

**Statement of the American Bar Association**  
**By Professor William Mock, American Bar Association Liaison to**  
**the United Nations Open-Ended Working Group on Ageing**

25 July 2018, afternoon session

*Perspectives on Palliative Care and Access to Justice*

Thank you, Madame Chair. I am Professor William Mock, here representing the American Bar Association at the Open-Ended Working Group.

Eighteen years ago this month, the American Bar Association adopted a Resolution calling upon all levels of government to amend their laws to remove unnecessary barriers to quality pain management. I quote:

*the American Bar Association urges federal, state, and territorial governments to support fully the right of individuals suffering from pain to be informed of, choose, and receive effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care, even if such pain and symptom management may result in analgesic tolerance, physical dependence, or as an unintended consequence shorten the individual's life.*

We stand by those words today.

Fundamental human rights address what it means to be a person with dignity and autonomy. Among these is the right to be free from unnecessary pain and suffering, whether from chronic illness or from the natural process of approaching death. In short, palliative care.

By themselves, fundamental rights are powerless except as broad principles. They need other, more instrumental human rights to give them practical effect, including rights of political participation, access to education and information, and access to justice. It is only with these more instrumental rights that it becomes possible to identify, remedy, prevent, and eliminate violations of our human rights. Thus, access to palliative care will remain merely a wonderful principle unless and until it is embodied in a legally-binding instrument that includes clear rights of access to justice.

In 2014, the WHO called for palliative care to be integrated as an essential element of the health care continuum. Yet palliative care remains fragmented, sporadic, largely local, and often limited to people with cancer and those who are dying. Today, most people living with serious chronic illnesses lack access to palliative care, including those living at home, those in assisted living facilities, and those in nursing homes. So long as recognition and regulation of palliative care rights remain fragmented and aspirational, so will palliative care itself.

Access to essential medicines for pain relief is distorted by policies unrelated to human needs. For all of these, remedial steps must involve both the recognition of palliative care as a fundamental human right and empowering those suffering from severe pain to seek legal remedy for unnecessary pain.

As one example, regulation of access to opioid medicines is seriously limited by national policies relating to prevention of drug abuse. Without recognition of palliative care as a fundamental and enforceable human right, the needs of those with severe and medically unnecessary pain remain hostage to a never-ending War on Drugs.

Seriously deficient palliative care should be actionable as sub-standard care, medical malpractice, and even elder abuse. In 2001, a California court found medical providers liable for Mr. William Bergmann's unnecessary suffering prior to death under that state's elder abuse statute. Even outside of California, every person should have a legally-enforceable right of meaningful involvement in all aspects of their care, including assessment of need, planning for care, delivery of care, and *post hoc* review. All of this requires recourse to institutions of justice.

In sum, the lack of a rights-based foundation to palliative care contributes significantly to preventable suffering. It is time for a legally-binding international document that includes both palliative care and access to justice.

Thank you.