## End-of-life Care in the Prison Environment

## Backgrounder Updated 08.01.2022



Photo Source: Lori Waselchuk, gracebeforedying.org http://bit.ly/30uttq8

n the following pages is a representative sample of articles, reports, etc., on hospice and palliative care in the prison environment noted over the past five years (2018-2022) in the weekly report Media Watch.1 Although a universal public health issue, it is in the United States that most interest and attention has been afforded the aging and the terminally ill prison population. This backgrounder begins with a selection of articles by way of a broad overview of the issue, followed by additional articles, etc., (in descending order of publication) that offer a national and (in the U.S.) state-by-state overview. This is followed by a list of articles, etc., from a variety of sources on end-of-life care in the prison systems in Australia, Canada, China, France, Germany, Ireland, New Zealand, Poland, Russia, Switzerland and the U.K.

#### Contents Selected Studies on End-of-Life Care in the Prison Environment 5 7 U.S.A. U.S.A. (State-by-State) Australia 10 Canada 12 13 China France 13 Germany 13 Ireland 14 New Zealand 14 Poland 15 15 Russia Switzerland 15 United Kingdom 15 **Appendix** 18

 Compiled by Barry R. Ashpole, links to the Media Watch archive are posted on several websites that serve the hospice and palliative care community-at-large, including the International Palliative Care Resource Center (<a href="http://bit.ly/2ThijkC">http://bit.ly/2ThijkC</a>) and the Palliative Care Network (<a href="http://bit.ly/2Ujdk2S">http://bit.ly/2Ujdk2S</a>).

**N.B.** See Appendix (p.18), featuring initiatives by the Worldwide Hospice Palliative Care Alliance, Human Prison Hospice Project and the European Association for Palliative Care.

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## Selected Articles, Reports, etc., on End-of-Life Care in the Prison Environment

2022

## Dying for a change: A systematic review of compassionate release policies

INTERNATIONAL JOURNAL OF PRISONER HEALTH | Online - 28 June 2022 - Added Stage 05.01.2022 Update
Within correctional facilities, correctional healthcare workers should play an integral
role in influencing prison and medical staff attitudes toward dving inmates by providing an understanding of how to

role in influencing prison and medical staff attitudes toward dying inmates by providing an understanding of how to effectively support this vulnerable population. Social workers should participate in research that focuses on effective guidelines for correctional facilities to provide compassionate end-of-life care for inmates. Racial disparities in the U.S. criminal justice system are prevalent and well documented, as individuals of color are arrested far out of proportion to their share of all individuals in the U.S. **Full text:** https://bit.ly/3ngybVk

## Selected journal articles on "compassionate release":

'Strategies to optimize the use of compassionate release from U.S. prisons,' American Journal of Public Health, 2020;110(1):S25-S26. Full text: <a href="http://bit.ly/2ScUqNe">http://bit.ly/2ScUqNe</a>

'U.S. Department of Corrections compassionate release policies: A content analysis and call to action,' *Omega – Journal of Dying & Death*, 2020;81(4):607-626. Abstract (w. references): http://bit.ly/2YBBjwE

'Early release rules for prisoners at end of life may be "discriminatory," say doctors,' British Medical Journal, 2019;365(8203):14140. Introduction: http://bit.ly/2WEwEIO

"No one wants to die alone": Incarcerated patients' knowledge and attitudes about early medical release,' Journal of Pain & Symptom Management, 2019;57(4):809-815. Full text: http://bit.ly/2VsHiSs

'Extraordinary and compelling: The use of compassionate release laws in the U.S,' Psychology, Public Policy & Law, 2018;24(2):216-234. Abstract: http://bit.ly/2VLY7wt

**N.B.** The issue of compassionate release is noted in a good number of the articles, reports, etc., noted in the following pages.

"We are all humans and deserve a decent way to go"

## Examining professionals' experiences with providing end-of-life care in correctional institutions

CRIMINAL JUSTICE REVIEW, 2022;47(2):225-242. The purpose of this study was to understand the challenges faced by correctional and medical professionals, focusing on job satisfaction, obstacles, and emotional effects of providing end-of-life care (EoLC)... The authors' data included seventeen face-to-face interviews with medical and correctional staff assigned to the EoLC unit in a southern state [in the U.S.]. Participants in the study noted several challenges and stressors, which included the lack of resources and difficulties in balancing care. It was emotionally stressful to maintain appropriate relationships with the inmates, deal with patient manipulation, and be surrounded by dying and death. Access full text at: https://bit.ly/3FKnfgA

## Older Adults' perspectives on death and dying in prison

JOURNAL OF CRIMINAL JUSTICE | Online - 31 May 2022 - Descriptions of death were most often framed with reference to health conditions versus violence. Fur-

ther, respondents' perceptions of death and dying were also linked to fears in three areas: dying while imprisoned, dying due to distrust of the prison healthcare system, and what happens to their personal effects and persons after death in prison. Findings of this study reinforce the importance of addressing carceral medical neglect, the potential role of hospice, and the need for correctional policy and practice to be attentive to disenfranchised grief. **Abstract (w. extracts from the full text):** <a href="https://bit.ly/3mlYdWs">https://bit.ly/3mlYdWs</a>



## End-of-life care in prisons

PENAL REFORM INTERNATIONAL | Online – 21 February 2022 – The number of older people in prisons has been rising in many countries. At present, there is no global data on the number of older persons in prison. Known rates from 1.8% of the national prison population in Indonesia to as high as 20% in Japan, and in many countries the number has been growing at a faster rate than the general prison population. This poses specific challenges for health and age-related policy and practice in prisons, as older people in prison are more likely ... to have disabilities, multiple, chronic health conditions or age-related cognitive impairment such as dementia. Palliative care in prisons can be challenging not least because of the restrictions of the environment. https://bit.ly/3leePJ4

### "It was like an animal in pain"

## Institutional thoughtlessness and experiences of bereavement in prison

CRIMINOLOGY & CRIMINAL JUSTICE, 2022;22(1):150-170. Drawing on in-depth qualitative research undertaken with bereaved prisoners, staff members and volunteers at a male prison in the North of England, the article explores how individual and institutional goals compete, compounding bereavement experiences and the management of grief. Findings demonstrate the tension between the policies and protocols prisons are tasked to follow, and unintended consequences for the individually bereaved. This article illuminates the need for far greater understanding of bereavement in the prison population and explores how a universal life experience can be particularly debilitating within the prison setting... Abstract (w. references): https://bit.ly/30jrQ3z

### Related:

'Bereavement behind bars: Grief support groups with and without therapy dogs for incarcerated females,' Bereavement, 2022;1:1-8. Full text (click on pdf icon): https://bit.ly/3LyF0v0

### 2021

## A systematic literature review exploring the psychosocial aspects of palliative care provision for incarcerated persons: A human rights perspective

INTERNATIONAL JOURNAL OF PRISONER HEALTH | Online – 15 December 2021 – The results from 26 articles revealed multiple models of care because of the use of trained incarcerated caregivers, working as aides to the interprofessional team. The barriers to adequate psychosocial care were negative public discourse, prison processes and resources, provider attitudes and the incarcerated person's level of knowledge and trust. Understanding the importance of psychosocial care for incarcerated persons with a life-limiting illness requires a shift in negative public discourse and the need for a stronger human rights focus. Some countries are achieving effective outcomes; however, countries such as Australia are yet to contribute to this knowledge base. Abstract: https://bit.ly/3dQSbsM

## The anticipation of an investigation: The effects of expecting investigations after a death from natural causes in prison custody

CRIMINOLOGY & CRIMINAL JUSTICE | Online – 29 June 2021 – The growing number of deaths from natural causes in prison custody adds urgency to the need to consider what influences the behaviour of prison staff towards dying prisoners. This article identifies the effects on prisoners, their families and prison staff of defining quality end-of-life care as that which meets the expected requirements of an anticipated post-death investigation. It explores the practical consequences, emotional effects and bureaucratisation of death arising from the anticipation of an investigation. This article focuses on the influence of anticipating an investigation by the Prison & Probation Ombudsman, but also the effects of expecting police and coronial investigations. Full text: <a href="https://bit.ly/3AMIKGp">https://bit.ly/3AMIKGp</a>

