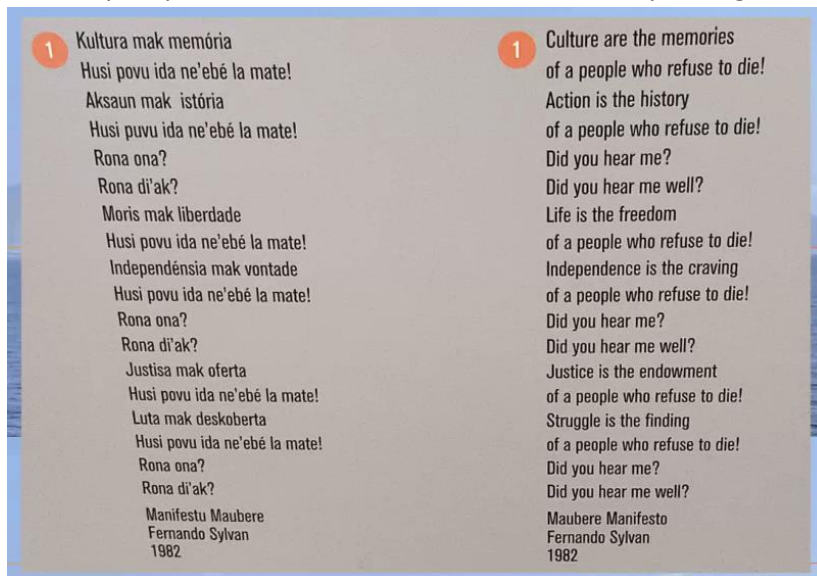


PallCHASE Webinar #11
Clinical Education Series: Hidden Lives, Hidden Patients

“Compassionate Communication,” the third of the four-part clinical education series, connects to this year’s World Hospice and Palliative Care Day (WHPCD) theme of compassionate communities. Dr Mhoira Leng chaired this webinar and shared a video from WHO, where Dr Tedros Adhamon Ghebrey called for increased palliative care initiatives worldwide.

Our first speaker, Dr Andre Belo, founded the SABEH organisation for primary and palliative care in remote areas of Timor Leste, and presented on Compassionate Communication in Humanitarian Situations. Dr Belo shared the turbulent history of Timor Leste, from a Portuguese colony, to Indonesian control, to a 24-year period of civil war where over 200,000 people died. With the war ending just last year in 2022, Dr Belo shared that in the community, there is high unemployment, poverty, many displaced or missing people, leading to much depression, PTSD, domestic violence, and separated families. On the government level, after such a long war, there is a gap of infrastructure and systems, including the health system which led to Dr Belo establishing SABEH, an organisation of 500 healthcare professionals, volunteering, to build up their communities.

We looked at the three levels of compassionate communication for healthcare professionals: family, community and government. In Timor Leste patients live with their family and depend on them for care, so communicating with the family is crucial for the healthcare professionals. Likewise, compassionate communication and education engages on a community level as well as the government, such as with advocacy for palliative care. Communication is not only talking; it is action. It is also the way that we



understand them and what they want. In a post-humanitarian setting such as Timor Leste, needs are great and compassion can be defined as, “presence in a drop oasis.” Dr Belo encouraged us, saying there is a hope in the community, and we must keep humility, collaboration, responsiveness, respect, and integrity as core values.

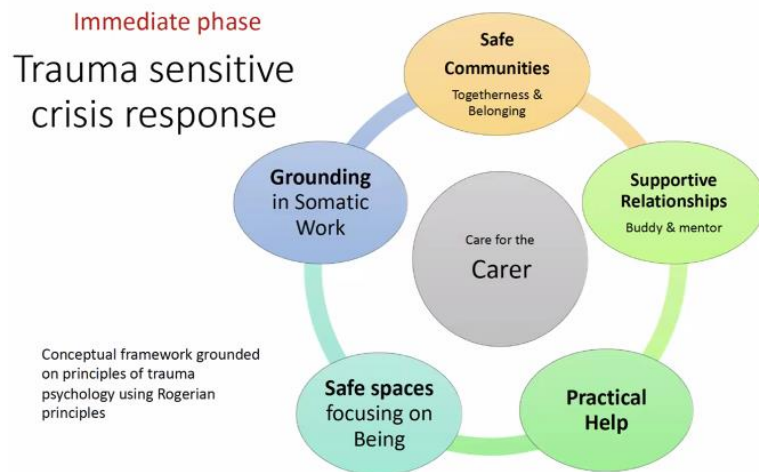
He read the Maubere Manifesto, to the left, words held dear to many in Timor Leste.

