# End-of-life Care in the Prison Environment (Supplement #4)



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Photo Source: Prison Terminal <a href="https://bit.ly/2LTYv7M">https://bit.ly/2LTYv7M</a>

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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, #2 & #3 (July, September, November 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**

## Forgotten and without protections: Older adults in prison settings

THE HASTINGS CENTER REPORT, 2023;53(6):17-24. This essay considers standards and resources for mitigating elder mistreatment in the community and residential-care settings in contrast to the available resources in prisons. Arguing that a conceptual model of elder abuse tailored to the prison population is needed, the essay proposes a research agenda through which such a model could be developed. The model could then be used in the creation of policy for detecting and mitigating elder mistreatment of incarcerated people. The essay concludes with a call to action to address the rift in legal protections and processes that leave older adults in prison at increased risk of abuse and neglect without a clear pathway for recourse. **Abstract (w. references):** https://onlinelibrary.wiley.com/doi/10.1002/hast.1540

## Older adults deprived of liberty: Their pain hurts more

CIÊNCIA & SAÚDE COLETIVA. 2023;28(11):3205-3214. This essay reflects on the incarceration of older adults in the U.S. and Brazil and mainly aims to observe how the situation is consistent and differs in the two countries. The bibliography on the subject is much more affluent and consolidated in the U.S. Several discrepancies are noted among scholars between data and authors' views. However, they all agree regarding: 1) the increased number of incarcerated older adults; 2) the inadequacy of prisons to house Page | 2 them; 3) the accelerated aging due to lack of healthcare; 4) the experiences of physical, musculoskeletal, and mental comorbidities; and, 5) the high costs of treating them adequately. Full Text (in Portuguese, w. English language abstract): https://www.scielo.br/j/csc/a/BkJkPRGk58LckFL7vmXz6tn/?lang=pt

## Prison Healthcare Services

#### There is little scrutiny of "natural" deaths behind bars

NATIONAL PUBLIC RADIO (U.S.) | Online - 2 January 2024 - The Center for Disease Control says natural deaths happen either solely or almost entirely because of disease or old age. Yet 70% of the inmates who died in federal prison the last 13 years were under the age of 65. After speaking to some of the families of these inmates, National Public Radio found that potential issues such as medical neglect, poor prison conditions and a lack of health care resources were left unexplained once a "natural" death designation ended hopes of an investigation. Meanwhile, family members were left with little information about their loved one's death. Full text: https://www.npr.org/2024/01/02/1219667393/there-is-little-scrutiny-ofnatural-deaths-behind-bars

## Lawmakers push for federal prison oversight after reports of inadequate medical care

NATIONAL PUBLIC RADIO (U.S.) | Online - 12 December 2023 - Two key senators on the committee tasked with overseeing the nation's federal prisons are now urging the Bureau of Prisons to fix a medical care system that has allowed people in its care to die preventable deaths. They were responding to an National Public Radio (NPR) report showing that federal prisoners die from treatable conditions that are not diagnosed or treated in a timely way within the prison system. NPR found at least 4.950 people had died in federal custody in roughly the last decade. Of those deaths, 1 in 4 occurred at a single place: the prison hospital within the federal correctional complex in Butner, North Carolina. Full text: https://www.npr.org/2023/12/12/1218627629/lawmakers-push-for-federal-prison-oversight-after-reportsof-inadequate-medical-

1. '1 in 4 inmate deaths happen in same federal prison. Why?' National Public Radio, 22 September 2023. Full text: https://bit.ly/3EWrAYN

## Lack of data raises questions about quality and cost effectiveness of Michigan's prison health care

RAPID GROWTH (U.S.) | Online - 16 November 2023 - The Citizen's Research Council of Michigan (CRC) recently reported that Michigan prisons spend approximately \$300 million per year to provide health care for more than 30,000 prisoners.1 Even after adjusting for inflation, the average per-prisoner health care cost has increased 34% over the last two decades. And, according to Michigan advocates for incarcerated and formerly incarcerated people, health care in prison is far less than adequate. The CRC report concluded that providing health care to inmates has high costs, which the state does not adequately assess; data is needed to identify cost drivers in order to improve quality of care and maximize costeffectiveness... Full text: https://www.rapidgrowthmedia.com/features/prisonhealthcare111162023.aspx

'The Lack of Data Impedes Cost-Effective Health Care in Michigan Prisons,' Citizen's Research Council of Michigan, September 2023. Download report at: https://crcmich.org/publications/lack-of-dataimpedes-cost-effective-health-care-in-michigan-prisons