## Mapping palliative care provision in European prisons: A European Association for Palliative Care task force survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 April 2021 – The survey consisted of 40 questions in six sections and was completed for eight countries. Three main findings are reported here: healthcare and palliative care (PC) provision in prisons, deaths in custody, and compassionate release. Despite increasing numbers of older prisoners, relatively few prisons provide inpatient care, and only one country has any prisons that provide dedicated PC services. Early release on compassionate grounds is extremely rare in most countries. For the principle of equivalence to be adhered to, facilities for sick and dying prisoners need to be improved, or many more people need to be released on compassionate grounds at the end of life. Abstract: https://bit.ly/2QPihnZ

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

CANCER NURSING, 2021;44(1):29-36. The need for palliative and hospice care for persons with life-limiting conditions who are incarcerated is increasingly common in correctional facilities worldwide. Key concerns and implications for nursing are illustrated through the discussion of a representative case scenario. By applying a family nursing approach, nurses practicing with correctional populations can ensure persons with life-limiting illnesses are not denied their right to appropriate end-of-life care by playing a key role in addressing barriers to palliative and hospice care access in corrections. Specific attention to relational issues and holistic care can contribute to enhanced palliative and hospice care, greater dignity in dying, and improved family and peer outcomes. Full text: <a href="https://bit.ly/2UxEHMK">https://bit.ly/2UxEHMK</a>

## 2020

### Healthcare needs of older women prisoners: Perspectives of the healthcare workers who care for them

JOURNAL OF WOMEN & AGING, 2020;32(2):183-202. The proportion of older incarcerated women is growing, yet little is known regarding their healthcare needs. The authors of this article sought to elucidate the unique healthcare needs of older women prisoners through the perspectives of correctional healthcare providers. Three organizing themes emerged regarding the health of older women prisoners: 1) The meaning of being "older" in the prison setting; 2) The challenges impacting correctional healthcare workers' care delivery; and, 3) The unmet healthcare-related needs. Correctional healthcare workers' insights can provide guidance regarding how to optimize the health of the increasing population of older women prisoners. Abstract (w. references): <a href="http://bit.ly/2uNwbsf">http://bit.ly/2uNwbsf</a>

## 2019

## Palliative care for inmates in the hospital setting

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2019;36(4):321-325. The aim of this study was to assess the frequency of palliative care (PC) consultation and nature of consultation requests for inmates who died while hospitalized at a large tertiary care hospital. A retrospective chart review of all inmate decedents over a 10-year time period was conducted. The reason and timing of consultation was noted in addition to symptoms identified and interventions recommended by the PC team. 45% of inmates were seen by PC prior to their death. Timing of consultation was close to the day of death. Inmates with cancer were significantly more likely to have a PC consultation prior to death. Abstract (w. references): http://bit.ly/2JqC0oS

## 2018

## Ageing and dying in the contemporary neo-liberal prison system: Exploring the "double burden" for older prisoners

SOCIAL SCIENCE & MEDICINE, 2018;212(9):161-167. Older prisoners face a "double burden" when incarcerated. This double burden means that as well as being deprived of their liberty, older people experience additional suffering by not having their health and wellbeing needs met. For some, this double burden includes a "de facto life sentence," whereby because of their advanced age and the likelihood that they will die in prison, they effectively receive a life sentence for a crime that would not normally carry a life sentence. There has been little popular or academic debate concerning the ethical and justice questions that this double burden raises. Many of the challenges discussed are emerging in other countries across the world. Full text: http://bit.ly/2Hyk34A

## Preparing to die behind bars: The journey of male inmates with terminal health conditions

JOURNAL OF CORRECTIONAL HEALTH CARE, 2018;24(3):232-242. The prison population is graying as more individuals are receiving longer sentences without opportunities for parole or release for health-related reasons. While research has expanded on end-of-life care in and out of prison settings, to date there has been little research conducted on how inmates experience dying behind bars. This qualitative study revealed four main themes: 1) Losing a piece of everything; 2) Not sure what to feel; 3) Where will I die; and, 4) Finding purpose in the midst of purposelessness. These themes characterize the central issues discussed by inmates as they considered death behind bars. This study provides insight into how inmates view their dying process. Abstract (w. references): http://bit.ly/2JqhKUI

## End-of-Life Care in the Prison Environment in the U.S.A.

2022

## Death and dying in carceral America: The prison hospice as an inverted space of exception

MEDICAL ANTHROPOLOGY QUARTERLY, 2022;36(2):177-197. Death by incarceration looms as inescapable for myriad inmates who are terminally ill or "graying" in prison. These realities informed this study of a prison-based hospice program staffed by male inmate volunteers in a mixed medium/maximum security facility. Of special concern were the experiences of the men who sit by the bedside of others who are dying. In this article, the author begins with the assumption that prisons loom as states of exception, epitomized by the realities of substandard prison medicine, the devaluation of care as anathema to prison survival, and the persistent neglect of the ill and aging. **Abstract:** https://bit.ly/3uewmN6

## Large-scale evaluation of a computer-based learning program to increase prison staff knowledge on geriatric and end-of-life care

INTERNATIONAL JOURNAL OF PRISONER HEALTH, 2022;18(2):185-199. Geriatric and end-of-life care in corrections is not as equitable as care in the free world. Technological delivery of geriatric training to staff through computer-based learning offers a novel approach to improve care and reduce disparities among those who are most vulnerable during confinement. Participants in this evaluation improved their knowledge after receiving the training. Correctional settings face increasing pressures to better address the healthcare and management needs of aged, chronically ill and dying incarcerated persons. This e-learning holds promise to contribute to better preparation of corrections staff to effectively care for these populations. **Abstract:** https://bit.ly/3DcxgMP

## Selected journal articles on education/training initiatives:

- 'Inmates Care: Computer-based training for geriatric and end-of-life care in prisons,' *Journal of Correctional Health Care*, 2021;27(2):132-144. Full text: <a href="https://bit.ly/3cB1CfX">https://bit.ly/3cB1CfX</a>
- 'Developing computer-based learning on care of aged and dying incarcerated people,' *Journal of Forensic Nursing*, 2020;16(1):36-46. Abstract: <a href="http://bit.ly/345V0iu">http://bit.ly/345V0iu</a>
- 'Developing educational modules to enhance care of aged and dying inmates: Set-up phase,' Public Health Nursing, 2019;36(3):401-410. Abstract: <a href="http://bit.ly/2DteEJV">http://bit.ly/2DteEJV</a>
- 'A brief video intervention to improve medical students' attitudes toward prisoners,' Journal of Contemporary Medical Education, 2019;9(2):46-52. Full text: http://bit.ly/2OSFeDL

## Palliative care for incarcerated adults

UPTODATE | Online - 22 May 2022 - As the population of aging and/or seriously ill incarcerated patients continues to grow, so does the need for palliative care (PC)...

