

Palliative Care and Standards on the Rights of Older People ***Recommendations for New Legal Instruments***

There is broad recognition that existing international and regional human rights norms are not being adequately applied to older populations, one of the most rapidly growing groups in the world. The United Nations and several regional inter-governmental organizations are currently exploring the possibility of developing new legal standards to address this protection gap. Our organizations believe that new standards on the rights of older people should include an explicitly articulated right to access palliative care, grounded in the existing rights to health, dignity and autonomy.

Palliative care seeks to maintain the best possible quality of life in persons with chronic, incurable illnesses and their families, from the moment of diagnosis to the end of life. Older people bear a disproportionately large burden of chronic, incurable illnesses, including cancer, diabetes, heart failure and dementia, bringing with it great palliative care needs. Yet, in many countries the availability of palliative care is very limited, resulting in unnecessary suffering for millions of patients.

Our organizations make the following recommendations for including access to palliative care into new standards on the rights of older people:

1. **Include access to palliative care in the article on the right to health.** In many countries, palliative care is a neglected health service that is not available to most patients and families who require it. It is therefore essential that the article on the right to health in a new standard on the rights of older people explicitly obliges countries to ensure that these health services are available for older people with chronic, incurable illnesses. ***Suggested language: States Parties shall ensure palliative care services of good quality are available and accessible for patients with incurable illnesses and their families.***
2. **Include reference to unnecessary, severe suffering in article on torture, cruel, inhuman and degrading treatment.** Patients with severe pain or other debilitating physical or mental symptoms often face suffering that is so extreme that they would rather die than have to live with them. The article on torture, cruel, inhuman and degrading treatment in a new standard should specifically state that parties must protect older people against unnecessary suffering due to failure to treat pain and other debilitating physical or mental symptoms. The provision on preventing cruel, inhuman and degrading treatment in older people could include the following language: ***“including as a result of the failure to adequately treat pain and other symptoms.”***
3. **Include an explicit right of older people to plan for the 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 preference for 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 services to address other relevant legal issues, including around inheritance and planning for underage children. Any new standard on the right of older persons should require states to establish procedures by which people with incurable illnesses or conditions may prepare advanced directives, living wills and/or other legally binding documents that set out their will

and preferences around healthcare interventions at the end of life, as well as make other relevant legal decisions.

4. **Include provisions regarding supported decision making.**¹ 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.
5. **Include references to palliative care in provisions on long-term care.** Many older people in long term care arrangements require palliative care due to chronic illnesses or general decline. Yet, availability of palliative care in long term care arrangements for older people is often limited. Any provisions on long-term care, whether home-based or institutional, should include references to the provision of palliative care by the providers of long-term care.
6. **Include reference to controlled medicines in any provision on access to medicines.** Controlled medications, medicines made of controlled substances, are essential for the treatment of many conditions that are prevalent among older people, including moderate to severe pain, depression, anxiety, and dyspnea. Although the UN Committee on Economic, Social and Cultural Rights has clearly stated that states must ensure the availability and accessibility of essential medicines, the vast majority of the world population does not have adequate access to controlled medications.² A specific reference to controlled medicines in an access to medicines clause would help improve their accessibility. ***Suggested language: States Parties shall ensure availability and accessibility of essential medicines, including controlled medicines, for the treatment of older people.***
7. **Include reference to the need for training in palliative care.** Lack of palliative care training for healthcare professionals is a major obstacle to the availability of this health 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 and nursing degrees.

¹ The United Nations have 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> (accessed April 8, 2012), pp. 89-90.

² 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 (2000), [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/40d009901358b0e2c1256915005090be?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/40d009901358b0e2c1256915005090be?Opendocument) (accessed November 4, 2010).

8. **Use the World Health Organization definition of palliative care.** 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 incurable illness and their families, including physical, psychosocial and spiritual care, as defined by the World Health Organization.³

Signatories:

African Palliative Care Association
Asociación Latino-Americana de Cuidados Paliativos
European Association of Palliative Care
Human Rights Watch
Indian Association of Palliative Care
International Association of Hospice and Palliative Care
Open Society Foundations
Pallium India
Worldwide Palliative Care Alliance

³ The current WHO definition of palliative care is: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”