## New report reveals shocking state of prisoner health. Here's what needs to be done

THE CONVERSATION (Australia) | Online – 14 November 2023 – A new report on the health of people in Australian prisons makes for sobering reading.1 Compared to the general population, people in prison have higher rates of mental health conditions, chronic disease, communicable disease... This is despite the fact the prison population is relatively young. Research shows mental health intervention and engagement helps reduce offending among offenders with serious mental illness. Good health care in pris- Page | 3 ons, with continuity of community healthcare upon release, not only helps the person being treated. It also helps the community through reduced levels of offending. Full text: https://theconversation.com/newreport-reveals-shocking-state-of-prisoner-health-heres-what-needs-to-be-done-217558

1. 'The health of people in Australia's prisons 2022,' Australian Institute of Health & Welfare, November 2023. Download report at: https://www.aihw.gov.au/reports/prisoners/the-health-of-people-inaustralias-prisons-2022/contents/about

## End-of-Life Care in Prisons

## **Hospice: Providing professional care**

NATIONAL ASSOCIATION FOR THE ADVANCEMENT OF COLORED PEOPLE (U.S.) | Online - 3 January 2024 - As a volunteer, I assisted the medical care team in their efforts to maintain the psychological and spiritual well-being of people who were terminally ill. My job duties consisted of feeding the patient, offering spiritual support through prayer, reading to the patient, changing linens, assisting with dressing, eating and oral care, helping the nurses with lifting and/or repositioning the patient, and a variety of other duties. I was there to help give as much comfort and support to the patient in the last phase of their incurable disease, or old age, as possible so that they could live as fully and comfortably as they could before they passed on. Full text: https://www.monaacp.org/hospice-providing-professional-care

# On dying alone in prison and the social responsibility of medicine: A pilot interview study of physicians caring for terminally ill incarcerated patients in Austria and the United States

ANNALS OF PALLIATIVE MEDICINE | Online - 18 December 2023 - The aim of this study was to examine the experiences of doctors caring for terminally ill patients inside prisons. This group of physicians is difficult to reach and small in number. While studies of palliative care and end-of-life (EoL) issues in prison have increased, especially in the U.S. and since the COVID-19 pandemic, they are still limited due to the constraints of carrying out research in carceral contexts. At present, there is very little knowledge of the experiences of physicians providing EOL care in prisons. The study reveals the difficulties physicians face when caring for dying incarcerated patients. Provider-patient relationships are hardly continuous. Full text: https://apm.amegroups.org/article/view/120002/pdf

N.B. See 'Stress and anxiety among correctional health care professionals in a U.S. state prison system during COVID-19,' Journal of Correctional Health Care. Posted online 4 January 2024. Abstract: https://www.liebertpub.com/doi/10.1089/jchc.23.09.0081



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.lv/3WWxUYC

# What it's like watching my friends die in prison

VERA INSTITUTE OF JUSTICE (U.S.) | Online - 7 December 2023 - I go into each room knowing that death is on the other side of that door. By the time I show up, there's no more hope. Can you imagine being in prison without any hope? I don't think it's right for any human to die in prison, but I've seen it so many times. I walk with death. I sit with death. With every new hospice patient, I try to assess the situation, to understand how far along he is. Some are further along than others, but they are all on the same path. Some crawl to the finish line. Some race. Some are brave. But some are so scared that it scares me. Some fight it. Some want it so bad that I want it for them. They all understand what is happening. And they all want somebody there. Full text: https://www.vera.org/news/what-itslike-watching-my-friends-die-in-prison

# As a Muslim incarcerated in New Jersey, I worry I will be cremated when I die

PRISON JOURNALISM PROJECT (U.S.) | Online – 23 November 2023 – Islamic beliefs dictate that a Muslim cannot be cremated; it is considered haram, a forbidden act. A Muslim's body must be given a ritual bath called ghusl, and covered with two white sheets or towels, known as kaffan. A janazah, or funeral, is then performed before burial. For Muslims, the last rites are a final farewell and a religious act carried out according to sincerely held beliefs in life after death, the day of judgment, and heaven and hell. The burial procedures are therefore of vital religious importance. <a href="https://prisonjournalismproject.org/2023/11/21/dying-in-prison-as-muslim/">https://prison-as-muslim/</a>

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## Humane Prison Hospice Project is transforming the way terminally ill people in prison die

COMPASSION & CHOICES (U.S.) | Online – 17 November 2023 – The Project was conceived as a way "to transform the way incarcerated people die through education, advocacy, and training to support their incarcerated peers as caregivers and grief companions." It offers training to peer-volunteers in end-of-life care (EoLC) and grief support, who work with staff... Hospice looks much the same inside and outside of prison: there is an interdisciplinary team of nurses, doctors, therapists and other EoLC professionals. The main difference is that people who are incarcerated are trained in EoLC to become volunteers and provide companionship to the dying. **Full text:** <a href="https://www.compassionandchoices.org/news/humane-prison-hospice-project-is-transforming-the-way-terminally-ill-people-in-prison-die">https://www.compassionandchoices.org/news/humane-prison-hospice-project-is-transforming-the-way-terminally-ill-people-in-prison-die</a>

