Palliative care and dementia statement – Worldwide Hospice Palliative Care Alliance

First WHO ministerial Conference on Global Action against Dementia

16-17 March 2015, Executive board room, World Health Organization, Geneva

Palliative care has been widely recognised as a key approach to improve the quality of life of people living with, and dying from, dementia, and their carers. Indeed the World Health Organisation recognises that all people living with a life-limiting illness should have access to quality, palliative care, as outlined in the recent resolution on palliative care passed at the World Health Assembly.¹ Figures in the WHO and WHPCA Global Atlas on Palliative Care At the End of Life² show that over 315,000 people who die of Alzheimer’s disease and other forms of dementia require palliative care at the end of life each year. This is likely to be a significant under-estimation. The figure does not include those living with dementia who die from other conditions and would benefit from palliative care. Nor does it include those living with dementia, who are not at the end of life, but experience pain and other symptoms during their life course. Unfortunately we believe that pain, symptoms and other palliative care needs of people with dementia are often under assessed and under treated around the world.

Palliative care not only improves the quality of life and death of people living with dementia but also provides vital support for carers and family members. This can be achieved by an approach which focusses on key interventions including person-centred care, continuity of care, psychosocial and spiritual support, optimal treatment of symptoms and providing comfort, family care and involvement and education of health care teams.³ The palliative care approach relies on an inter-disciplinary team and should be available in many settings including the home, residential and long term care centres, the community and hospitals.

Palliative care has also been shown to help avoid overly aggressive, burdensome or futile treatment for people living with life-limiting illness. While the focus of the palliative care community is on ensuring quality of life for people and their families, it is also a cost effective approach. The extent to which palliative care can reduce the costs of care for patients as well as improving quality of life is

¹ World Health Assembly. Strengthening of palliative care as a component of comprehensive care throughout the life course Resolution WHA67.19 Available at: http://apps.who.int/medicinedocs/en/d/Js21454en/

Website: www.thewhpc.org Email: info@thewhpc.org Twitter: @thewpca
something that has been clearly seen in respect to cancer and other life-limiting illness. More research needs to be done on the cost-effectiveness of palliative care for people with dementia.

There are numerous barriers to the provision of quality palliative care for people with dementia. Palliative care advocates, particularly in countries with less developed health systems, recognise that lack of early diagnosis for people living with dementia is one of the major issues preventing access to treatment and care. In addition, the need to integrate knowledge, skills and training in hospice and palliative care for those caring for people with dementia is also recognised, particularly in settings where many people living with dementia are in long term care and nursing facilities.

As our populations age it is absolutely fundamental that we build health and social care services around the world to provide person centred care right through the life course to the end of life. There is always something that can be done, even when cure is not possible, and the palliative care approach should be available to all those living with, and dying from, dementia and other life-limiting conditions.

The WHPCA requests ministers to ensure that:

1. National dementia strategies are developed which include explicit reference to palliative care. Palliative care is a person-centred approach and should be available from the point of diagnosis. However, we particularly call on ministers to ensure the inclusion in national dementia strategies of prognostication, timely recognition of dying and preparations for the last phases of life. These are areas, which have been shown to be neglected.

2. Palliative care is included in all health and social care workforce-training curricula to ensure that all health professionals and carers in dementia are trained in palliative care.

3. Since people living with dementia in many parts of the world are commonly cared for in long-term care facilities, including care homes, special attention needs to be paid to ensuring that all staff in these facilities has minimum basic training in palliative care.

4. More research funding is allocated to palliative care for people with dementia especially in developing countries. There is currently limited knowledge around the need, service provision, economics and policies around palliative care for people with dementia.

5. Appropriate pain medications, including opioids, should be made available and accessible to address pain and suffering, whether as a result of dementia or other conditions.

6. Funding is allocated to the development and provision of dementia services, which includes a continuum of care through the life course to the end of life, and includes provision for palliative care services in multiple settings, including the home.

---


6 Froggart, K and Reitinger, E (Jan 2013) “Palliative care in long-term care settings for Older People’ EAPC taskforce 2010-2012

Website: www.thewhPCA.org Email: info@thewhPCA.org Twitter: @thewpca