# End-of-life Care in the Prison Environment (Supplement #3)



Photo Source: Prison Terminal (https://bit.ly/2LTYv7M)

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THIS SUPPLEMENT LISTS SELECTED ARTICLES, REPORTS., ETC., published in the literature and in the news media in recent months. The last 'Backgrounder,' dated 1 August 2022, can be downloaded from the Palliative Care Network website at: <a href="https://bit.ly/3JkYGVg">https://bit.ly/3JkYGVg</a>. Download Supplements #1 and #2 (July, September 2023) at: <a href="https://bit.ly/2Rdegnl">https://bit.ly/2Rdegnl</a>. Also included in this supplement is a listing of selected resources.

## Aging Prison Populations

# These prisons are not for old people

#### Aging, prison and social reinsertion: A literature review

REVISTA IBERO-AMERICANA DE HUMANIDADES, CIÊNCIAS E EDUCAÇÃO, 2023;9(8):23-40. The high aging of the world population is reflected in the prison population... The scientific literature has been demonstrating the complexity of problems associated with the aging of the prison population. This literary review work reflects on the aging of the population in prison, more specifically on the challenges it brings to the prison system and the social reintegration of this population. Studies on aging in a prison context are small and there is a need to deepen the discussion and defense of the rights of this population, as well as the need to create a national strategy for the social reintegration of the elderly detained population... English language abstract (click on pdf icon for full text in Portuguese): <a href="https://bit.ly/3Zy2M30">https://bit.ly/3Zy2M30</a>

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#### End-of-Life Care in Prisons

### I was a prison hospice worker during the pandemic

PRISON JOURNALISM PROJECT (U.S.) | Online - 7 November 2023 - During the pandemic, the news broadcast an image of a window in a Missouri prison with the words "HELP WE MATTER" scrawled across it. Inmates at that prison had been locked in their cells for days, sick with COVID-19. At Jefferson City Correc-



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tional Center, a maximum security prison in Missouri, the image hit close to home. When COVID-19 struck prisons, it struck hard. We were quarantined for days and released from our cells only for an occasional shower. A prison is hardly an ideal place for social distancing. Working as a hospice care volunteer in the prison.... I saw the deepening impact of the pandemic. Full text: https://bit.ly/46eaa5l

## Breaking into prison – re-establishing a palliative care service for imprisoned people

BMJ PALLIATIVE & SUPPORTIVE CARE | Online - 1 November 2023 - The U.K. prison population is growing older and sicker with deaths from natural causes increasing by 77% in the last 10 years.1 This service evaluation aimed to develop hospice input to the local prison, improving communication and support for prison healthcare staff. Commitment to a virtual multidisciplinary team strengthened communication and relationships with prison healthcare staff and improved care for patients. Designating two clinicians to lead the service ensured continuity and momentum to successfully re-establish the service, whilst policy writing and joint visits across the team has allowed the growth of knowledge and expertise within our organisation. Conference Posted Presentation: https://bit.lv/46eSnL4

1. 'Dying Behind Bars: How can we better support people in prison at the end of life?' Hospice UK, April 2021. Download report at: https://bit.ly/3nzbECA

# Palliative care among incarcerated populations: A national survey of radiation oncologists' perspectives and experiences

INTERNATIONAL JOURNAL OF RADIATION, BIOLOGY, PHYSICS | Online - 1 October 2023 - A KAP (Knowledge, Attitudes & Practice) survey was distributed to 150 medical and radiation oncologists in the U.S., randomly selected from two national societies membership directories. Most radiation oncologists who responded had experience providing cancer care for incarcerated patients and acknowledged disparities in later-stage disease presentation in this patient population. Interventions are needed to ensure cancer-related pain is appropriately managed among patients experiencing incarceration. Further studies are required to understand practice patterns and ensure equitable cancer treatment for carceral populations. Abstract: https://bit.ly/48BY88e



#### How Buddies have helped support palliative care in prison

RECOOP (U.K.) | Online - 21 September 2023 - 844 people aged 50 or over died of natural causes whilst in prison in 2020, therefore, dying in prison is fast becoming a reality for many older individuals serving a sentence. The end-of-life (EoL) process can be even harder for someone serving a sentence. Dependent on the prison, there may not be a specific healthcare wing or facilities to properly accommodate an individual going



through palliative care. Due to staffing levels and potential disconnect from family and friends, care may be sporadic and many individuals can be left feeling isolated. As part of Recoop's Buddy program, many Buddies undertake additional modules in EoL care and bereavement. https://bit.ly/3ESzBhw



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#### Frail in jail: How U.K. prisons are failing dying inmates

SOCIAL CARE TODAY | Online - 115 August 2023 - Moving forward, prison staff require in-depth training to understand how to support someone at the end of life, especially given the security constraints of a prison setting. With some prison staff feeling like carers, informed and updated training of staff is desperately needed as the first vital step towards more widespread and radical prison reform. The health challenges of prisoners must not be approached in isolation. As Louise Ridley, Senior Lecturer in Criminology Page | 3 at Northumbria University informed Social Care Today, "The health challenges faced by older prisoners relate to continuity of care, health journeys are pitted with poor provision of medications, lack of identification of new health problems and long delays in identifying these problems." https://bit.ly/40dUugZ

