

To: The Open Ended Working Group on Aging  
From: The International Association of Gerontology and Geriatrics (IAGG)  
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## **Long-Term Care and Palliative Care in the USA**

**Long-term care** in the USA is a fragmented system of services. There is no federal provision for long-term care nor a universal right to it. Medicare, the primary federal health insurance program for persons over age 65, covers up to 100 days of care in a nursing facility but persons must have been transferred directly from a hospital. Home health care services, restricted to those who will be recovering, are not intended to provide chronic or long-term care.

Medicaid, a federal-state program, does cover long-term care. Eligibility is based on a means test and is thus focused on low-income persons. It is the major payer of nursing homes and also covers community and home care services for persons meeting state eligibility criteria. In many places there are long waiting lists for these services. Under the Medicaid waiver programs available in many states, persons may receive services that will maintain them in the community as long as the cost does not exceed that of institutional care.

Accessing long-term care is a major challenge for older persons and their families. Many are shocked to find that Medicare does not cover long-term care and their incomes and resources exclude them from Medicaid. Paying for needed supports poses a financial burden on many older persons and their caregivers. Moreover, there is little financial support for family caregivers with limited family leave programs. Consequently, both availability and accessibility to services is problematic.

Long-term care remains focused on institutional care and persons may enter institutions due to a lack of home or community based services. Nursing home regulations require compliance with specific standards in order to receive payments under Medicare and Medicaid. These include staffing requirements, individualized person-centered care, care plans, protections against abuse, neglect, and exploitation. training requirements for staff, freedom from restraints. and protection from over prescription of antipsychotic drugs. Resident rights are regulated federally, and by most states as well, with established reporting and investigation procedures for those who feel their care rights or their relatives' rights have been violated.

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While there is no uniform American law governing **Palliative Care**, professional medical and nursing organizations and palliative care non-profit organizations influence the policy framework nationally. In New York State, for example, laws pertaining to palliative care include: the Palliative Care Information Act, the Palliative Care Access Act, the Family Health Care Decisions Act, and the state department of health endorsed Medical Orders for Life-Sustaining Treatment (MOLST).

These laws require physicians and providers to offer terminally-ill patients information and counseling concerning palliative care and end-of-life options. The laws are intended to insure that patients with a terminal illness are fully informed of the options available to them, so that they can make choices consistent with their wishes, beliefs, and goals for care, and to optimize their quality of life. The laws also require health care institutions and community based health care agencies to provide information and access to counseling regarding options for palliative care, and to facilitate access to appropriate palliative care, including pain management and hospice. Palliative care is not yet included in the New York State patient bill of rights.

The laws intend palliative care to be offered to all patients, including older persons and their families, on a non-discriminatory basis in all health care settings, both inpatient and outpatient, including long-term care settings, through generalist and specialist level care.

Hospice is a type of palliative care which provides care, comfort, and support for persons with life-threatening illness and their families. In the USA, hospice is a service benefit offered under Medicare to persons with an illness or condition reasonably expected to cause death within six months. Hospice, typically offered through a certified hospice agency, is required to offer interdisciplinary staff, including physician, nurse, social worker, and spiritual care, and care services are regulated by law. Palliative care, by contrast to hospice, is meant to be appropriate at any stage of serious, chronic, or life-threatening illness, to a broader segment of persons.

Despite the state laws noted, challenges facing older persons in the USA regarding end-of-life care include adequate access to palliative care, especially in rural areas, where specialist providers of palliative care may not be available, or where hospice agencies are far from persons who need them. Another challenge to access is accurate prediction as to when an older person, especially those with multiple chronic illnesses, may best benefit from palliative care. Although prognostication steadily improves with diagnostic score calculators, medical science will remain an imprecise art to some extent.

Palliative care and hospice are aspects of health care that will be needed by most older persons, as they face the illnesses and conditions that accompany the end of life. Palliative care, therefore, ought to be enshrined as a human right, especially for older persons.