# Compassionate Release

# Compassionate release of dying inmates: A step toward social justice in the criminal justice system

INNOVATION IN AGING, 2023;7(Suppl):488-489. To obtain compassionate release (CR), the first step is to identify eligible inmates with a terminal illness and a life expectancy of less than six months, which must be confirmed by a medical evaluation. The second step involves filing a petition for CR with the appropriate authority, including medical records, a statement from the treating physician, and a plan for the inmate's release and care in the community. The third step entails advocating for the inmate's release, which may involve working with advocacy groups, contacting elected officials, and raising public awareness. By granting CR to dying inmates, we can provide them with the opportunity to die with dignity **Abstract:** https://academic.oup.com/innovateage/article/7/Supplement 1/488/7488214



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## Seeking redemption for aged and infirm prisoners amid Alabama's high bar for parole

NATIONAL PUBLIC RADIO (U.S.) | Online - 10 December 2023 - Alabama's prison commissioner has said an aging and sicker population is taking a toll on a system that is already chronically overcrowded and radically understaffed. In September (2023), for example, there were more than 20,000 prisoners in a system designed to house 12,000. About 14% of them are over 60. Another 24% are between 51 and 60. Alabama's broken parole system has become a fiscal burden. "We've basically become an old folks' Page | 5 home where we're caring for people who are no longer a threat to society, which means that they cost more," says. Alabama State Representative Chris England, of the state's prison oversight committee. https://www.npr.org/2023/12/11/1217710630/prison-parole-alabama-redemption-earned-prisonersrelease

# A dying man won release from prison after Spotlight PA highlighted his case. It shouldn't be that hard, advocates say

SPOTLIGHT PA (U.S.) | Online - 21 November 2023 - The current compassionate release statute [in Pennsylvania] purports to provide sick and aging incarcerated people with a way to spend the end of their life free from prison. In reality, it is so narrowly written that Raymond Caliman is one of only 48 people to successfully use it in 14 years. The law grants release only to those who are sick or older, cannot walk and have less than a year to live. Because of the narrow criteria, the state has received very few petitions since the legislature established the process in 2009. And in many cases, petitioners have died before their petitions came before a judge. Full text: https://www.spotlightpa.org/news/2023/11/pennsylvaniaprison-release-sick-elderly-compassionate-release-success-rate/

## A view of end-of-life care, from behind bars

WEST VIRGINIA CENTER ON BUDGET & POLICY (U.S.) | Online - 16 November 2023 - In West Virginia, an incarcerated person with an "extreme life-threatening" medical condition may petition for clemency from the governor. A person who is terminally ill or has "an extremely serious" medical condition may receive a medical respite release from the governor. And yet, this almost never happens. In the last 21 years, only two people were released by Medical Respite and only one person was released through Clemency from the governor. In that same period, 478 people died in prison. West Virginia prisons can expect to provide more costly end-of-life care. Since 2002, the number of people aged 50 and older in West Virginia prisons has nearly tripled. Full text: https://wvpolicy.org/a-view-of-end-of-life-care-frombehind-bars/

#### Care Planning & Serious Illness Conversations

# Decision-making for hospitalized incarcerated patients lacking decisional capacity

JAMA INTERNAL MEDICINE | Online - 4 December 2023 - Incarcerated patients admitted to the hospital face threats to their rights to privacy and self-determination in medical decision-making. Little is known about medical decision-making processes for this population who lack decisional capacity. In this in-depth description of decision-making practices for hospitalized incarcerated patients lacking decisional capacity, admissions of these patients generated uncertainty about their rights, sometimes infringing on patients' privacy and autonomy. Clinicians encounter incarcerated patients in both hospital and clinic settings and should receive education on how to support ethically and legally sound decision-making practices... Abstract (w. key points): https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2812545

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: <a href="https://bit.ly/3eqeVh9">https://bit.ly/3eqeVh9</a>

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 Endof-Life Care (Lancaster University): https://bit.ly/3AlpfWa

U.K. | Nursing in Prison (Springer Publishing): https://bit.ly/3OQ77KV

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

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

U.S. | Hosparus Health Hospice Prison Program: <a href="http://bit.ly/3TXY9w8">http://bit.ly/3TXY9w8</a>

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: http://bit.ly/43q4MvO

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

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

U.S. | Prison Terminal <a href="https://bit.ly/2LTYv7M">https://bit.ly/2LTYv7M</a>

U.S. | Release Aging in People in Prison <a href="https://rappcampaign.com/">https://rappcampaign.com/</a>

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

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

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