Most incarcerated persons have similar end-of-life goals as those in the community; they want to have their symptoms controlled, to spend time with friends and family, and to be able to find meaning in their lives. The authors describe health concerns of incarcerated patients in the U.S. and approaches to the provision of PC, including barriers and strategies for overcoming these barriers. The authors are not able to provide specific information or recommendations for incarcerated persons outside of the U.S. **Introduction (w. references):** https://bit.ly/3R32IJ5

2021

## Death and dying in prison: An integrative review of the literature

JOURNAL OF FORENSIC NURSING, 2021;17(2):115-125. Mass incarceration has been a major issue in the U.S., with rates sharply increasing since the 1970s. In the past two decades, the number of older incarcerated persons has grown by 500%, highlighting the importance of end-of-life (EoL) care and decisions among this demographic. Searches yielded 233 articles published after 2000. 29 full-text articles were assessed for eligibility, and seven qualitative studies met the authors' criteria and were included in the review. Five main categories were observed across the themes elicited by the studies: 1) EoL services in prison; 2) Social contact and human interactions; 3) Thoughts of death and fear of dying; 4) Wishes and decision-making; and, 5) Guilt and coping. **Abstract:** https://bit.ly/3mGhb9V

## 2020

## Characteristics of hospice and palliative care programs in U.S. prisons: An update and 5-year reflection

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2020;37(7):514-520. Individuals with terminal illness are dying behind bars and many state prison administrators have incorporated on-site hospice and palliative care (PC) services. The authors provide an updated description and reflection of current hospice and PC programs in state prisons serving incarcerated persons with terminal illness. A cross-sectional survey was sent to representatives of all known prisons offering hospice and PC programs and services. Responding representatives indicated interdisciplinary teams remain integral to care, peer caregivers continue to support dying patients, and perceived public support for these programs remains low. **Abstract (w. references):** http://bit.ly/2DOp3Ay

## Should patients who are incarcerated on death row receive palliative cancer care?

THE LANCET ONCOLOGY, 2020;21(3):337-338. In modern society, it is accepted that individuals have the right to die with dignity. Since 1976, in the U.S., people who are incarcerated have a limited constitutional right to healthcare, consistent with the country's Eighth Amendment. At present, there are more than 2,600 incarcerated men and women in the U.S. who have been sentenced to death, most of whom have less than a high school diploma or High School Equivalency Certificate, and are disproportionately of minority racial or ethnic backgrounds (42% African American representation on death row vs 13% African American representation in the U.S. census). Abstract (w. references): http://bit.ly/2PGBggL

#### Related:

'Improving care for the overlooked in oncology: Incarcerated patients,' The Lancet, 2019;20(10):1342-1344. Abstract (w. references): http://bit.ly/2ngCuly

2019

#### Shackled at the end of life: We can do better

AMERICAN JOURNAL OF BIOETHICS, 2019;19(7):61-63. In Estelle v. Gamble the U.S. Supreme Court established that deliberate indifference to serious medical needs of prisoners is a violation of the Eighth Amendment, which prohibits "cruel and unusual punishment." Subsequent case law has established that the incarcerated have a de facto right to a "community standard" of healthcare. Similarly, the United Nations 'Standard Minimal Rules for the Treatment of Prisoners' (Mandela Rules) dictate that "all prisoners shall be treated with the respect due to their inherent dignity and value as human beings" and "enjoy the same standards of healthcare that are available in the community." First page view (w. references): http://bit.ly/2YdU8pJ

2018

## End-of-life care in prison

SOCIAL WORK TODAY, 2018;18(6):16. For many of the individuals incarcerated across the U.S., dying is more than a possibility or passing thought. Given their sentences, their age, and, often, their health, dying in prison is inevitable. The circumstances of the death vary based not only on the person but the facility as well. For some, dying in their cell with their cellmate nearby is the best of terrible options. "They die in their 'homes,' where their cellmates are, their friends are," says Marvin Mutch, of the Humane Prison Hospice Project... Mutch was imprisoned for 41 years after a wrongful conviction in 1975 and was released in 2016. Dying in one's cell, however, is difficult, not only for the prisoner but also for their cellmate. **Full text:** http://bit.ly/2w8vvOl

### Prison hospice care: Life and death behind bars

AMERICAN JOURNAL OF PSYCHIATRY, 2018;13(3):3. Hospice care is a unique field that enables psychiatrists to use their skill set to improve the quality of life and experience of death for terminally ill patients and their families. Prison hospice is an expanding specialty that should be considered by physicians who are interested in the legal system, hospice care, and care for vulnerable populations. An increase in both the U.S. prison population and average inmate age has burdened the correctional system with caring for chronically and terminally ill incarcerated persons. One response to this problem was the Sentencing Reform Act of 1984, which provided the option of compassionate release for dying inmates. However, this policy has been largely ineffective... Full text: http://bit.ly/2Jx5bXF

### The health of America's aging prison population

EPIDEMIOLOGIC REVIEWS, 2018;40(1):157-165. The authors summarize the epidemiologic evidence of the health challenges facing the aging U.S. prison population. Their comprehensive literature search focuses on health outcomes, including diseases, comorbid conditions, mental health, cognition, and mobility. From 12,486 articles identified from the literature search, the authors reviewed 21 studies published between 2007 and 2017. All were observational and cross-sectional, and most were based on regional samples. Sample sizes varied widely, ranging from 25 to 14,499 incarcerated people... In general, compared with their younger counterparts, older incarcerated individuals reported high rates of diabetes mellitus, cardiovascular conditions, and liver disease. Full text: http://bit.ly/2Eh46yT

## Dying behind bars

JOURNAL OF GERONTOLOGICAL NURSING, 2018;44(1):2-3. Despite the push in nursing research to devote attention to the process of healthy aging, and to better understand the needs faced by the aging population, injustice has occurred for a marginalized group of aging Americans: prisoners. The prison population is aging rapidly. In 2008, more than 74,000 men and 4,000 women older than 55 were in prisons nationwide. In upcoming decades, that number is likely to skyrocket because approximately 162,000 individuals are currently serving life sentences. As a community of nurse scientists, we have neglected the prison population while focusing our attention on the benefits of hospice care and our human right to choose how we die. Full text: <a href="http://bit.ly/2W69EX7">http://bit.ly/2W69EX7</a>

## End-of-Life Care in the Prison Environment in the U.S.A. (State-by-State)

#### California

THE DESERT SUN (Palm Springs) | Online – 22 June 2022 – 'California Added Since 05.01, 2022 Update can find better ways of dealing with dying prisoners.' People who are incapacitated or nearing the end of their lives are the most expensive to incarcerate and the least likely to reoffend. California law permits courts to resentence certain people who meet strict criteria on time served so that they may live their final months outside a prison. But this system, referred to as compassionate release, is hampered by eligibility criteria that are too narrow and by a process that funnels meritorious cases through a single actor. https://bit.lv/3zYsHpJ

THE PRESS DEMOCRAT (Santa Rosa) | Online – 7 October 2021 – 'Sebastopol woman works to dignify death for San Quentin prison's ailing inmates.' People incarcerated on life sentences in San Quentin have few options for where and how they'll take their last breaths: they may die in the prison infirmary, alone. If lucky, they may fill one of 17 dedicated palliative beds at California Medical Facility ... one of the only prisons out of the state's 32 that has hospice services. They may be brought to a hospital in the outside community, where they are chained to a bed and guarded until they die. Or they die in their prison cell, with their cellmate sent to grieve afterward in isolation... https://bit.ly/3iJEcbj

REUTERS | Online – 19 June 2018 – 'Inside the prison hospice where no inmate dies alone.' One of Fernando Murillo's greatest fears is dying in prison. The 38-year-old former gang member, serving a sentence of 41 years to life for second-degree murder when he was 16, says it is that fear which helps him empathize with the terminally ill inmates he looks after at a California prison hospice. Murillo's work in the 17-bed hospice unit at the medium-security California Medical Facility in Vacaville, about 55 miles (88.51 km) northeast of San Francisco, includes helping dying prisoners take a shower or go to the bathroom. But there is another, more important element to the job, he says. https://reut.rs/2LUZuVg

THE NEW YORK TIMES | Online – 16 May 2018 – 'Where both patients and caregivers are prisoners.' The hospice at the California Medical Facility is one of the nation's first and the only licensed hospice unit inside a California prison. Built in 1993 in response to the AIDS crisis and inmate-led demands for more humane care, the hospice was originally populated with young men dying of complications of the disease. Today, the 17-bed unit is filled with a different demographic: graying men with everything from end-stage cancer to Alzheimer's shuffle around with walkers, sit in wheelchairs watching television or lie curled up under heavy blankets. https://nyti.ms/2Jrs3rg

