



February 1, 2019

Normative elements of a right to palliative care for older persons
Recommendations for a binding instrument
Submitted in preparation for OEWSGA10 per request of the Bureau

Prepared by Katherine Pettus, IAHPC
kpettus@iahpc.com

The International Association for Hospice and Palliative Care (IAHPC) believes that new standards on the rights of older persons within a binding convention on the rights of older persons, should include an explicitly articulated right to access palliative care, grounded in the recognized rights to health, dignity and autonomy.¹ This submission aligns with the Declaration of Astana, the 2015 UNGASS Outcome Document, and the 2030 Agenda for Sustainable Development.²

Palliative care seeks to maintain the best possible quality of life for patients and their families facing serious health related suffering, from the moment of diagnosis to natural death.³ Yet, in many countries the availability of palliative care is very limited, resulting in preventable severe, health related suffering for millions of patients.⁴

IAHPC, a non-state actor in official relations with the World Health Organisation, and in consultative status with ECOSOC, is making the following recommendations for including the right to palliative care into new standards on the rights of older people:

¹ See INTER-AMERICAN CONVENTION ON PROTECTING THE HUMAN RIGHTS OF OLDER PERSONS (A-70) Articles. Chapter 2, general principles. And Article 6, Right to life and dignity in old age.

http://www.oas.org/en/sla/dil/docs/inter_american_treaties_A-70_human_rights_older_persons.pdf

² <https://www.who.int/primary-health/conference-phc/declaration/>;

<https://www.unodc.org/documents/postungass2016/outcome/V1603301-E.pdf>

<https://sustainabledevelopment.un.org/post2015/transformingourworld>

³ Suffering is health-related when it is associated with illness or injury of any kind. Health related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social and/or emotional functioning. Available in <http://pallipedia.org/serious-health-related-suffering-shs/>. Severe illness is understood as any acute or chronic illness and/or condition that causes significant impairment, and may lead to long-term impairment, disability and/or death. Available at <http://pallipedia.org/serious-illness/>

⁴ Knaul, F. M., Farmer, P. E., Krakauer, E. L., De Lima, L., Bhadelia, A., Kwete, X. J., ... & Connor, S. R. (2018).

Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report. *The Lancet*, 391(10128), 1391-1454.



A binding convention on the rights of older persons should

I. Employ the IAHPC consensus definition endorsed by 828 individuals and 140 organizations around the world.⁵

II. Include access to palliative care in any article on the right to health. In many countries, palliative care is unavailable to the majority of patients and families who require it. A new standard on the rights of older people must explicitly oblige countries to ensure that palliative care is available for older persons experience severe health related suffering. *Suggested language: States Parties shall ensure palliative care services of good quality are available and accessible for patients and their families facing severe health related suffering.*

III. Include reference to preventable, severe suffering in an article referencing torture, cruel, inhuman and degrading treatment. Patients with severe pain or other debilitating physical or mental symptoms, who lack access to palliative care and controlled medicines, often endure suffering so extreme that they would rather die than continue to live with them. A binding convention should include a new standard enjoining parties to protect older people against preventable suffering due to failure to treat pain and other debilitating physical, psycho-social or spiritual symptoms.⁶ A provision on the prevention of cruel, inhuman and degrading treatment in older people should include the following language: *“including as a result of the failure to adequately treat pain and other symptoms.”*

IV. Include an explicit right of older people to plan for care during serious illness and end of life. Patients should be able to make their own decisions about care, such as continuing or discontinuing curative treatment, whether or not to allow life-prolonging interventions, and their choice of place of care (hospital, hospice, or home), supported by medical professionals and together with loved-ones. In reality, however, it is often healthcare providers who make these decisions with little consideration for patients’ rights, will and preferences. Patients should also have access to legal services to address other relevant legal issues, including inheritance, and planning for underage children. Any new standard on the right of older persons should require states to establish procedures that allow persons to prepare advanced directives, living wills and/or other legally binding documents that set out their will and preferences around healthcare interventions, as well as make other relevant legal decisions.

