with department oversight. The prison provides an opportunity to address complex health needs in a vulnerable and disadvantaged population that is typically harder to reach... Aboriginal community-controlled organisations can provide high quality, culturally safe health and wellbeing services for First Nations people in prison. The results of this study support the trial of similar community-controlled services in other jurisdictions around Australia, whilst future research may seek to consolidate the evidence base for this novel model of care. Full text: https://bit.ly/30lpHcW

Cancer mortality in Louisiana's correctional system, 2015-2021

JAMA NETWORK OPEN (U.S.) | Online – 20 November 2024 – Human rights, healthcare disparities, economics, and public policy intersect when evaluating mortality in incarcerated populations. With increasing medical costs, it is critical to evaluate the quality and costs of healthcare associated with terminally ill incarcerated individuals. The cancer-specific mortality rate among incarcerated individuals in Louisiana was higher than the national rate but lower than the state's, with the majority of these deaths occurring among those older than 55 years. Medical compassionate release remains an underutilized option, and the effect of providing a dignified death for families, healthcare professionals, incarcerated individuals, payers, and policymakers needs further evaluation. Full text (click on pdf icon): https://bit.ly/3ATz4xy

Establishing national standards for carceral healthcare: The Federal Prison Oversight Act

JAMA INTERNAL MEDICINE (U.S.) | Online – 18 November 2024 – While imprisoned, unhealthy and unsafe conditions compound existing health disparities resulting in excess morbidity and a 2-year decrease in life expectancy for each year served. Carceral conditions also negatively affect the health of facility staff, with correctional officers experiencing elevated rates of posttraumatic stress disorder, traumatic injury, and suicide. With 95% of incarcerated individuals eventually returning to our communities and tens of thousands of employees cycling through carceral facilities daily, prison health is public health. Abstract: https://bit.ly/3ZbaL7v

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'Talking about incarceration history: Engaging patients and healthcare providers in communication,' *Journal of General Internal Medicine* (U.S.) | Online – 31 October 2024 – Despite the longstanding history of incarceration in the U.S. and associated challenges faced by individuals and communities most directly impacted, healthcare providers often lack specific training on how to effectively care for patients who have experienced incarceration. **Full text:** <u>https://bit.ly/3AFkVUi</u>

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Understanding health and illness among incarcerated persons in the Slovenian correctional system: A qualitative study

SOCIAL SCIENCE & MEDICINE (Serbia) | Online – 7 November 2024 – The aim of this study was to explore and understand the complex, multi-dimensional experiences of health and illness among incarcerated persons within the Slovenian correctional system. Four major themes were identified: 1) Perspectives on health and illness during incarceration; 2) Healthcare access and self-care during incarceration; 3) Social contacts and their impact on health; and, 4) Programmes and activities to enhance well-being. The findings highlighted a shift in perception among participants from a traditional view of health as merely the absence of illness to a more dynamic and holistic understanding, encompassing physical, mental, and social determinants of health. Full text: <u>https://bit.ly/48B5U2x</u>

Perceptions of prison health care delivery in Western Canadian prisons

HANDBOOK ON CONTEMPORARY ISSUES IN HEALTH, CRIME & PUNISHMENT (Canada) | Online – Accessed 7 November 2024 – Prison healthcare is often described as substandard and reduces the quality of life for those experiencing incarceration. However, examining incarcerated peoples' perceptions of prison health care reveals specific nuances on the topic. A substantial minority of [study] participants describe prison healthcare as a positive part of their experience, specifically detailing its impact on substance use and chronic health problems. Participants describe gaps in prison healthcare, with a specific focus on medication provision and communication. Participants describe prison healthcare as a form of capricious governance, which increases the pain of incarceration. Abstract: https://bit.ly/3UUC5V0

End-of-Life Care in Prisons

Redefining palliative and end-of-life care in prisons

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (U.S.) | Online - 19 November 2024 - A project based in California is looking to transform the way people die in prison through education, advocacy and training to support their peers as caregivers and grief companions. The Humane Prison Hospice Project program is not just about teaching and reinforcing valuable skills - it's about transforming lives ... [and in the belief] ... in the power of human connection and the idea that all people, regardless of their circumstances, deserve to be treated with empathy and respect - especially during their final days. By empowering incarcerated individuals to provide compassionate care to their peers, "we are not only changing the way end-of-life care is delivered in the prison system but fostering a sense of solidarity and humanity in an unlikely environment." Full text: https://bit.ly/3AXfMaj

