



Statement to The Ninth Working Session of the Open-ended Working Group on Ageing: Long term and Palliative Care

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Long- term and Palliative Care

“Long-term care for older people is, mainly, about care for people with dementia.”

Most of the estimated 50 million persons in the world with Alzheimer's and related irreversible dementia are older than 60. Over 50% suffer from at least one additional chronic disease, and it is widely believed that, **over time**, the symptoms of progressive dementia - impaired thinking, remembering, ordering and organizing tasks for oneself and judgement -interfere with the persons ability to manage their other chronic diseases, rendering persons with dementia in need of care and support. All over the world this support is largely from families, and not paid, formal, medical and/or social care support.

However, policymakers need to pay much more attention to the importance of dementia as the most common underlying condition, and, very often, the root cause of older peoples' need for care. The current and future course and costs of long-term care will be determined, to a large extent, by the course of the global dementia epidemic.

All governments should initiate national debates regarding the future of long-term care, with all stakeholders and an informed public. For future generations of older people, the numbers of them requiring long-term care, and their profile of needs, is already predictable within narrow limits of uncertainty. **Long-term care for older people is, mainly, about care for people with dementia.** Around half of all people with dementia need personal care (and the others will develop such needs over time).

From a rights perspective we believe that persons with dementia should be included in debates about the management of multiple health problems in older people. Their values and preferences for treatments may differ in important ways from people who do not have dementia, as may the outcomes that are most important to them.

At the personal level, wishes for care expressed early in the disease process, or over person's life, need to be documented through some form of advance planning directive or health care proxy and then respected by health care authorities. Autonomy and choice should be promoted at all stages of the dementia journey, prioritising the voices of people with dementia and their caregivers

The current most egregious violations of rights of persons with dementia are occurring in long term care homes in which anti-psychotic medications and restraints are often thoughtlessly used in the name of controlling behavior. One major policy feature of national dementia plans in these countries has been proactively reducing the overuse of these methods, though they still persist.



The quality of care in care homes should be monitored through the quality of life and satisfaction of their residents, in addition to routine inspections, as care homes will remain an important component of long-term care.

Palliative Care

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals. Alzheimer's Disease International supports efforts to further the reach and impact of palliative care programs and systems at the country level, including health system policies that integrate palliative care services into the structure and financing of national health-care systems at all levels of care and embedding palliative care into the core curricula of all new health professionals, as well as educating volunteers and the public.

Understanding that persons with dementia have other chronic disease for which a palliative care approach is suitable, they should not be excluded from these programs. Further, health professionals need specific training in recognizing the signs of untreated pain and relieving pain in persons with dementia. At the policy level, a medicines policy which ensures the availability of essential medicines for managing symptoms, in particular opioid analgesics for the relief of pain and respiratory distress, is vital.

Further, there are significant gaps to fill in research into health service and system innovations in the effectiveness of advanced care planning and palliative care approaches to end-of-life care for persons with dementia.

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