

Dying an expected death in prison: a growing reality

A range of complex demographic, social and legal factors collectively contribute to the growing number of people who will die an expected death while serving a custodial sentence (Australian Healthcare Association, 2020). People in prison experience a disproportionate burden of chronic, progressive life-limiting illnesses, and age faster than the general population (Baidawi, 2015). First Nations people are also overrepresented in the custodial setting in Australia, and experience poorer health outcomes (Baidawi, 2015; Australian Healthcare Association, 2020). Managing the palliative care needs of the growing proportion of older people in prison, who are either incarcerated for the first time later in life; returning to prison after a period of freedom, serving an extended sentence; or incarcerated for short periods later in life is a priority area for many countries (Baidawi, 2015).

People in prison with palliative care needs are often older, frail and vulnerable. They often require more intensive, specialised and costly healthcare, particularly if they have a progressive chronic illnesses or end-of-life care needs (Australian Healthcare Association, 2020). Many have unrelieved symptoms, are isolated from others, live with multiple disadvantages and have a limited ability to advocate for themselves or participate in medical decision-making (Baidawi, 2015; Australian Healthcare Association, 2020).

Despite these needs, access to palliative care in prisons continues to be challenging, and rarely reflects the standard of care that people in the community receive. In part, this is due to the conflict between custody and care, which is the unintended consequence of the physical and organisational structures and policies used to control the lives of people in prison (Turner et al, 2012). This divide contributes to the fact that correctional healthcare providers and correctional services personnel often have conflicting goals; this normalises the separation of these into two distinct professional groups hampering communication and collaborative problem-solving (Turner et al, 2012). The juxtaposition of disciplinary policies and the goals of healthcare makes it challenging to provide evidenced-based, person-centred and culturally safe integrated care. As a result, correctional healthcare providers can be forced to adjust the comprehensiveness and quality of the care they provide, depending on degree of access they have to the patient (Turner et al, 2012).

Despite rising interest in addressing the unmet needs of people in prison (Baidawi, 2015; Australian Healthcare Association, 2020), few countries have developed policies or models of care that support the integration of palliative care needs with custodial requirements. While not mandatory, some countries have developed practice standards that focus on, or include, elements of care that address palliative care needs (Ambitions for Palliative and End of Life Care Partnership, 2018; Her Majesty's Inspectorate of Prisons for Scotland, 2018). The lack of standards, policies and processes is a significant barrier to improving palliative care access for people in prison (Australian Healthcare Association, 2020).

In addition to tensions between the prisoner's security and wellbeing, and the limited evidence about effective palliative care models in the custodial setting, the lack of awareness and understanding of palliative care by correctional healthcare providers and personnel also effectively limits access to palliative care in prisons (Australian Healthcare Association, 2020). People in prisons may distrust healthcare services and professionals, and their challenging family relationships also add to the obstacles to providing effective palliative care to this population (Australian Healthcare Association, 2020).

Despite these challenges, there are numerous opportunities to strengthen palliative care access for this population. Capacity-building initiatives, underpinned by cultural safety and trauma-informed care principles, can positively impact the care provided by correctional healthcare providers and correctional services personnel (Australian Healthcare Association, 2020), as can palliative care programmes (Cloyes et al, 2017). The development of palliative care-specific guidelines and pathways, building relationships with external specialist palliative care services and providing alternative accommodation for people in prison with palliative care needs, will improve the outcomes of people in prison with palliative care needs (Australian Healthcare Association, 2020).

Given the growing number of older people in prison with palliative care needs, the development of new and innovative palliative care models for this population, which balances justice, healthcare, human rights and societal expectations, is urgently required.

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Ambitions for Palliative and End of life Care Partnership. Dying well in custody charter: a national framework for local action. 2018. <https://pdf4pro.com/amp/cdn/dying-well-in-custody-charterendoflifecareambitions-org-uk-4fab9b.pdf> (accessed 23 July 2021)

Australian Healthcare Association. Exploratory analysis of barriers to palliative care: issues report on people who are incarcerated. 2020. www.health.gov.au/sites/default/files/documents/2020/01/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-who-are-incarcerated.pdf (accessed 23 July 2021)

Baidawi S. Managing the health of an ageing prison population: a review of the challenges to be addressed by effective models of care. 2015. https://www.academia.edu/35744043/Managing_the_health_of_an_ageing_prison_population_a_review_of_the_challenges_to_be_addressed_by_effective_models_of_care_an_Evidence_Check_rapid_review_brokered_by_the_Sax_Institute_www_saxinstitute_org_au_for_the_Justice_Health_and_Forensic_Mental_Health_Network_January_2015 (accessed 23 July 2021)

Cloyes KG, Rosenkranz SJ, Supiano KP, et al. Caring to learn and learning to care: inmate hospice volunteers and the delivery of prison end-of-life care. *J Correction Health Care* 2017; 23:43–55. <https://dx.doi.org/10.1177%2F1078345816684833>

Her Majesty's Inspectorate of Prisons for Scotland. Standard 9: health and wellbeing. 2018. <https://www.prisoninspectorscotland.gov.uk/publications/inspecting-and-monitoring-standard-9-health-and-wellbeing> (accessed 23 July 2021)

Turner M, Payne S, Barbarachild Z. Care or custody? An evaluation of palliative care in prisons in North West England. *Palliat Med*. 2011; 25(4):370–377. <http://dx.doi.org/10.1177/0269216310393058>