Nebraska Department of Correctional Services launches hospice care volunteer program

NEBRASKA DEPARTMENT OF CORREC-TIONAL SERVICES (**U.S.**) | Online – 4 November 2024 – The Nebraska Department of Correctional Services has launched a program aimed at bringing transformative change to end-of-life care (EoLC) in Nebraska correctional facilities. Designed with a holistic approach to EoLC, volunteers work in collaboration with services' team members and healthcare providers to address the physical, emotional, and spiritual needs of incarcerated individuals who have a terminal diagnosis. **Full text:** https://bit.ly/3AiTK1H

N.B. The hospice program is described in detail in the 2024 annual report of the Office of Inspector General of the Nebraska Correctional System (scroll down to p.50): <u>https://bit.ly/3O7J3lz</u>. Video of Nebraska Department of Correctional Services program: <u>https://bit.ly/4eiHLiDT</u>.

Cont.

Related:

"They won't die alone": Lori Waselchuk on documenting hospice behind bars,' WWNO Radio (**U.S.**) | Online –20 November 2024 – The Louisiana State Penitentiary at Angola houses over six thousand men. 80 percent of them will die behind bars. An Angola hospice program trains volunteers from the prison population to care for their dying peers. From 2007 to 2009, photographer Lori Waselchuk documented the work of these incarcerated caregivers for her series, 'Grace Before Dying.' Link to interview: https://bit.ly/4fYXrlQ

Fast Facts: At least 75 of the more than 1,200 state and federal penal institutions nationwide have implemented formal hospice programs: https://bit.ly/4907IHP

The Voices of Underserved Communities in Palliative Care: Palliative care for incarcerated people

TE ĀRAI RESEARCH GROUP (**New Zealand**) | Online – Accessed 2 November 2024 – The impact of inequities on health outcomes is well established. There has been less attention paid to how these inequities impact on end-of-life (EoL) experience. In particular, the voices of people from communities traditionally underserved by palliative care rarely feature in policy and service development. Dying in prison is viewed by some as a "double punishment." For others, prison is a safe environment. Being in prison provides structure and support to have basic needs met... The resulting institutionalisation of some peoples as they move in and out of prison can mean they are unable to consider the outside world as a safe home at the EoL. **Download report (scroll down to p.13) at:** https://bit.ly/3UVgV9b

The complexity of palliative care for those in prison

CARESEARCH (**Australia**) | Online – Accessed 3 November 2024 – A growing number of prisoners will live out a large portion of their lives and eventually die in prison. Much of the literature on prisoners and palliative care comes from the U.S., and acknowledgement is needed of the differences in population and healthcare systems. However, many issues identified in the U.S. are likely to become an increasing challenge in Australia, for example:

- Many of these prisoners are aging and are more likely to have existing co-morbidities.
- Prisoners have little or no choices regarding decision-making.
- Advocacy by healthcare professionals may be difficult, and conflict with prison regulations.
- Security is seen as a priority and may restrict or delay timely access to external healthcare, as hospital transfers are costly and pose security risks.
- Issues of litigation and liability (inferring neglect) may mean prisoners are sent to hospital to die (in custody), unless they agree to a 'Do Not Resuscitate' order.
- Inmates who die in prison potentially do so alone as family visits may be limited or families may be estranged.
- In prison, family may also mean other prisoners.

- Access to compassionate leave (medical parole) varies, and is likely to be in the last few days of life.
- There can be restrictions on care delivery in prison, with limited access to urgent facilities, restriction on drugs (due to concerns about addiction) and problems with dispensing drugs (such as breakthrough medication).
- There can be restrictions on care delivery in prison, with limited access to urgent facilities, restriction on drugs (due to concerns about addiction) and problems with dispensing drugs (such as breakthrough medication).
- Prison has a certain culture of toughness. Issues such as masculine and / or cultural responses to grief, as well as prison restrictions (such as limited options for attending funerals) can have a strong impact on the ability of prisoners to resolve issues of loss and grief

If a prisoner dies while in a hospital or hospice, they are still considered to be in custody. The room the patient is in at the time of death is considered to be a crime scene and nothing must be touched including the patient, until the investigating officers have finished. The death then requires investigation by the State Coroner, who will look at the patient's treatment during the course of their illness to ensure they have received fair and equitable treatment. **Full text:** <u>https://bit.ly/3BGjohe</u>