PALLIATIVE MEDICINE, 2018;32(1):17-22. 'Differences between incarcerated and non-incarcerated patients who die in community hospitals highlight the need for palliative care services for seriously ill prisoners in correctional facilities and in community hospitals: A cross-sectional study.' Overall, 745 incarcerated and 370,086 non-incarcerated individuals died in California hospitals between 2001 and 2013. Incarcerated decedents were more often male, Black, Latino, younger, and had shorter hospitalizations ...and, fewer had an advance care plan. Incarcerated decedents had higher rates of cancer, liver disease, HIV/AIDs, and mental health disorders. Abstract (w. references): http://bit.ly/2w7Ur97

### Illinois

WTVO (Chicago) | Online - 21 August 2021 - 'Illinois to release some incapacitated or terminally ill prisoners.' Illinois Governor JB Pritzker signed legislation which would allow for the release of incapacitated or terminally ill prisoners from incarceration. HB 3665 allows for the discretionary early release of those who are medically incapacitated or terminally ill who are serving time in the Illinois Department of Corrections. Currently, the Prisoner Review Board (PRB) determines conditions of parole and notifies victims and families when an inmate will be released from custody. The board also makes recommendations for clemency petitions to the Governor. <a href="https://bit.ly/3zitWwX">https://bit.ly/3zitWwX</a>

THE SOUTHERN ILLINOISAN | Online – 26 May 2019 – ""We carry a light": Inmates at Shawnee Correctional Center care for the prison's dying.' Karen Smoot ... has worked for the Illinois Department of Corrections since 2016, and said hospice or end-of-life care (EoLC) is different for prisoners. They are not in their homes, in their own beds, and oftentimes are not surrounded by loved ones. But still, Smoot sees it as her job to comfort them. "We're tasked with taking care of him and providing for him the appropriate and humane EoLC," she said. Another thing that separates hospice care at Shawnee is the team of caretakers Smoot has assembled. <a href="http://bit.ly/2VSGLt0">http://bit.ly/2VSGLt0</a>

### Louisiana

JOURNAL OF CORRECTIONAL HEALTH CARE | Online – 31 May 2022 — Added Since 05.01.2022 Update 'Louisiana State Penitentiary: A textual analysis of correctional staff views on end-of-life care.' Scarce attention has been devoted to the views of correctional staff who provide essential end-of-life care to dying incarcerated individuals. They must maneuver their diverse responsibilities and emotional perspectives to deliver compassionate care to a marginalized population. Researchers explored the transformative experiences resulting from staff members' collaboration with incarcerated volunteers to dispense hospice-based care for critically ill the incarcerated. Abstract: <a href="https://bit.ly/3tbSQ04">https://bit.ly/3tbSQ04</a>

JOHN A. HARTFORD FOUNDATION | Online - 3 August 2018 - 'As America's incarcerated age, the need for hospice rises.' At the Louisiana State Penitentiary over 80% of the 6,500 inmates are serving life sentences and can expect to die behind bars. Of those who eventually receive terminal medical diagnoses, many voluntarily choose to enter an innovative hospice program in lieu of pursuing medical care. Hospice care programs have opened across the country in prison facilities desperate for ways to meet the needs of their increasingly aging incarcerated populations. Some proponents of humane end-of-life care in prisons are advocating for even more wardens to implement hospice programs... http://bit.ly/2JPkp9M

#### Maine

THE BANGOR DAILY NEWS | Online - 8 February 2020 - 'An inmate serving 50 years for attempted murder is an unlikely caretaker for dying prisoners.' Prison might be the worst place you can think of to die. Isolated from the outside world, perishing behind concrete walls and metal locking doors because death caught up with you while you were serving a sentence. That is the reality for inmates housed in Maine State Prison's infirmary because they are suffering from a terminal illness and are not expected to live longer than six months. But a group of inmates has made it their mission to make sure no prisoner dies alone. The prison began offering hospice services when its new facility opened in 2001... Ihttp://bit.ly/39nBHUD



### Maryland

NATIONAL PUBLIC RADIO (WYPR, Baltimore) | Online – 8 November 2021 – 'Perspectives on providing end-of-life care for the nation's incarcerated.' According to the Maryland Center for Economic Policy, the state of Maryland spends about \$1 billion per year incarcerating roughly 20,000 people convicted of crimes. In 2015, the state spent \$17 million locking up people from one neighborhood alone. For many of those who are given long sentences, their lives will end while they are behind bars. An essay in *The Baltimore Sun*, a couple of months ago, about palliative care for prisoners when they are diagnosed with terminal illnesses caught this station's attention,¹ ... https://bit.ly/3H56B60

 'Dying prisoners deserve dignity and palliative care, if not compassionate release,' The Baltimore Sun, 28 September 2021. [Noted in the 1 November 2020 'Prison Backgrounder'] https://bit.ly/3igico2

### Massacheusetts

WBUR-FM (Boston) | Online - 24 May 2022 - 'Compassionate release for aging prisoners isn't enough.' Massachusetts is ranked second-

highest in the nation for its number of older people who are incarcerated, with more than 15% of its currently incarcerated population over the age of 55. With more people dying in prison of old age than ever before, legislators are left pondering what to do with the aging prison population. One proposed solution is compassionate release, a policy that advocates for medical parole for those who are terminally ill or incapacitated so that they may receive proper medical support and end-of-life treatment. <a href="https://wbur.fm/3NnOQBk">https://wbur.fm/3NnOQBk</a>

#### Missouri

KBIA RADIO | Online – 10 January 2018 – 'Missouri offenders help their peers come to terms with death.' Offenders in some Missouri prisons are breaking down walls – emotional walls. They're demolishing the barriers they've spent years building while inside a prison cell. But it's only at the end of their sentence, the end of their life, that those walls finally crumble. And they crumble with a fellow inmate by their side. It's all part of the Missouri Department of Corrections Hospice Program... Missouri prisons have anywhere between eight to 10 hospice patients each month. In the two hospice care rooms located in the infirmary at Jefferson City Correctional Center, offenders live out their final days.http://bit.ly/2M6CPWj

#### Nevada

THIS IS RENO | Online – 25 August 2018 – 'Nevada's first prison hospice opens.' The Northern Nevada Correctional Center opened the first of its kind dorm-style hospice unit in the Nevada prison system to serve inmates with severe life-ending illnesses. There are approximately 100 prisons across the country that acknowledge the unique long-term physical, psychological, and spiritual needs of aging inmates. Hospice programs are a part of the solution to tackle the heavy financial burden and growing medical needs of what is reported to be the fastest growing incarcerated population... Approximately 10% of inmates serve life sentences and another 11% are sentenced to serve 20 years or more. http://bit.ly/2LV2Es6

## New York State

NEW YORK DAILY NEWS | Online - 31 May 2021 - 'Aging and dying behind prison bars.' Our prisons have essentially turned into inhumane nursing homes - trapping people who bear no risk to public safety. This isn't just a problem in New York. Nationwide, of the 200,000 people serving life sentences, nearly one-third are 55 or older. Fortunately, momentum is building across the country for reforms that would reevaluate long sentences for incarcerated people, according to a new report from The Sentencing Project.¹ In New York, lawmakers are considering legislation that would allow many incarcerated people with extreme sentences to be eligible for parole. https://bit.ly/34DIAIK

1. 'A Second Look at Injustice,' The Sentencing Project, May 2021. Download at: https://bit.ly/3yREL9b

PALLIATIVE MEDICINE, 2018;32(5):969-979. "People don't understand what goes on in here": A consensual qualitative research analysis of inmate-caregiver perspectives on prison-based end-of-life care. There is growing research support for prison-based end-of-life care programs that incorporate inmate peer caregivers as a way to meet the needs of the elderly and dying who are incarcerated. Study participants were incarcerated at Briarcliff Correctional Facility, a maximum security, state-level correctional facility in New York State. Three over-arching/distinct domains emerged: 1) Program description; 2) Motivation; and, 3) Connections with others. Abstract (w. references): <a href="http://bit.ly/2EhnknN">http://bit.ly/2EhnknN</a>

