



## World's Largest Palliative Care ECHO Session – Q&A

### 1. How do we look at medical assistance in dying within the context of palliative care?

**Answered by:** Olivia Nguyen, MD, MM, CCMF(SP), FCMF, FRCPC, Palliative Medicine – Canada (Quebec)

From my perspective as a full-time palliative care physician: Medical aid in dying has been part of Quebec's landscape since December 2015; thus, we've had time to adapt to this new reality. Advance requests for MAiD are coming into effect today, so it's hard to say how it will impact palliative care.

What we do see is that patients and families know much more about MAiD than they do palliative care, and many think MAiD is the only option if they want a peaceful death. We talk a lot about MAiD in practice. However, independently of how patients wish to die, palliative care is so important on helping them live in the way they wish, respectfully of their values, and I believe it is more needed than ever.

For some patients who wanted MAiD, palliative care lets them be comfortable and supported enough that they decided not to go forward. For some it is deeply in concordance with their philosophy on life, yet they appreciate the palliative care they receive until MAiD. In any case, we approach all our patients the same: with empathy, compassion, objectivity and professionalism.

### 2. Do you find palliative for different countries depends on its resources and product availability?

**Answered by:** Luís Fernando Rodrigues, MD, MAHR Palliative Care – Brazil

Certainly! I have a strong belief that the development of palliative care depends on the number of public resources that are available to fund the initiatives that will support such development. It is not clear to me what exactly "product" refers to. If the term "product" refers to necessary goods to be used in order to mitigate suffering, like analgesics, laxatives and so on, then yes, it depends too much on what types of products are available. And also, what proportion of the population has accessibility to teams and services capable in offering good quality palliative care.

### 3. Are there cultural practices that might be harmful to people in palliative care?

**Answered by:** Olivia Nguyen, MD, MM, CCMF(SP), FCMF, FRCPC, Palliative Medicine – Canada (Quebec)

I believe that a culture where palliative care professionals don't act in partnership with patients and their families, without cultural sensitivity, without respecting patients' wishes and values, and without the medical competence needed (for medical professionals) is a harmful culture for the people that we see, and for palliative care in general.



BY



#### 4. How can patients accept death?

**Answered by:** Sarah Nyariki, Palliative Care Program Coordinator - AMPATH/Moi Teaching and Referral Hospital – Kenya

Proper, adequate and timely end-of-life care results in a high and easy acceptance process of imminent death or dying. End-of-life care is the support and medical care given during the time surrounding death. It does not happen only in the moments before breathing ceases and the heart stops beating but must start as soon as diagnosis of a chronic illness is made and may last for days, weeks, and even months before death.

Those who are dying need care in four areas: Physical comfort, mental and emotional needs, spiritual needs and practical tasks. Families also need support with practical tasks and emotional distress.

**Physical comfort** - Relief symptoms such as:

- Pain
- Breathing problems
- Skin irritation, including itching
- Digestive problems
- Temperature sensitivity
- Fatigue

**Mental and emotional needs**

- **Provide physical contact.** Try holding hands or a gentle massage.
- **Set a comforting mood.** Some people prefer quiet moments with fewer people. Use soft lighting in the room.
- **Play music at a low volume.** This can help with relaxation and lessen pain.
- **Engage the dying person.** If the person can still communicate, ask them what they need.
- **Be present.** Visit with the person. Talk or read to them, even if they can't talk back. If they can talk, listen attentively to what they have to say without worrying about what you will say next. Your presence can be the greatest gift you can give to a dying person.

**Spiritual needs** - Spiritual needs may include finding meaning in one's life, ending disagreements with others, or making peace with life circumstances.

**Practical tasks** - Everyday tasks can also be a source of worry for someone who is dying and can overwhelm a caregiver.



## 5. How do nurses help patients realize their wishes?

**Answered by:** Sarah Nyariki, Palliative Care Program Coordinator - AMPATH/Moi Teaching and Referral Hospital – Kenya

By supporting them in making difficult decisions about end-of-life care, which can be overwhelming not only for the patient but also for their family members.

A nurse can help the patient, and their family feel more confident by providing information and support.

### Understand their wishes and values

- Nurses can facilitate discussions with patients and family members about the patient's goals and values related to their end-of-life care as well as understanding the patient's religious beliefs, cultural practices, and personal preferences.
- Being aware of this information can assist the nurse in tailoring the care plan to the patient's wishes.

### Foster open communications

- Nurses can create a safe and supportive environment, allowing patients and their families to express their thoughts and feelings about end-of-life care.
- This can include answering any questions the patient may have, providing educational resources, or facilitating dialogue between the patient and family members.
- By fostering open communication, the patient can feel more in control and confident in their care decisions.

### Support and empathize

- Finally, it is essential to support and empathize with the patient and their family throughout the end-of-life process.
- This can be a challenging and emotional time, and nurses can provide emotional support and resources to assist with coping to include connecting the patient and their family with support groups, social workers, or chaplains.
- Providing support and empathy can help alleviate stress and anxiety for patients and their families.

### Conclusion

- End-of-life care requires sensitivity, compassion, and support from the healthcare team, especially nurses.
- By understanding the patient's wishes and values, encouraging the creation of an advance directive, fostering open communication, providing palliative care, and supporting and empathizing with the patient and their family, nurses can assist patients with end-of-life decisions and provide quality care.
- Healthcare providers must ensure that patients receive care according to their wishes and needs, especially at the end of life.



BY



## **6. What are the key challenges you've encountered in implementing palliative care policies at a national or regional level, and how have you successfully navigated?**

**Answered by:** Luís Fernando Rodrigues, MD, MAHR Palliative Care – Brazil

Until May 2024, here in Brazil, we did not have a National Palliative Care Policy, but as of May 7th, the 3681 Act was published by the Health Ministry, giving the essential guidelines to implement palliative care as a Public Health Policy. Nevertheless, we have still other challenges. One of the most important is that Health Care Providers still do not give the appropriate importance to palliative care as an ethical, good and suitable manner to offer care to those in need of it. I have a feeling that, when talking to HCP in general, either they do not care about the theme, or they think they already know to apply palliative care; therefore, they believe that they do not need training or education. It seems that only when they face personal suffering with a loved one becoming ill is when they start to understand that other types of care can be available.

In summary, we can say that a lack of education is because of a lack of interest. At the national level, the challenges are the distances, the cultural, economic, political, and geographical differences that we have in our country and the little number of skilled people ready to train and to educate HCP. But this is an issue that is being covered by the new National Palliative Care Policy. And lack of proper funding is another problem. In my case I have to share time between essential activities (to see patients and take care of the medical residents) and other projects like ECHO. And I do not have a secretary that can help me with administrative issues like registration data and general indicators. What have we done? Choosing some tools (ECHO, e.g.) believing in it and being persevering, tenacious, not giving up of our aims and goals. And managing the time as it is possible.