#### Prison Healthcare Services

## 7 stories on health care in prisons

PRISON JOURNALISM PROJECT (U.S.) | Online - 12 November 2023 - Americans are no strangers to the complexities and burdens of the country's health care system. In prison, many of these issues are exacerbated. In the 1976 Supreme Court case Estelle v. Gamble, the court held that failure to provide adequate



health care to incarcerated people as a result of "deliberate indifference" is unconstitutional. The court cited the Eighth Amendment in this decision, writing that such indifference constitutes cruel and unusual punishment. Nonetheless, nearly five decades after the verdict, more than 1 in 5 people incarcerated in state facilities lack treatment for ongoing medical issues.1 https://bit.ly/47gMVsM

1. 'The health and health care of U.S. prisoners: Results of a nationwide survey,' American Journal of Public Health, 2019;99(4):666-672. Full text: https://bit.ly/3QW5DA0

# How to be a prison doctor

INSIDE TIME (U.K.) | Online - 1 November 2023 - The National Health Service provides healthcare in U.K. prisons and it has a policy of "equivalence of care." This means the care prisoners get should be as good as the care everyone else gets. According to the definition drawn up by the National Prison Healthcare Board, it means that prisoners should receive healthcare "at least consistent in range and quality ... with that available to the wider community, in order to achieve equitable health outcomes." So does that mean being a prison doctor is just like being any other kind of doctor? Not at all. Dr. Jake Hard ... explains: "You'll see it written that the healthcare quality should be the same, whereas in fact it can't be the same, nor should it be." https://bit.ly/3MqX9hv

# Prioritizing diversion and decarceration of people with dementia [in U.S. prisons]

AMA JOURNAL OF ETHICS, 2023;25(10):E783-E790. An aging prison population means more people who are incarcerated will experience dementia and related symptoms... This article canvasses clinical and ethical complexities of caring for people with dementia who are incarcerated and examines how to adapt carceral settings to better meet the needs of people with dementia. This article recommends policy reforms, such as treatment-based diversion programs, early parole, and medical release, to decrease numbers of individuals with dementia who are incarcerated whenever possible. Although the total number of people who are incarcerated in the U.S. at a given time has decreased in recent years, the number of people age 55 or older in state and federal prisons has increased... Full text: https://bit.ly/3M6Etnp



Please report any broken links.

# Understanding the organisational influences on the quality of and access to primary care in English prisons: A qualitative interview study

BRITISH JOURNAL OF GENERAL PRACTICE | Online - 4 September 2023 - Primary care services are delivered across many prisons every day in England but there is little previous research exploring the key organisational factors influencing quality of care and access in this setting. This study with people who had been in prison and prison healthcare staff found that understaffing ... was the core organisational is- Page | 4 sue that influenced quality and access. Understaffing is rife across many sectors of healthcare in England but it is particularly fraught within the prison estate where it collides with a higher disease burden and exacerbates health inequalities. Factors that influence the quality of and access to prison healthcare deserve to receive mainstream research and policy attention. Full text: https://bit.ly/46pXCII

# Mass incarceration and cancer health disparities in the United States: Reimagining models of care delivery

JNCI: JOURNAL OF THE NATIONAL CANCER INSTITUTE, 2023; djad136. The authors provide an overview of cancer health disparities among incarcerated individuals, noting profound inequities and an absence of research data to inform policies and healthcare delivery approaches to address inequities among people with a history of incarceration or who are incarcerated. They outline a set of principles on how cancer care should be delivered to these high-risk populations, e.g., strategies for compassionate release of late-stage patients, cancer prevention services, screening and treatment in carceral settings, access to health insurance following incarceration, education for clinicians, and using carceral sites for health promotion that include a plan for transition to community care. Full text: https://bit.ly/46oA7Q3

#### 1 in 4 inmate deaths happen in same federal prison. Why?

NATIONAL PUBLIC RADIO (WBFO, Buffalo, New York) | Online - 22 September 2023 - Close to five thousand people have died in federal prison since 2009. There are 100 federal prisons across the U.S. An NPR investigation found that a guarter of those deaths happened at one federal prison - Butner Federal Correctional Complex in North Carolina. Inmates have a constitutional right to healthcare. Being denied care is considered cruel and unusual punishment. But many of the sick inmates who wind up at Butner don't get the healthcare they are entitled to - and some end up dying. https://bit.ly/3EWrAYN

# Health literacy strengths and challenges of people in New South Wales prisons: A cross-sectional survey using the Health Literacy Questionnaire

BMC PUBLIC HEALTH | Online - 10 August 2023 - This study provides insights into the health literacy profile of this population and how it could inform practice and policy for authorities providing healthcare in prisons. Findings highlight several areas in which adults in prison and particular participant characteristic groups may require additional support to understand, use and navigate the prison healthcare system. The findings suggest that authorities need to consider how health literacy-informed programs could reduce the observed health disparities and inequities of these marginalised populations. A more proactive and responsive approach is needed to be taken by prison and healthcare decision-makers for health literacy; in particular, interventions and actions focusing on long term health benefits. Full text: https://bit.ly/45guS3X