## Pennsylvania

COURIER EXPRESS (DuBois) | Online – 21 April 2022 – 'Compassion hard to come by in broken prison system.' Some people incarcerated in Pennsylvania state prisons are as far as one could imagine from being a threat to society. They can barely take care of themselves, let alone hurt others – and some are terminally ill. The need to care for these people is so great that last year the Department of Corrections announced a new unit, specifically to treat those who are imprisoned and suffer from dementia. Pennsylvania's "compassionate release" law ...allows people who meet extremely strict criteria to be transferred from prison to a hospital, long-term care facility, or hospice. https://bit.ly/3L4qHiz

PITTSBURGH POST-GAZETTE | Online - 30 March 2022 - 'Broken "compassionate release" rules strand Pennsylvania's sickest prisoners as costs to taxpayers soar.' There are few ways for people getting older behind bars to get out unless their death is imminent. Under the current state law, there are no parole opportunities for people serving life, even if they're decades removed from the crime, sick and determined to no longer be a danger to the public. One of the only options, Pennsylvania's version of "compassionate release" for the sick and dying, is so narrowly written only 31 people have successfully petitioned for it in thirteen years. https://bit.ly/3iVI8Fv

PENNSYLVANIA CAPITAL-STAR | Online – 19 August 2021 – 'Life without parole has turned Pennsylvania's prisons into hospices for the hopeless.' Over 10 years ago I was in prison, tasked with the strange job of changing diapers, bathing paralyzed men, and preventing bedsores. I watched incarcerated people enter hospice and die, with me as a volunteer and stranger serving the role of their only family. While I'd come to think prisons were intended to rehabilitate people, my time spent incarcerated opened my eyes. People were aging and dying in prison, withering away to nothing with no chance of ever returning to the free world. https://bit.ly/3ATWhtN

## Virginia

THE DAILY PROGRESS | Online – 7 July 2019 – 'First compassionate care program in state offers inmates chance to care.' Melanie Mason, a social worker for the Hospice of the Piedmont, received a call from the Fluvanna prison, notifying her that a new inmate had previously received hospice care at a different facility and had requested hospice care at Fluvanna. The prison didn't have trained medical staff who were available to sit by the woman's bed 24/7, so Mason, hospice nurse Ruth Hurley and prison nurse manager Mikayla Osborne suggested asking other inmates to volunteer. "This was a patient who didn't have a strong family background and unfortunately had to do this process by herself," Osborne said. http://bit.ly/2JGvNTJ

### Wisconsin

THE MILWAUKEE JOURNAL SENTINEL | Online – 18 April 2018 – 'Release programs for sick and elderly prisoners could save millions. But states rarely use them.' Early release provisions for elderly and infirm prisoners are billed as a way to address problems such as prison overcrowding, skyrocketing budgets and civil rights lawsuits alleging inadequate medical care. Of the 47 states with processes to free such prisoners early or court rulings requiring them to do so, just three released more than a dozen people in 2015. The reasons for the low numbers are usually found in the statutes that created the programs, known as compassionate release, geriatric release and medical parole, among other things. <a href="http://bit.ly/2HGcx7w">http://bit.ly/2HGcx7w</a>

## End-of-life care in the Prison Environment in Australia

### The aged-care crisis in prisons

THE SATURDAY PAPER | Online - 18 June 2022 - Many studies classify "ageing prisoners" as those aged 45 and older, given the higher likelihood these people will

have a range of health problems and the accelerated ageing that prison causes. This cohort has more than doubled during the past 20 years and accounted for nearly a quarter of the roughly 43,000 inmates in Australian prisons as of the end of last year. The increase is due to the ageing population in general... Many studies classify "ageing prisoners" as those aged 45 and older, given the higher likelihood these people will have a range of health problems and the accelerated ageing that prison causes. <a href="https://bit.ly/3OaEq96">https://bit.ly/3OaEq96</a>

### Ensuring the quality of palliative care in Australia's prisons

AUSTRALIAN HEALTHCARE & HOSPITALS ASSOCIATION | Online – 10 May Added Since 05.01.2022 Update 2022 – People in Australian prisons experience a higher burden of chronic disease and age-related disease earlier than those in the community. Consequently, they require palliative care (PC) earlier in life. People in prison are entitled to receive healthcare, including PC, that is equitable to care in the community. However, the prison environment introduces additional barriers to PC provision than are faced in the community. The current demand for PC in the prison setting is unknown due to a lack of available data... **Download brief at:** https://bit.ly/3Pf8hOk

## Palliative care needs and experiences of people in prison: A systematic review and meta-synthesis

PALLIATIVE MEDICINE, 2022;36(3):443-461. People in prison expect to receive high-quality palliative care (PC), but their experiences often do not match their expectations. Experiences of people in prison regarding PC related to two themes: 1) Expectations versus experiences of PC; and, 2) Prison context complicates access to and provision of PC. People in prison with PC needs want to feel safe, cared for, and acknowledged as they face an expected death. The prison environment can severely restrict access to PC, leaving people in prison feeling isolated and powerless. Numerous structural and organisational challenges complicate the provision of PC in prisons, limiting accessibility of care. Abstract (w. references): <a href="https://bit.ly/3sKtXJm">https://bit.ly/3sKtXJm</a>

N.B. Palliative Care in Prisons Project, University of Technology Sydney, Australia: https://bit.ly/32GrcOy

## Caring for the terminally ill in prison

UNIVERSITY OF MELBOURNE | Online – Accessed 1 February 2022 – Consider for a moment how it might feel to be told you have a diagnosis of advanced cancer. Uncertainty? Fear? Grief? Everything is different, and your family and friends matter more than ever. Now consider the same advanced cancer diagnosis and picture that you are in prison when you get this news. What does the lens of "prison" mean when living with and dying from serious illness? And how do clinicians providing care perceive the effects of being in prison for patients facing end of life? Research has uncovered the opportunities perceived by health professionals to improve the models of care for prisoners dying with progressive and life-limiting illnesses. <a href="https://bit.ly/3eqeVh9">https://bit.ly/3eqeVh9</a>

### Comprehensive indigenous healthcare in prisons requires federal funding of community-controlled service

THE CONVERSATION | Online – 20 May 2021 – The Royal Commission into Aboriginal Deaths in Custody Report made over 200 directives about improving the health of people in prisons in its 339 recommendations in 1991.¹ One of these recommendations included additional funding to provide better health services for Aboriginal and Torres Strait Islander people in prison. The Commission and the United Nations recommend people in prisons have access to healthcare equivalent to what is available in the community. However, the system is still strained, as the multiple deaths of Aboriginal people in custody in recent months reveal... Palliative care (PC) specialists and nurses with PC training are almost entirely missing. <a href="https://bit.ly/3ypW0hA">https://bit.ly/3ypW0hA</a>

 'Royal Commission into Aboriginal Deaths in Custody: Final report,' Australasian Legal Information Institute, April 1991. Download/view at: <a href="https://bit.ly/3yr4Bkb">https://bit.ly/3yr4Bkb</a>

## Identifying barriers and facilitators to implementing care planning in prisons: A rapid literature review

HEALTH & JUSTICE | Online – 21 September 2020 – Limited academic literature related to the implementation and experience of advance care planning (ACP) in prisons is available... Barriers and facilitators related to the implementation of ACP in prisons were grouped into systems-based factors, attitudes and perspectives of staff and prisoners, and understanding and knowledge of ACP by staff and prisoners. ACP and substitute decision-making appears poorly integrated into correctional health currently, and barriers exist at the system, staff, and prisoner levels. As the number of older prisoners dying from natural causes is increasing, improving ACP uptake in prisons is essential to ensure prisoner medical treatment preferences are respected. Full text: https://bit.ly/2RQbIUS

