INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE
Advancing Hospice & Palliative Care Worldwide

Briefing Note for Palliative Care Partners re 146th WHO Executive Board Meeting 2020, 2/3-8/20

Introduction: In the first week of February, 2020, your Health Minister, or a high level person representing the ministry, will participate in the 146th Executive Board meeting of the World Health Organization. Here is the list of members. Your country may be listed. Non-board members and civil society members such as IAHPC can also speak after the EB members (NGOs are called on following member state speeches) The EB agenda considers a number of items regarding governance, administrative, and global health issues. Some of these implicate palliative care service delivery.

The IAHPC Advocacy Program is requesting your participation as advocates in your countries in two of those issues – primary health care and universal health coverage, discussed below. We hope you will do the following

- Develop a short statement for your minister or delegation member to deliver at the EB, on how palliative care affects the two topics below, or lack of it challenges appropriate development and service delivery. Help your delegation shine by reporting accurately on progress!
- Develop a briefing note for your minister or delegation with all the relevant information about palliative care in your country and how your organization can help. You will present this as soon as possible, preferably in person, but definitely before the February meeting.

IAHPC will participate in the WHO EB as a "Non-State Actor" in official relations with WHO. *But* **your** *countries will participate as member states*, most of them as members of the Executive Board of the WHO. Their voice is much more powerful than ours! You can inform your ministers of the gains of your country regarding implementation of their multilateral treaty commitments through training of palliative care providers, institutionalization of services, etc. and offer to help with the national statements.

Use DATA: Lancet Report and Map with clear instructions on how to use for your specific country.

Help your government make an informed national statement. Your ministers or national delegation will make national statements on the issues listed on the agenda. Main documents are here. These national statements will have been prepared well ahead! We suggest you develop talking points to your delegation on the two issues discussed below, so that the words "palliative care" can be included in your national statement. Brief is best, so if you can formulate one "high value" sentence on how palliative care workers are being trained in your country, or controlled medicines are being distributed more equitably, this would help tremendously in raising the *global* profile of palliative care. Many delegations that travel to Geneva from your national capitals do not know of the work you are doing and don't know how to report on it at multilateral meetings. It helps if you can
give them their lines. The following points will give you some ideas about how to prepare your minister or delegation. We are commenting specifically on two documents and ask you to formulate one paragraph on *both* those documents based on the specific situation of your country.

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Document One:
EB 146/5 Primary health care Draft operational framework Primary health care: transforming vision into action Report by the Director-General EB
This creates a draft operational framework for primary health care.

Talking point: Read the report and remind your government that palliative care is part of primary health care, as stipulated in the Declaration of Astana, which *they* approved in 2018.. Then offer them one or two sentences on how palliative care is expanding in your country. Is it delivered as primary health care or as specialized private care?

Paragraph 20 on engaging stakeholders is interesting: "The engagement of people, as individuals, and communities, and of stakeholders from all sectors to work together to define health needs, identify solutions and prioritize action is central to primary health care. *Special effort should be made to reach and meaningfully engage vulnerable and disadvantaged populations* who disproportionally experience poor health, while often lacking the resources to participate in traditional engagement mechanisms. Promotion of social accountability will strengthen community engagement. Optimally, engagement of communities and other stakeholders should be integrated across sectors."

How do you engage stakeholders? As patients and/or as other providers? We can also just welcome the inclusion of direct stakeholders in a dialogue about how best to deliver palliative care.

Document 2:
EB 146/6 Report of the Secretariat on High Level Meeting on UHC (Catastrophic Health Expenditure)
WHO's monitoring report notes that the incidence of catastrophic health expenditure (defined as large out-of-pocket spending in relation to household consumption or income) increased continuously between 2000 and 2015. To arrest that unacceptable situation requires action to implement evidence-based health financing measures. I believe we have permission to use this quote for a general statement: "The substantive finding over the past two decades has been the huge economic cost of dying without care", [Liz Grant] says. "*Dying creates intergenerational poverty.* Those who don't know that their disease is incurable and are constantly seeking cures and never finding them… animals are sold and children are taken out of school." Palliative care can be a way out of this if integrated into primary health care.

Question: Do you have any data about the catastrophic cost of cancer or dying in your country?

