Palliative care consultation response to the draft WHO global action plan on the public health response to dementia 2017-2025

October 15 2016

African Palliative Care Association	
Asociación Latinoamericana de Cuidados Paliativos	
European Association of Palliative Care	
Human Rights Watch	
International Association for Hospice and Palliative Care (IAHPC)	
International Children's Palliative Care Network	
UICC	
Worldwide Hospice Palliative Care Alliance (WHPCA)	

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1. Summary

We welcome the publication of the ñDraft WHO global action plan on the public health response to dementia 2017-2025ôand the opportunity to participate in the consultation. While we welcome the inclusion of care throughout the document, we are extremely concerned with the absence of any explicit reference to palliative care. In summary, we would like to raise the following points:

1. **We register our concern about the absence of any explicit reference to palliative care within the draft action plan and request this is rectified with the addition of strong language on palliative care as outlined in section 2 of this document.**

2. **According to WHA resolution 67.19, the WHO Secretary General is requested "to ensure that palliative care is an integral component of all relevant global disease control and health system plans, including those relating to noncommunicable diseases and universal health coverage, as well as being included in country and regional cooperation plans;"[1]**

3. **Palliative care is a fundamental component of the continuum of care for people living with Alzheimer's and other dementias from early in the course of the condition until the end-of-life, including supporting carers throughout and into bereavement stages. Alzheimer's and other dementias are recognised as conditions that require palliative care in the WHO and WHPCA Global Atlas on Palliative Care at the End of Life published in 2014.[2]**

4. **While a palliative care approach has been recognised as applicable for people living with Alzheimer's and other dementias from early in the course of the condition,[3] there is a need to undertake further research to provide recommendations on when and how palliative care may be most relevant.[4,5]**

5. **Globally over 315,000 of the total number of people who die of Alzheimer's disease and other dementias each year require palliative care at the end of life.[6] However, this figure does not include those living with dementia who die from other conditions and would benefit from palliative care nor those who are not at the end of life but may be living with pain and other symptoms.**

6. **Palliative care offers various critical interventions for people living with dementia including addressing their physical, psychosocial and spiritual issues, supporting carers and family members and providing support for advance care planning from early in the course of the condition through to the end of life to improve quality of life.[7] People with dementia have specific palliative care needs.**

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[1] WHA resolution ñStrengthening of palliative care as a component of comprehensive care through the life courseô http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (Accessed October 2016)
[2] WHO and WHPCA Global Atlas on Palliative Care at the End of Life http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care (Accessed December 2015)
[3] https://www.nice.org.uk/guidance/cg42/chapter/1-guidance#palliative-care-pain-relief-and-care-at-the-end-of-life-for-people-with-dementia (Accessed May 2016)
[4] Van Der Steen, Jenny T et al ôWhite paper defining optimum palliative care in older people with dementiaô in *Palliative Medicine* 2014, Vol. 28(3) 197ï209
[5] WHPCA (2016) Position statement on palliative care and alzheimers and other dementias http://www.thewhpca.org/resources/item/whpca-position-paper-on-dementia-and-palliative-care (Accessed Oct 2016)
[6] WHO and WHPCA (2014) óGlobal Atlas on Palliative Care at the End of Life http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care (Accessed December 2015)
[7] WHO definition on palliative care http://www.who.int/cancer/palliative/definition/en/

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7. **The palliative care needs of people with dementia are often poorly addressed, symptoms such as pain are under-treated and many people are over-subjected to burdensome interventions.[8] There is concern and increasing evidence that access to palliative care for people with dementia globally is inequitable.[9],[10]**

8. **Palliative care is one of the essential and basic health care services within Universal Health Coverage as outlined within the WHO definition.[11]**

9. **Palliative care, including access to pain treatment, is explicitly recognised under the human right to health.[12]**

2. Suggested language and edits

2.1 We request the following paragraph is added following current paragraph 12.

"Palliative care is a core part of the continuum of care for people living with dementia from early in the course of the condition through to the end-of-life and into the bereavement stages for carers. It provides physical, psychosocial and spiritual support for people with dementia and their carers including support with advance care planning. A minimum of 315,000 people per year require palliative care at the end of life due to death from Alzheimer's and other dementias. Many more require palliative care through the course of the condition, including when living with and dying from other co-morbidities."