## Related:

"We take care of patients, but we don't advocate for them": Advance care planning in prison or jail,' Journal of the American Geriatric Society, 2018;66(12):2382-2388. Abstract: <a href="http://bit.ly/2HnEsu0">http://bit.ly/2HnEsu0</a>

## End-of-life Care in the Prison Environment in Canada

## Understanding the policy landscape surrounding medical assistance in dying in Canada's federal prison system

JOURNAL OF CORRECTIONAL HEALTHCARE, 2022;28(2):75-79. Medical assistance in dying (MAiD) has been legal in Canada since 2016, and implementation of MAiD for people incarcerated has raised ethical and procedural concerns. The authors review the current Correctional Service Canada guideline on MAiD alongside a report by the Office of the Correctional Investigator (OCI) and the Canadian Human Rights Commission (CHRC) on aging and dying in prison. They echo concerns raised by the OCI and the CHRC about the limits of adequate end-of-life care currently provided and offer an analysis of the procedural guideline for MAiD in prison, which they argue to be inadequate in support for patient-centered care and equality in access to healthcare. Abstract: <a href="https://bit.ly/3sBy2xZ">https://bit.ly/3sBy2xZ</a>

'Aging and Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody,' Correctional Investigator of Canada & Canadian Human Rights Commission, 28 February 2019. Download/view at: <a href="http://bit.ly/2GP4aZr">http://bit.ly/2GP4aZr</a>

### Additional journal articles on medical assistance in dying:

"Dying with a smile, just knowing that somebody's listened to me": End-of-life care and medical assistance in dying in Canadian prisons,' Omega – Journal of Death & Dying, published online 31 December 2021. Full text: https://bit.ly/3eFoWtl

'Assisted dying for prison populations: Lessons from and for abroad,' *Medical Law International*, 2019;19(2-3):207-225. Abstract: http://bit.ly/2ZENp8m

### Life and death in Canadian penitentiaries

CANADIAN FAMILY PHYSICIAN, 2020;66(10):759. 25% of the individuals incarcerated in federal prisons are older than 50. They have higher rates of mortality and morbidity for most illnesses. They go through a process of accelerated aging (i.e., they have the health problems of someone 10 to 15 years older than them in the community). Their life expectancy is around 62 years, compared with the Canadian average of 82 years. The aging of the incarcerated population creates unexpected challenges. These include high rates of comorbidities, and illnesses and symptoms commonly associated with aging, such as dementia... Prisons were never meant to be nursing homes, and yet they are increasingly asked to perform this function. **Full text:** https://bit.ly/34fvScl

## As the prison population ages, parolees with age-related illnesses struggle to find support

THE TORONTO STAR | Online - 3 February 2020 - Resources for elderly parolees is one part of a new guidebook released by the Provincial Human Services & Justice Coordinating Committee that provides a crash course in navigating the criminal justice system for people with age-related illnesses and their caregivers. There really isn't a lot of information out there for family members or caregivers of people that are caught up in the justice system, or are getting out. What supports or resources are available in the community on their release?" said Jeff Morgan, a case manager at Haley House... There is a growing number of inmates over the age of 50 in the prison system - now 25% of the population... http://bit.ly/2ttKplc

- 1. 'Older Adults and the Justice System: A navigational guidebook for caregivers and service providers,' the Provincial Human Services & Justice Coordinating Committee, February 2020. **Download/view at:** <a href="http://bit.ly/3927nim">http://bit.ly/3927nim</a>
- 'Aging and Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody,' Correctional Investigator of Canada & Canadian Human Rights Commission, 28 February 2019. Download/view at: <a href="http://bit.ly/2GP4aZr">http://bit.ly/2GP4aZr</a>

## Barry R. Ashpole

MY INVOLVEMENT IN HOSPICE AND PALLIATIVE CARE DATES FROM 1985. As a communications consultant and educator, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current focus is advocacy and policy development in addressing

issues specific to those living with a terminal illness – both patients and families. See biosketch on the International Palliative Care Resource Center website: <a href="http://bit.ly/2RPJy9b">http://bit.ly/2RPJy9b</a>

### End-of-life care for federally incarcerated individuals in Canada

MCGILL JOURNAL OF LAW & HEALTH, 2020;14(1):1-50. The authors review the current legislation, policies, and practices related to end-of-life care (EoLC) for federally incarcerated individuals as set out in statutes, guidelines, and government reports and documents that were either publicly available or obtained through Access to Information requests from the Parole Board of Canada and Correctional Service of Canada (CSC). They describe the *status quo*, identify gaps, and offer reflections and raise concerns regarding EoLC for federally incarcerated individuals. There are significant information gaps about the number of people seeking EoLC and about how CSC is managing the provision of such care. Full text (click on pdf icon): https://bit.ly/3cQVH4t

## Palliative care and the injustice of mass incarceration: Critical reflections on a harm reduction response to end of life behind bars

WITNESS: THE CANADIAN JOURNAL OF CRITICAL NURSING DISCOURSE, 2019;1(2):4-16. Due to the criminalization of marginalized people, many markers of social disadvantage are overrepresented among prisoners. With an aging population, end of life in prison thus becomes a social justice issue that nurses must contend with, engaging with the dual suffering of dying and of incarceration. Prison palliative care (PC) has much to learn from harm reduction. Critical reflections from harm reduction scholars and practitioners hold important insights for prison PC: decoupled from its historical efforts to reshape the social terrain inhabited by people who use drugs, harm reduction can become institutionalized and depoliticized. Full text: http://bit.ly/2VqLGFI

### End-of-life Care in the Prison Environment in China

#### Behind bars, hospital care is blind to crime

CHINA | Shanghai Daily | Online – 24 November 2019 – Doctors working at a unique hospital in Shanghai can rarely hope that a patient who is successfully treated will walk out into the sunshine. Their domain is Shanghai Prison General Hospital, the only one of its kind in the city prison system. Besides ordinary departments, the 450-bed hospital has specialized sections for prisoners suffering from AIDS, tuberculosis, drug addiction and mental diseases. Many young doctors who work in the hospital initially regard the patients as beasts shut in cages, but that impression fades as time passes and they treat what is certainly an unusual population of people suffering from poor health. Inmates with treatable maladies remain in the prison hospital. http://bit.ly/34iw9bU

#### End-of-life Care in the Prison Environment in France

### Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national survey

PALLIATIVE MEDICINE, 2018;32(1):6-16. Overall, France has been reluctant to promote palliative care units in the prison sector, probably because terminally ill prisoners are supposed to be released, given that the law provides for this option. Prison palliative and hospice care units have been created in the U.S. and the U.K., and many promising practices have already been proposed, such as the use of peer volunteers, multi-disciplinary teams, special health units inside the prison, staff training, and partnerships with community hospices. Nevertheless, figures are not easily available to plan for resources. This study contributes to providing important data regarding end-of-life care in prisons in France and could serve as an example for other countries... Full text: <a href="http://bit.ly/2WcATPC">http://bit.ly/2WcATPC</a>

## End-of-life Care in the Prison Environment in Germany

## The fragmented picture of social care for older people in German prisons

JOURNAL OF AGING & SOCIAL POLICY | Online – 8 March 2022 – Older people in prisons are a vulnerable group with complex health and social care needs. German prisons have started to adapt to demographic changes and exemplary support services for older people are available in a few prisons, but a lack of age-specific support is widespread. National standards are needed to provide predictable conditions of imprisonment for older people. In order to achieve the goal of reintegrating older people into society on their release, more support is needed to help them age successfully. Expertise on aging should be used and fostered more widely. Palliative care services need to be developed. **Abstract:** <a href="https://bit.ly/3aJitiu">https://bit.ly/3aJitiu</a>