# Compassionate Release

# Expanded prison medical release eligibility provides opportunity for more sick, aging incarcerated people to go home before they die

NORTH CAROLINA HEALTH NEWS (U.S.) | Online - 3 October 2023 - Sixty-five people since 2019 have been granted medical release from prison by the Parole Commission, according to data from the Department of Adult Correction... Language in this year's state budget that passed last month expands the eliqibility criteria for medical release from North Carolina prisons, potentially providing more sick and aging incarcerated people the opportunity to go home before they die. The new law rolls back the eligibility age for "geriatric" medical release by 10 years – from 65 to 55 – and decreases the risk standard guiding all releases. The new guideline says that people must pose "no risk or low risk" to public safety, instead of the previous absolute of "does not pose a safety risk." **Full text:** <a href="https://bit.ly/3LOsLO4">https://bit.ly/3LOsLO4</a>

#### Dying and disabled Illinois prisoners

ILLINOIS TIMES (U.S.) | Online – 28 September 2023 – Phillip Merritt's deteriorating condition makes Page | 5 him a prime candidate to get out of prison under the Joe Coleman Medical Release Act, a pivotal criminal justice reform bill touted ... as an effective way to alleviate the state's decrepit prison health care system, reduce the "staggering" costs of caring for ailing people in prison, and reunite families with frail loved ones. 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... 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... https://bit.ly/3RSGBTo

#### "Like a nursing home"

#### Inside Alaska's aging inmate population

ANCHORAGE DAILY NEWS (U.S.) | Online - 23 September 2023 - Alaska's spending on physical healthcare for prisoners increased 105% over the past decade, from about \$31.5 million in 2012 to \$64.8 million in 2022. Prison officials say the factors driving the increase are complicated, but include ballooning costs associated with an aging, medically complex inmate population. To address the mounting problems, Alaska created special medical and geriatric parole to potentially release some of the most aged and ill prisoners who have been found to no longer pose a risk to the public. While most states [in the U.S.] have some mechanism to apply for the release of terminally ill or elderly prisoners, they are rarely used. That's the case in Alaska. Full text: https://bit.ly/3ENX0AK

# **Grief & Bereavement**



#### How to grieve and find comfort in death behind bars

PRISON JOURNALISM PROJECT (U.S.) | Online – 21 September 2023 – Death visits the incarcerated frequently. Some greet it with open arms, some brush it off without incident, some crumble under its emotional weight. Either way, we must be able to cope within the limited environment where we stand. At Colorado state prison incarcerated people receive notice of a loved one's passing only after the



prison ... incarcerated people receive notice of a loved one's passing only after the Colorado Department of Corrections (CDOC) has verified both the death and the relation. When a family member calls the facility, CDOC connects the caller to the correct staff member, who asks questions about the hospital or funeral home and the deceased to expedite verification. **Full text:** https://bit.ly/3PQfK8Z

#### Related:

'Helping dying prisoners has taught me to be more compassionate,' Prison Journalism Project, 7 September 2023. **Full text:** https://bit.ly/3Q9EKrR

'It's time to forgive and free older people in prison,' Prison Journalism Project, 2 August 2023. **Full text:** <a href="https://bit.ly/3RPS8CI">https://bit.ly/3RPS8CI</a>

## Medical Assistance in Dying

# Red-flags raised around medically-assisted death in Canada's prisons

GLOBAL NEWS | Online – 13 October 2023 – Since it first became legal in Canada in June 2016, 10 federal prisoners have been granted a medically-assisted death [sic] (MAiD), according to the Correctional Service of Canada (CSC). CSC also says that as of 31 August this year, a total of 32 prisoners have requested MAiD. The numbers rose slightly from 31 May 2023, when the number of requests totalled 29.

At that time, nine people were deemed eligible, and granted a medically-assisted death. The CSC declined to provide a further breakdown of the numbers, citing privacy reasons. But the procedures and practices of accessing MAiD in Canada's prisons is a cause for concern among advocates and experts alike. Full text: <a href="https://bit.ly/3PV6gbs">https://bit.ly/3PV6gbs</a>

# Selected Resources

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

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

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

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AUSTRALIA | University of Melbourne: <a href="https://bit.ly/3eqeVh9">https://bit.ly/3eqeVh9</a>

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

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

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

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

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

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

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

EUROPE (Switzerland) | Prison Research Group (University of Bern): https://bit.ly/42gerD2 U.S. | Prison Policy Initiative <a href="https://bit.ly/425vyb0">https://bit.ly/425vyb0</a>

U.K. | International Observatory on Endof-Life Care (Lancaster University): https://bit.ly/3AlpfWa U.S. | Prison Terminal https://bit.ly/2LTYv7M

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

U.S. | University of Minnesota (School of Nursing): <a href="http://bit.ly/41lGbGi">http://bit.ly/41lGbGi</a>

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

Barry R. Ashpole, Ontario, CANADA

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