Next, Dr Ann Toh, a home hospice physician based in Singapore, spoke on “Compassionate Connection in Humanitarian Settings,” with a particular focus on the micro, or individual level, especially when it comes to communication and trauma. In responding to trauma, a person goes into a flight, fight, or freeze model. For healing to happen, Dr Toh recommended the person needs to reach the social engagement zone (connection) instead. In trauma, words often fail us. In the other three modes, there is slowing down of cognition and forgetfulness. When people are traumatized, words will fail us and the right words to say cannot always reach the other person. We then reviewed a picture of a tree growing on a rock in Timor Leste; a symbol of perseverance, the tree growing on the rock still flourishes and have

leaves. When words fail us, stories, symbols, archetypes can touch us and unite us. Every culture has our own culture, stories, and archetypes. For example, the Chinese word for communication has much symbolism: ears, complete, eyes, one, heart, and king; to listen with all we have.

With compassion, our seemingly insignificant words, actions, or even posture become very powerful and can transform the conversation. Dr Toh pointed out the significance of even our expressions and tone of voice, advising that to make a compassionate connection with a patient and/or family, can give the entirety of your being to them. This level of attention and kindness is universally accepted and appreciated.

Dr Toh concluded with the importance of care for the carer. She gave the example of the first speaker, Dr Andre Belo, and while he mentors young doctors and volunteers, he seeks other colleagues in PallCHASE for support. Can we remember that we are mind, body, and emotion, she asked, and think of things like cooking together or fishing or farming together? We need to remember that we are not alone.



Dr Anna Cleminson then presented an informative guide to “Working with Patients and Families to Identify Goals of Care.” Dr Cleminson works at Northwest Hospice Ireland as a palliative care consultant and brought examples from her time in Ireland and in Gaza (Palestine). She clarified that each culture has a different use of language, who is addressed in patient care, and how we talk to the patient too, so her presentation can be taken as a guide to fit in our own individual settings.

The aims and purpose of care involve collaboration (like Dr Andre Belo spoke about) and connection (as discussed by Dr Ann Toh). As health professionals, we take the palliative care approach and apply our skills to assess, identify problems and offer solutions. Dr Cleminson warned against becoming a healthcare hero and ignoring the perspective and values of the patient when identifying goals of care. We note that the patient and family’s goals of care are influenced by many factors, so planning goals of care must be done in an individual basis. By the healthcare professionals, patients and families

Patient and Family Goals of Care

Influenced by:

- Values
- Culture
- Beliefs
- Experience
- Context
- Family
- Need

Are individual to each patient &/or family unit



developing goals together, they can ensure the patient is listened to, support hope and meaning in this time, and also agree on planned care and realistic interventions.

Dr Cleminson explained that we must acknowledge that goals change as the illness changes. We should review goals of care regularly from the first point of contact, when planning changes in care, or when changes in

health or circumstances change. How do you create these shared goals? She advised us to listen to the patient and the family, clarify, reframe and plan together. If a goal is not possible, find the underlying desire and how to meet this desire. Prepare with the patient and family and when suggesting a time to meet, help them not to be fearful and think the meeting for goals of care is more bad news.

During a goals of care meeting, establish what is known about the illness and clarify misunderstandings. Ask what matters to the patient and family and why; establish what is important and why it is important. Listen to them. Set realistic goals by clarifying their proposed goals and meaning, considering if the goals are realistic(possible) and reframing aims. These goals of care meetings should happen at regular intervals where you should review and adapt goals. Dr Cleminson noted that it is not just the patient's health that may change and need a new goal; caregivers can change too, becoming exhausted, scared or fearful. In these meetings, use tools like REDMAP and REMAP to addressing goals of care.

The webinar ended with a response from a nurse named Annalice Otoro, working in Dadaab Refugee Camp in Kenya, who spoke to the communication skills in crises settings. She thanked all presenters and affirmed what they shared, underlining compassionate communication, especially in humanitarian situations. "We cannot also have a curative approach and make patients take medicine type after medicine," Annalice reported, "What Anna Cleminson shared about listening, clarifying, and reframing and coming together, is important. Yet it is difficult in the refugee camp; they move back and forth – they are always relocating and our resources are very limited."

Final thoughts were shared on the importance of compassionate care and truth telling (versus collusion). Dr Ann Toh shared that in Singapore; different family members will collude against each other; but know that there is a motivation of love here, not simply deception. Dr Andre Belo shared that for most of the interactions, they need to use non-verbal communication due to the diversity of languages so compassion was mostly action. Dr Anna Cleminson pointed out the power of presence; being with one another and standing together.

Our next PallCHASE webinar will be on January 24th and 25th of 2024. If you have not done so already, join our PallCHASE [network here](#) and also enrol for the second instalment of the Grief 101 Workshop on November 23rd, 2023 at 8pm Eastern Standard Time, please register [here](#).