⁵ See “Consensus Based Definition of Palliative Care” <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/>

⁶ Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment Special Rapporteur on Torture (2013) 35. “Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak (2009) para 72



V. Include provisions regarding supported decision making.⁷ Illness such as dementia or cognitive decline due to advanced age may limit the ability of some older people to make decisions independently. In line with the requirements of the Convention on the Rights of Persons with Disabilities, standards on the rights of older people should require states to ensure processes are in place for supported decision making, but retaining full legal capacity, for such persons.

VI. Include references to palliative care in provisions on long-term care. Many older people in long-term care require palliative care due to chronic illnesses or general decline. Yet, availability of palliative care in long term care for older people is often limited. Any provisions on long-term care, whether home-based or institutional (including in nursing home, refugee, and prison populations *inter alia*) should include references to the provision of palliative care.⁸

VII. Include reference to availability of controlled essential medicines in any provision on access to medicines. Medicines containing controlled substances [“narcotics” *sic*], are necessary for the treatment of many conditions prevalent among older persons. These conditions include moderate to severe pain, depression, anxiety, and dyspnea. Although the UN Committee on Economic, Social and Cultural Rights, the Independent Expert on the Rights of Older Persons, and the Special Rapporteurs on Health and Torture, have emphasized that states parties to the relevant conventions must ensure the availability and accessibility of essential medicines, the vast majority of the world’s population still has no or inadequate access to them.⁹ A specific reference to controlled medicines in an access to medicines clause would

⁷ The United Nations has described “supported decision making” as follows: “The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual... Paragraph 4 of article 12 calls for safeguards to be put in place to protect against abuse of these support mechanisms.” See: United Nations Department of Economic and Social Affairs, Office of the High Commissioner for Human Rights and Inter-Parliamentary Union, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities*(Geneva: United Nations, 2007) <http://www.ipu.org/PDF/publications/disabilities-e.pdf> pp. 89-90.

⁸ See, for instance, Smets, T., Pivodic, L., Piers, R., Pasman, H. R. W., Engels, Y., Szczerbińska, K., ... & Van den Block, L. (2018). The palliative care knowledge of nursing home staff: The EU FP7 PACE cross-sectional survey in 322 nursing homes in six European countries. *Palliative medicine*, 32(9), 1487-1497. And Smets, T., Onwuteaka-Philipsen, B. B., Miranda, R., Pivodic, L., Tanghe, M., van Hout, H., ... & Wichmann, A. B. (2018). Integrating palliative care in long-term care facilities across Europe (PACE): protocol of a cluster randomized controlled trial of the ‘PACE Steps to Success’ intervention in seven countries. *BMC palliative care*, 17(1), 47.

⁹ UN Committee on Economic, Social and Cultural Rights, “Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights,” General Comment No. 14, The Right to the Highest Attainable Standard of Health, E/C.12/2000/4



help improve their accessibility. *Suggested language: States Parties shall ensure availability and accessibility of essential medicines, including internationally controlled medicines, for the treatment pain and symptoms in older persons.*

VIII. Include a reference to the need for workforce training in palliative care. Lack of palliative care training for healthcare professionals, including community health workers, is a major obstacle to the availability of this service. It is therefore recommended that any provision in a new standard on the rights of older person on training of health and care personnel should specifically refer to training in palliative care at the undergraduate level in healthcare professions, especially medical, pharmacy, and nursing degrees.

Appendix

The definition: Any instrument and/or drafting or explanatory notes should make it clear that the term “palliative care” refers to a comprehensive set of health services aimed at improving the quality of life of patients with severe health related suffering due to severe illness.¹⁰

(2000), [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument) (accessed November 4, 2010).

¹⁰Palliative Care Definition (IAHPC)

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering¹ due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.

Palliative care:

- Includes, prevention, early identification, comprehensive assessment and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based.
- Provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care.
- Is applicable throughout the course of an illness, according to the patient’s needs.
- Is provided in conjunction with disease modifying therapies whenever needed.
- May positively influence the course of illness.
- Intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process.
- Provides support to the family and the caregivers during the patient’s illness, and in their own bereavement.
- Is delivered recognizing and respecting the cultural values and beliefs of the patient and the family.
- Is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary).
- Can be provided by professionals with basic palliative care training.
- Requires specialist palliative care with a multiprofessional team for referral of complex cases.

<https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/>