## End-of-life Care in the Prison Environment in Ireland

## Prisoners near death housed in "unsuitable" environment

THE IRISH TIMES (Dublin) | Online – 6 July 2021 – Chaplins' reports reveal harsh reality of jail life and death for prison inmates and staff. Some prisoners in Irish jails were so fragile and close to death they were unable to use a telephone yet little and no palliative care (PC) was being provided to them... It details how "many" prisoners in the Midlands Prison – the largest jail in the Republic – were "elderly men" who "need specialist PC and at some stage may need end-of-life care." While the medical staff and carers working in the prison "do a wonderful job," a prison environment was not suitable for men clearly approaching the end of their lives. The chaplains' reports for all of the jails in the Irish prison system have been published by the Department of Justice. https://bit.ly/3dREXfQ

## Watchdog criticises refusal to allow prisoner to die in a hospice

THE IRISH EXAMINER | Online – 28 November 2020 – A state watchdog has expressed concern at the rejection by the Irish Prison Service of several of its recommendations following an investigation into the death of a terminally ill prisoner refused compassionate temporary release to allow him to die in a hospice. The Inspector of Prisons, Patricia Gilheaney, said the decision to refuse compassionate release was contrary to the advice of medical staff and was "at odds" with the view of the prison's management and pastoral team, who believed the appropriate setting to provide end-of-life care was in a hospice. "A prison cell cannot be equated to a hospital or hospice setting," said Ms. Gilheaney, in a report into the death of the prisoner at the Midlands Prison in Portlaoise. https://bit.ly/3gaHC8O

 'Investigation Report into the circumstances surrounding the death of Mr. O 2018, aged 56, at the Midlands Prison on 30 October 2018,' Office of the Inspector of Prisons, November 2020. Download/view report at: <a href="https://bit.ly/39pmYMk">https://bit.ly/39pmYMk</a>

**N.B.** A report on the investigation into the circumstances that surrounded the death of Mr. O included the following recommendation: "It is recommended that the decision-maker in each case should visit and speak directly with the prisoner concerned, relevant medical, nursing and other healthcare personnel providing care and treatment in the prison and also prison management and chaplaincy." The Irish Prison Service did not accept this recommendation. **Download report at:** https://bit.ly/3ll3MBR

## End-of-life care in the Prison Environment in New Zealand

## Access to palliative care services in prison: Who cares?

WHITIREIA NURSING & HEALTH JOURNAL, 2018;25(1):53-59. The Aotearoa New Zealand prison system houses a growing number of chronically ill prisoners and ... the need for end-of-life care is evident. There are significant barriers restricting the provision of palliative care for this most vulnerable group, including delays in physical and psychological assessments, restricted access to medications and regulations preventing timely interventions to alleviate suffering. Ethical considerations of "custody versus care" and negative public attitudes contribute further barriers against the provision of equitable care for the dying prisoner. Compassionate release or admission into a purpose-built high-dependency unit are the only options available for the terminally ill prisoner. Abstract: http://bit.ly/2ZhScxE

## The operations of the prison service towards the social inclusion of convicts: The cooperation with palliative care institutions

SOCIAL STUDIES: THEORY & PRACTICE, 2018;4(1):31-43. Among the author's professional experiences, a special place is occupied by those connected with the issue of hospice voluntary service of persons deprived of their liberty. He presents a bold idea consisting of preparing and directing prisoners to help the terminally ill pass away in a dignified manner. Many years of experience — of hospice staff, employees of prisons, members of patients' families and firstly, patients — confirm that this is a very good direction for activating convicts who have an opportunity to experience their humanity on a daily basis. Hospice, contact with other people, contact with patients — all this transforms their thinking, behavior, allows it to verify the hierarchy of personal values. Full text: http://bit.ly/2QfIVC4



Closing the Gap Between Knowledge & Technology http://bit.ly/2DANDFB

## End-of-life care in the Prison Environment in Poland

## Solidarity and compassion: Prisoners as hospice volunteers in Poland

ANNALS OF PALLIATIVE MEDICINE, 2018;7(Suppl 2):109-117. The project of hospice volunteering of prisoners in Poland has helped to break down stereotyping and the perceptions of prisoners, starting with the Gdansk experience, where they gradually became full members of a care team. Over 600 prisoners have passed through the hospice in Gdansk in over 10 years of cooperation. Convicts, who are mostly doing time on charges of burglary, non-payment of alimony and petty crime, see working in the hospice as a chance to change their attitudes. They see a different world, in which compassion and understanding for other people are most important. Some volunteer prisoners, after their release from a correctional facility, have been employed by the hospice in Gdansk. Full text: <a href="http://bit.ly/2Q9Wq64">http://bit.ly/2Q9Wq64</a>

### End-of-life care in the Prison Environment in Russia

## Russian Justice Ministry proposes to set palliative care procedure for convicts

RUSSIAN LEGAL INFORMATION AGENCY | Online – 13 August 2019 – The Justice Ministry of Russia has developed a draft order to organize the delivery of palliative healthcare services for detainees and inmates, a ministry's statement reads. According to the document, the penitentiary system medical organizations would provide palliative care (PC) to convicts and detained defendants when indicated. If the restrictive measure is changed, in particular for health reasons, but a person needs the continuation of treatment or PC, penitentiary doctors would give him or her a tertiary referral, the order says. Amendments are proposed to the Order of healthcare delivery to persons detained or serving sentence in custody, approved by the Justice Ministry's decree of 28 December 2017. http://bit.ly/2TrYmZn

## End-of-life care in the Prison Environment in Switzerland

## Dying in dignity behind bars

SWISSINFO | Online – 23 August 2019 – The number of older inmates is steadily increasing. In 2017, there were 828 prisoners over the age of 50. Yet most prison facilities lack the necessary infrastructure to meet their needs. For some people, prison is not just a place to live, but also a place to die. "No one should have to die in prison against their will," says anthropologist Ueli Hostettler. The question of death is one that brings us all together in a way. Hostettler is a researcher at Bern University's Institute of Criminal Law & Criminology, and led the project 'End of life in prison: Legal context, institutions and actors.' The study found Swiss prisons, designed for offenders between 20 and 30 years old, are not ready to meet the different needs of the growing group of over-50s. http://bit.ly/2TWuTXG

## End-of-life Care in the Prison Environment in the U.K.

## Dying in the margins: A literature review on end of life in English prisons

RELIGIONS, 2021;12(6):413. While dying in prison has wider implications for various groups within prison, the majority of dying in prison is not witnessed by people in the general population and thus not clearly understood. There is little evidence that helps understand the experience of dying from the perspective of those dying in prison. While deaths in custody are investigated, more attention could be given to what happens prior to death. The authors of this article looked at four types of dying related to prison: suicides in prison, deaths in older age, deaths post-release, and COVID-19 deaths. These four "types" only begin to scratch the surface of how loss, death, and dying are inherent within custodial environments. **Full text:** https://bit.ly/3uT6i71

### "He wanted to die in prison ... his home"

POLITICS.CO.UK | Online – 27 April 2021 – For those facing their last days in prison, Society continues to fail them, with palliative and end-of-life care needs remaining consistently unmet by the justice system. Today, the prison system is the nation's largest provider of residential care for frail, older men. Increasingly more people are dying behind bars as a consequence of the number of incarcerated people aged over 60 tripling in the past two decades. Indeed, in the 12 months to June 2020, there were 218 deaths in prison due to natural causes, an increase of 77% compared to a decade prior. This trend is the consequence of harsher, longer sentences and the absence of timely and transparent compassionate release processes when terminally ill people in prison approach death. <a href="https://bit.ly/32RfuNH">https://bit.ly/32RfuNH</a>