2.2 Throughout the text of the Global Plan we request that wherever **'prevention, treatment and care'** is mentioned, it is followed by the text **'including palliative care'**. Unfortunately, we know from plans, strategies and resolutions on other issues that if palliative care is not explicitly mentioned, it is often neglected in the response. Alternatively, we request that the language 'prevention, treatment and care' is replaced in line with Universal Health Coverage essential health care services to **"health promotion, prevention and treatment, rehabilitation and palliative care"**

2.3 We request that additional language on palliative care is explicitly added to the following paragraphs in the draft Global Action Plan on Dementia. Suggested added text is highlighted in bold.

14. At the same time, the gap is wide between the need for prevention, treatment and care for dementia and the actual provision. Dementia is underdiagnosed worldwide, and, if a diagnosis is made, it is typically at a relatively late stage in the disease process. Long-term care pathways for people with dementia **from early in the course of the illness until the end-of-life** are frequently fragmented if not entirely lacking. Lack of awareness and understanding of dementia are often to blame, resulting in stigmatization and barriers to diagnosis and care. It is also widely recognized that people with dementia are frequently denied their human rights both in the community and in care homes.

18 e) Universal health coverage for dementia: There needs to be equitable access to a full range of health and social care services needed for people with dementia and their carers, regardless of age, gender,

[8] Harris D. 'Forget me not: palliative care for people with dementia' in *Postgrad Med J. 2007* Jun; 83(980): 362–366. doi: 10.1136/pgmj.2006.052936

[9] Dixon J et al (2015) Equity in the provision of palliative care in the UK. Personal Social Services Research Unit, London School of Economics and Political Science 2015

[10] Alzheimer's Disease International (2016) Improving healthcare for people with dementia https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf

[11] http://www.who.int/health_financing/universal_coverage_definition/en/ (Accessed October 2016)

[12] WHO Palliative Care Factsheet (2015) http://www.who.int/mediacentre/factsheets/fs402/en/

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socioeconomic status, race, ethnicity or sexual orientation. **The full spectrum of essential, quality health services include health promotion, prevention and treatment, rehabilitation and palliative care.**[13]

56. Dementia is associated with complex needs and high levels of dependency and morbidity during the later stages, requiring a range of health services and long-term-care. These include identification, diagnosis, treatment, rehabilitation, **palliative care** and other services such as home help, transport, food, services, and the provision of a structured day with meaningful activities.

58. A number of key principles are suggested for organizing and developing the health and long term care system for dementia. These include, a timely diagnosis; the integration of dementia treatment and care into primary care; continuity of health and long-term care between different providers and system levels, **quality palliative and end-of-life care,** and active collaboration between paid and unpaid care providers.

61. Develop an efficient coordinated care pathway for dementia that is embedded in the health and social care system to link people with dementia to integrated, person-centred care as and when it is required. The pathway should combine multiple sectors including primary health care, specialist medical care, rehabilitation services, **palliative care services,** household help, food and transport services, meaningful activities and other social welfare services into a seamless bundle that enhances the capacity and functional ability of people with dementia.

66. Develop and implement guidelines, tools and training materials such as model curricula on dementia core competencies for health and long-term care workers in the field and provide technical support to Member States on ability-oriented, person-centred integrated long-term care provision **from early in the course of the illness to the end-of-life.**

93. If the incidence of dementia is to be reduced, and the lives of people with dementia are to be improved, research and innovation as well as their implementation in daily practice are crucial. It is important not only that funding and appropriate infrastructures for dementia research and innovation are available but also that mechanisms are in place that assist appropriate recruitment of people with dementia, their carers and families into research studies. A balance is required between research into prevention, treatment, care **(including palliative care**) and cure. Collaboration across Member States and all stakeholders to implement a coordinated strategic dementia global research agenda will increase the likelihood of effective progress toward better prevention, diagnosis, treatment, and care, **including palliative care**, for individuals around the world who are living with dementia.

[13] WHO website. What is Universal Health Coverage? http://www.who.int/mediacentre/factsheets/fs395/en/ (accessed October 2016)

Appendix 1: Supporting evidence and documents

Additional selected evidence

Birch, D. and Draper, J. (2008), ôA critical literature review exploring the challenges of delivering effective palliative care to older people with dementia.ô *Journal of Clinical Nursing,* 17: 1144ï 1163. doi:10.1111/j.1365-2702.2007.02220.x

Goodman, C et al (2010) ôEnd of life care for community dwelling older people with dementia: An integrated reviewôInternational Journal of Geriatric Psychiatry, vol 26, no 4, pp.329-337 10.1002/gps2343

Husebo BS, Ballard C, Sandvik R, Nilsen OB, Aarsland D. (2011) ôEfficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial.ôin *Br Med J*. 2011;343:d4065.