This is an interesting article on the cost of illness: Russell, S. (2004). The economic burden of illness for households in developing countries: a review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome. *The American journal of tropical medicine and hygiene*, *71*(2_suppl), 147-155.

Jane Bates is doing some important work with this in Malawi.

See also The Value of PC in Low Income Settings by Liz Grant "in a cohort of patients with cancer in Ethiopia, we found that reported medical costs, including medications, treatments and travel to health facilities, necessitated the sale of livestock, homes, wedding gold, as well as pulling children from school as the fees became unaffordable. In studies conducted in Malawi, Kenya, Rwanda, Uganda and Zambia, we identified that families prioritised the immediate need to seek for cures for their ill family member over saving funds for future household costs. The reluctance of clinical staff to break bad news about illness progression and prognosis contributed to this prioritisation of a search for a cure." "Poverty reduction in India: the value of palliative care"

*Questions: Can you describe to your minister the cost of **not** integrating palliative care into primary health care in your country? How does palliative care offset household costs? Does it offset health system costs?*
Can you write one sentence about this for your country?

Pediatric Palliative Care: Paragraph 7 says -- 7. Other monitoring reports issued in 2019 highlight the significant health challenges affecting the most vulnerable population groups. Almost half all deaths of children under 5 years of age in 2018 (47%) occurred in newborns in the first month of life.1 Many neonatal deaths can be prevented by low-cost interventions that can be delivered through primary health care. In 2017, sub-Saharan Africa and southern Asia together accounted for 86% of all maternal deaths, most of which were preventable.2 Ten countries account for 60% (11.7 million) of children worldwide who are not protected by vaccinations, and unprotected children disproportionately live in fragile settings.3 These adverse outcomes occurred despite the world's health and development efforts undertaken since 2000, which have led to dramatic improvements in other places.

What are your countries doing to develop pediatric palliative care?

Workforce:
"countries will need to recruit and train 18 million health workers globally – not only to achieve the universal health coverage targets but also as an investment in human capital and sustainable development."

What is your country doing to train health workers and PC workers in particular?

"All people should be able to receive high-quality health care without financial hardship – as rights holders, citizens and taxpayers." Refugees, migrants, and prisoners, among other vulnerable groups, are rights holders and usually citizens, even if they are not taxpayers.

The Report notes that up to 5 billion people in the world lack healthcare. Of course this also means they lack palliative care. WHO's new special programme on primary health care (see paragraph 14 below) to customize support for implementation to meet country-specific needs; promoting innovation and equity-, gender- and rights-based programming approaches to scale up access to health care and financial protection and reach those furthest left behind; WHO's special programme on primary health care will tailor support to countries' specific health and demographic needs and systems requirements. Specifies that providers will work with regional offices.

Most of our countries are in **Quadrant III**. "Countries with low service coverage and high financial hardship (mainly lower-income countries) need comprehensive reform of both their service delivery and health financing arrangements, giving priority to addressing inequities." *Can your country report progress here?* Ask governments to respond to and report on this ask if relevant: "When you are setting up interdepartmental and interdisciplinary teams, please make sure that these include palliative care, and we offer ourselves as a partner to tackle this priority issue for an area of great need."

Sustainable Development Goals: Agenda 2030 "monitoring of progress on the high-level political declaration's commitments to universal health coverage will be aligned with monitoring of progress towards the Sustainable Development Goals. Countries are being asked to report at GA77. Will be used to inform HLM 2023" Poverty reduction is a key element of the 2030 Sustainable Development Agenda. It is Goal One. If you can make the case with your ministry that publicly provided palliative care can reduce help reduce poverty, they can report positively on Goal One at the UN.

Your governments may not understand that they will need to integrate palliative care in order to achieve the SDGs and it's good to start collecting data on your progress early. Remind them that there is "no UHC without palliative care, and UHC and SDG 3 requires UHC and access to essential medicines. Both require palliative care and adequate access to essential palliative care medicines, many of which are under international control. If you need a refresher on this, check out the new Advocacy Course free to members. It defines all these terms as they are used in the multilateral space. Remember time is of the essence, as we should really have *your* material to your governments by Friday, January 10. I can help you develop it until January 3. Please let me know if you have any questions at all. Have a wonderful holiday season with your friends and families.

Thank you for your work.
Katherine

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