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Research project

Saying your goodbyes in prison: Palliative care provision for people in Belgian prisons

VRIJE UNIVERSITEIT BRUSSEL (**Belgium**) | Online – 1 November 2024 – This research investigates palliative care (PC) provision for incarcerated persons in Belgium, aiming to understand their experiences, challenges and needs along with those of their families, healthcare professionals and prison officers, within a thoughtlessness institution where balancing care and custody proves challenging. The research comprises three primary objectives: 1) comprehending PC provision for incarcerated persons, gaining insight into the number of individuals in detention who require PC, their profile and the utilization of compassionate release; 2) exploring diverse experiences and challenges in delivering PC in prisons; and, 3) establishing actions for practical changes based on stakeholders' input. **Abstract:** https://bit.ly/3Z5INJ4

Grief & Bereavement

Bereavement support in prisons: Sharing hospice knowledge to upskill staff

BMJ SUPPORTIVE & PALLIATIVE CARE (U.K.) | Online – 21 November 2024 – Grief is a normal response to death that can affect everyone, but the prison environment with its logistical and security concerns can negatively impact on the grieving process. Factors associated with people in prison include high rates of trauma, multiple bereavements and mental illness. The prevailing culture of masculinity can result in disenfranchised grief and increased risk of complicated grief for the person in prison. Strathcarron Hospice developed a community of practice where prison staff could explore current models of support for bereaved inmates. This provided an opportunity for prison staff to increase their knowledge and confidence in discussions about loss and grief... Abstract: https://bit.ly/3B3OdMA

Related:

'Palliative, end of life and bereavement training to prison staff,' *BMJ Supportive & Palliative Care* (U.K.) | Online – 21 November 2024 – St. Peter's Hospice partnered with three local prisons. Prison staff identified the need to improve palliative and end-of-life care and learn how to develop bereavement support to imprisoned people and their families. Bereavement training enabled prison staff to provide informed, compassion-ate bereavement support to imprisoned people, and their families. **Abstract:** https://bit.ly/4fCvt5W

N.B. 'End-of-life and bereavement training for local prisons,' St. Peter's Hospice: https://bit.ly/496NVB6

'Breaking out: Working with grief in prison,' *BMJ Supportive & Palliative Care* (**U.K.**) | Online – 21 November 2024 – Prisoners experience bereavement at a much higher rate than the general population and are likely to have suffered many losses, both prior to and as part of their sentences. Specialist bereavement support breaks the destructive experience of historical and newly experienced grief in prison and profoundly changes lives and futures. Abstract: <u>https://bit.ly/3CFwCLw</u>

Care Planning & Serious Illness Conversations

New fellowship will help imprisoned women plan for end of life

CAHNRS NEWS (**U.S.**) | Online – 20 November 2024 – Incarcerated individuals have few personal rights, but one they do retain is the ability to create advance directive plans for their healthcare. "When folks are incarcerated, they lose most of their bodily autonomy and basically become property of the government," said Tosha Big Eagle, a member of the Hunkpati Dakota Tribe of Crow Creek, South Dakota, and a doctoral student at Washington State University. "Advance directives are one outlier, but nobody tells them about that right." Life in a state prison is almost completely separate from life outside, Big Eagle said. Even if someone has an advance directive plan set up before going to prison, it doesn't carry over. They must create a completely new plan after they are incarcerated, she said. **Full text:** https://bit.ly/412msP1

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Compassionate Release

Oregon's laws for when aging inmates can leave prison are among the nation's most vague

WILLAMETTE WEEK (U.S.) | Online 27 November 2024 – Almost every U.S. state has what are known as compassionate release laws, which give elderly and severely ill inmates a chance for early release. Oregon's laws are some of the worst in the country, according to a 2022 scorecard released by the non-Page | 7 profit Families Against Mandatory Minimums. What stood out ... helped land Oregon at 44th among 50 states, was the state's extremely vague eligibility criteria. That makes it easier for officials to deny applications. For many years, only a handful of inmates successfully completed the process. Oregon's prison population is aging at an "alarming rate," leading to skyrocketing medical costs at prisons that are not designed to operate as nursing homes. Full text: https://bit.lv/41dDD06

N.B. See 'Compassionate release: Call for humility and more leniency,' https://bit.ly/4fuzXuU

Related:

'Compassion beyond hospital curtains and prison bars,' Baylor College of Medicine (U.S.) | Online - 22 November 2024 - Compassionate release aims to address barriers to end-of-life care in correctional facilities, allowing terminally ill prisoners to spend their final days outside prison walls. However, the reality is starkly different. Approval rates are alarmingly low. Many applicants are denied compassionate release, and some pass away before their applications are even processed. Full text: https://bit.ly/3CJSuW7

'Extraordinary and compelling reasons,' Criminal (U.S.) | Online - 15 November 2024 - In 1993, Gary Settle was sentenced to 177 years in prison. Twenty-six years into his sentence, he started helping other inmates get out of prison through ... compassionate release, a policy that allows people in prison to petition to be let out for "extraordinary and compelling" reasons. Diagnosed with terminal cancer, Settle's own application for compassionate release has been denied. Download interview at: https://bit.ly/40VWpJv

'Unlocking compassion: Why correctional facilities should more widely implement medical parole for incarcerated individuals in Massachusetts,' Journal of Health & Biomedical Law (U.S.) | Online - 12 November 2024 - Milton Rice, a seventy-six-year-old individual incarcerated at Massachusetts Correctional Institution ... applied for medical parole in March 2020... His medical parole was granted November 24, 2020. The day after his release, he died of COVID-19 related complications. Full text: https://bit.ly/4fOCfFh

'Ending life peacefully and with dignity,' Handbook on Contemporary Issues in Health, Crime & Punishment (U.S.) | Online - 7 November 2024 - Numerous state penal systems have at least one compassionate release policy: however, state and the federal systems seldom use these policies or have complex processes that make it difficult for incarcerated adults to successfully gain release. Data suggest the public is in favor of releasing geriatric and terminally ill incarcerated adults Chapter 29 abstract: https://bit.ly/3YU5LUD

N.B. Download abstracts of each chapter of the Handbook on Contemporary Issues in Health, Crime & Punishment at: https://bit.ly/3NUsqtM

Interesting Reads You Might Have Missed

"A different sense of what we do here, who we are and what we deliver": Provider perspectives on the effects of a change in governance of healthcare services in correctional facilities in British Columbia

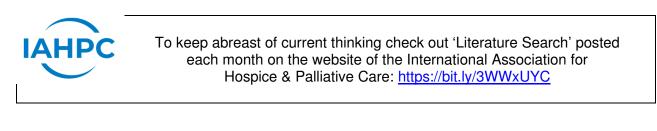
HEALTH SERVICES MANAGEMENT RESEARCH (Canada) | Online – 29 November 2023 – Healthcare leadership in British Columbia's provincial correctional facilities identified many ways in which the transfer to Provincial Health Services Authority improved important factors of work-life and job satisfaction for healthcare providers. Participants also felt these changes had made a difference in the quality of care they were able to provide for clients and the impact of their work on health outcomes. These improvements are important from both an individual and health systems perspective; in addition to promoting retention and a healthy workforce, job satisfaction among providers has been linked to quality, safety, and patient satisfaction with care. Full text: https://bit.ly/3YNdzg1

Healthcare during incarceration: A policy position paper from the American College of Physicians

ANNALS OF INTERNATIONAL MEDICINE (U.S.) | Online – 22 November 2022 – The American College of Physicians (ACP) has a long-standing commitment to improving the health of all Americans and opposes any form of discrimination in the delivery of healthcare services. ACP is committed to working toward fully understanding and supporting the unique needs of the incarcerated population and eliminating health disparities for these persons. In this position paper, ACP offers recommendations to policymakers and administrators to improve the health and well-being of persons incarcerated in adult correctional facilities. Incarceration can have a sustained and recurrent effect on the health and well-being of persons sentenced to prison. Full text: https://bit.ly/48mWqru

Palliative and hospice care in correctional facilities: Integrating a family nursing approach to address relational barriers

CANCER NURSING, 2021;44(1):29-36 (**Canada**). Incorporation of family nursing and holistic care principles in palliative care (PC) delivery can have significant implications for persons who are dying while incarcerated and the well-being of their families and peers, as well as having benefits to correctional settings and society as a whole. Nurses are central to ensuring timely, ethical, effective holistic PC and addressing relational aspects of dying. Furthermore, nurses can raise awareness of how persons who are incarcerated and their families are impacted by institutional policies and social stigma. As such, nurses advocate adoption of a holistic, family nursing approach to PC within corrections that recognizes the human right to appropriate care... **Full text:** https://bit.ly/4e9wgtC



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