Rosenwax, Lorna et al (2015) ôCommunity-based palliative care is associated with reduced emergency department use by people with dementia in their last year of life: A retrospective cohort studyôin *Palliative Medicine 2015* Sep;29(8):727-36. doi: 10.1177/0269216315576309. Epub 2015 Mar 17.

Torke AM (2014) ôBuilding the evidence base for palliative care and dementiaôin *Palliative Medicine 2014* Mar;28(3):

Van der Steen, Jenny et al (2013) ôWhite paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Careôin *Palliative Medicine 2014*, Vol. 28(3) 197ï 209

Van der Steen JT. (2010) ôDying with dementia: what we know after more than a decade of researchô *J Alzheimers Dis*. 2010;22:37ï 55.

Key UN statements, resolutions and reports

WHA resolution on palliative care - ñStrengthening of palliative care as a component of comprehensive care through the life courseô(WHA67.19)[14]

Global Action Plan for the prevention and control of noncommunicable diseases[15]

WHO and WHPCA Global Atlas on End of Life Care[16]

UNGASS 2016 resolution entitled ñOur joint commitment to effectively addressing and countering the world drug problemò[17]

Civil society position statements and reports

WHPCA statement at the High Level Ministerial Meeting on Dementia (2015)[18]

World Alzheimers report (2015) ñThe Global impact of dementiaò[19]

[14] WHA resolution óStrengthening of palliative care as a component of comprehensive care through the life courseô http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf (Accessed October 2016)
[15] http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf?ua=1 (Accessed October 2016)
[16] WHO and WHPCA (2014) Global Atlas on Palliative Care at the End of Life http://www.thewhpca.org/resources/global-atlas-on-end-of-life-care (Accessed December 2015)
[17] https://documents-dds-ny.un.org/doc/UNDOC/GEN/N16/110/24/PDF/N1611024.pdf?OpenElement (Accessed Oct 2016)
[18] http://www.who.int/mental_health/neurology/dementia/NSA_WHPCA.pdf (Accessed October 2016)
[19] https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf (Accessed October 2016)

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World Alzheimers report (2016) ñImproving healthcare for people with dementiaò[20]

National strategies, reports and responses to dementia

Nationally, progressive action plans and strategies strongly include palliative care to address the identified need but inclusion in policies and implementation of palliative care for people with dementia is inequitable.

Australia

The ôNational Framework for Action on Dementia 2015-2019ôin Australia has ôaccessing end of life and palliative careôas one of the 7 areas of priority actions.

ñAccessing appropriate end of life care and palliative care is essential for people with dementia and their carers, and the presence of an advance care plan may facilitate delivery of care that meets their expressed preferences. End of life care and palliative care have many aspects that are unique to people with dementia, specifically as a result of the disease trajectory of dementia which differs to that of many other chronic diseases.ò(National Framework for Action on Dementia 2015-2019)

UK

In September, 2016 Public Health England published a briefing report entitled *'Dying With Dementia'*[21]. The report highlights the inequalities people with dementia face at-the-end of life in the UK.

Recommendations from the report include focusing on dementia specific palliative services, improving the adoption and quality of advanced care planning and advocating GP led holistic reviews for more co-ordinated care.

Alistair Burns, National Clinical Director for Dementia for NHS England and chair of the PHEôs DIN leadership group commented on the report ñHigh Quality end of life care is a key aspect of the quality of dementia servicesò

Zimbabwe

There is no dementia strategy in Zimbabwe. Island Hospice and Health Care Service, an NGO focussed on palliative care recognises the need for palliative care for people with dementia from the early in the course of the condition and encounters the need regularly in their day to day work. They would like to see dementia included in a national palliative care strategy and health care providers trained in palliative care for people with dementia as a priority.

A case study

ñRecently we visited a 91-year-old man with dementia. He is restless and has occasional epileptic fits. His 82-year-old wife cannot cope and they have employed a nurse aid to assist but the aid is not trained to provide the care he needs and the patent is agitated. This then alarms his wife and family who feel he is in pain and they cannot cope. Island has been called on multiple occasions about this case because the family cannot cope with his restlessness. They live in an isolated area. We continue to provide the support they require but it is difficult in the absence of other social support.ò(Island Hospice and Healthcare Service)

[20] Alzheimerôs Disease International (2016) Improving healthcare for people with dementia https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf

[21] Public Health England (2016) Dying with Dementia. (produced by National Dementia Intelligence Network and National End of Life Care Intelligence Network)