### Dying Behind Bars: How can we better support people in prison at the end of life?

HOSPICE UK | Online – 26 April 2021 – The number of over-60s in the prison population has more than tripled in the past two decades, and in the past ten years alone deaths in prison due to natural causes have increased by 77%... This significant rise in deaths, together with an increasingly sick and older prison population, has led to a corresponding rise in the need for end-of-life care, a need that this report demonstrates is not being adequately met. Among the challenges this report identifies are the widespread inappropriate use of restraints, delayed or absent consideration of compassionate release, and care that did not make use of the skills and specialisms available from the health and social care sectors. **Download Hospice UK report at:** https://bit.ly/3nzbECA

## Caring, sharing, preparing and declaring: How do hospices support prisons to provide palliative and end-of-life care? A qualitative descriptive study using telephone interviews

PALLIATIVE MEDICINE, 2020;35(3):563-573. The typology presented describes the ways that hospices in Scotland engage with prisons in Scotland. This typology is of international relevance, particularly to the many countries who have not established hospices 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

## Prisoners "dying from poor care"

INSIDE TIME | Online – 2 November 2020 – A report by nurses, leaders and an official watchdog found the average age of someone dying from natural causes was 56 in prison, compared with 81 in the general population. It warned residents' chronic long-term conditions were being poorly managed in jails, and concluded: "Evidence suggests many of these deaths are preventable." The report called for: 1) A better system for escorting prisoners to hospital appointments, so that fewer are cancelled; 2) Better use of "medical holds" to ensure continuity of care for sick prisoners; 3) An overhaul of the compassionate release process to make it "transparent, timely and fair"; and, 4) Better transfer of information when patients enter and leave custody. https://bit.ly/34RCfmk

1. 'Avoidable natural deaths in prison custody: putting things right,' Independent Advisory Panel on Deaths in Custody and the Royal College of Nursing, September 2020. **Download the report:** https://bit.ly/3JzUwao

### Ageing prison population "sees officers working as carers"

BBC NEWS | Online – 21 October 2019 – The ageing jail population has left prison officers providing care for a growing number of older inmates "dying in front of them." The warning from the Prison Officers' Association (POA) has come as new figures revealed the oldest prisoner in England & Wales was 104 years old. The data showed there were 13,617 inmates aged above 50 out of a prison population of 82,710 in June 2019. More and more inmates were frail, incontinent or had dementia, the POA said. The number of prisoners over the age of 50 has almost tripled from 4,824 in 2002, the point at which comparable records start, to 13,617 in 2019. The overall prison population in England and Wales has risen 16% in that time. <a href="https://bbc.in/2qBkg20">https://bbc.in/2qBkg20</a>

### The ethics and practicalities of dealing with prisoners who are growing old and dying in custody

THE CONVERSATION | Online – 4 October 2019 – Research has shown high levels of frailty and vulnerability in the older prisoner population... Many prisons are simply not suitable for old, frail people, and the equipment and resources needed to care for them are often not available. Prison staff with responsibility for older prisoners need adequate training and support, particularly when dealing with deaths in custody. The United Nations General Assembly has endorsed a set of standard minimum rules for the treatment of prisoners. Rule 24 states: "Prisoners should enjoy the same standards of healthcare that are available in the community, and should have access to necessary healthcare services free of charge without discrimination on the grounds of their legal status." http://bit.ly/2OnGZZ3



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### How dying prisoners are treated at HMP Dartmoor

PLYMOUTH LIVE | Online – 16 September 2019 – The healthcare team who provide dignified and compassionate end-of-life (EoL) care for prisoners at Her Majesty's Prisons Dartmoor have spoken about how they look after dying prisoners. Care UK's Health in Justice team recently won the top award in the EoL category in this year's *Health Service Journal* Patient Safety Awards.¹ The awards are among the most prestigious in healthcare and recognise the hard work and dedication of teams across the country to patients' care and safety. Natasha Head, head of healthcare at the prison, said: "It is an award that has been made possible by lots of committed and compassionate people." http://bit.ly/2m2dslc

 'Organisation in collaboration sets up a project to deliver compassionate care to patients in prison settings, delivering personalised care and enabling patients to spend their last days with dignity,' *Health Service Journal*, 2019. **Outline:** http://bit.lv/2kRu99d

### "We call it jail craft"

## The erosion of the protective discourses drawn on by prison officers dealing with ageing and dying prisoners in the neoliberal, carceral system

SOCIOLOGY, 2018;52(6):1152-1168. The U.K. prison population has doubled in the last decade, with the greatest increases among prisoners over the age of 60 years, many of whom are sex offenders imprisoned late in life for "historical" offences. Occurring in a context of "austerity," an under-researched consequence of this increase has been the rising numbers of "anticipated" prison deaths; that is, deaths that are foreseeable and that require end-of-life care. The authors focus on "jail craft"; a nostalgic, multi-layered, narrative or discourse, and set of tacit practices which are drawn on by officers to manage the effective and practical challenges of working with the demands of this changed prison environment. Full text: <a href="http://bit.ly/2Eeyzxk">http://bit.ly/2Eeyzxk</a>

## What does the implementation of peer care training in a U.K. prison reveal about prisoner engagement in peer caregiving?

JOURNAL OF FORENSIC NURSING, 2018;14(1):18-26. The number of aging and chronically ill prisoners continues to rise within the U.K. prison demography; consequentially, many institutions face health and social care crises of immense proportions. The needs of this group are both complex and costly and in the U.K. this is set to a backdrop of overcrowding, increasing violence, and public spending cuts in line with government austerity targets. The development of prisoner peer caregiving is proposed as an approach to mitigating the effects of aging, disability, and illness. A qualitative study was implemented to design, deliver, and evaluate a peer care training intervention within a U.K. prison. Abstract: <a href="http://bit.ly/2EgwPDQ">http://bit.ly/2EgwPDQ</a>

## **Appendix**

# "Tool kit" for World Hospice & Palliative Care Day addresses end-of-life care in the prison environment

Key messages for the 9 October 2021 event identified by the Humane Prison Hospice Project include:

Governments that provide palliative care (PC) to prisoners are fulfilling their obligation to respect their right to health, setting a precedent of acknowledging and responding to our shared humanity.

Prison populations in many counties are rapidly aging; by 2030, older prisoners, many of whom have PC needs, are expected to account for one-third of the incarcerated population in the U.S.

Incarceration shortens life expectancy and hastens physiological aging, compounding existing health issues and heightening the risk that prisoners will develop PC needs.



Considering how prisoners die "inside" is imperative and requires appropriate investments and training.

Prison PC, when compassionate release is unavailable, allows prisoners to "die at home," cared for by other prisoners with whom the patient has formed a familial bond. These trained prisoner volunteers can provide cost-effective and transformative PC while working with compassionate clinical staff.



Worldwide Hospice Palliative Care Alliance: https://bit.ly/3lmKhMM



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

**Footnote on the illustration:** "Lenny" is one of the 'Brother's Keepers' at San Quentin State Prison in the U.S. who participated in the Humane Prison Hospice Project training program to become peer support counselors and compassionate end-of-life caregivers. His words were captured by graphic journalist Wendy MacNaughton and was originally published in *The California Sunday Magazine* (see <a href="https://bit.ly/2WXBgjb">https://bit.ly/2WXBgjb</a>).

## European Association for Palliative Care Task Force on End-of-Life Care in Prisons

The Task Force's two main aims are to undertake scoping work in at least five countries to map the current provision of palliative care (PC) for prisoners,<sup>1</sup> and to develop an international network of professionals interested in PC for prisoners from as many European countries as possible, as well as other countries outside of Europe. **Task Force website:** <a href="https://bit.ly/2WLZSLv">https://bit.ly/2WLZSLv</a>

 'Mapping palliative care provision in European prisons...,' BMJ Supportive Palliative Care, published online 22 April 2021. [Noted in Media Watch 26 April 2021 (#714, p.7)] Abstract: <a href="https://bit.ly/2QPihnZ">https://bit.ly/2QPihnZ</a>

Barry R. Ashpole, Ontario, CANADA

e-mail: BarryRAshpole@bell.net