TO COMFORT ALWAYS



INTERVIEW WITH PROF ANNE MERRIMAN

Interview by A/Prof Goh Lee Gan

Prof Anne Merriman (AM) focuses on ensuring that palliative care reaches the poorest people in the world. After working in Ireland, Nigeria, the UK, Malaysia, Singapore and Kenya, she founded Hospice Africa in 1993 and, through their model, the Hospice Africa Uganda (HAU), which has worked with over 20 countries in Anglophone and Francophone Africa.

Prof Merriman attended the 12th Asia Pacific Hospice Conference in July this year, and A/Prof Goh Lee Gan (GLG) took the opportunity to speak with her on the work she did in Singapore at a time when both geriatric and palliative care were in their early years of development. They also discussed her work on palliative care development in Africa. Prof Merriman lived in Singapore from 1984 to 1990.



GLG: Hello Anne, welcome back to Singapore. How has Singapore changed since you last visited us in 2011? What do you find good about Singapore?

AM: For me, coming back to Singapore in 2017 is like landing on a different planet! The buildings are higher and people are more numerous. However, the people are just as welcoming and helpful as ever. You have a caring and compassionate community in Singapore.

With regard to my special interest palliative care - it has moved faster here than in any other country. I noted that in Singapore today, 70% of cancer patients receive some form of palliative care in the disease trajectory. Services are multi-faceted and available at all levels of specialty and practice. Communities are providing care and facilities in both the Housing and Development Board estates and other housing areas.

Singapore should be very proud of her level of palliative care, and even more so of how the experience in Singapore has spread to the rest of the world - not only in Southeast Asia but in Africa as well!

GLG: Tell us more about your work with HAU.

AM: At 82, I am long past my sell by date! But I remain the director of International Programmes (IP) at HAU. Our department is small with four team members - two for Anglophone and two for Francophone Africa. My role is to coordinate our training programmes that are held twice a year for those initiating new services in African countries. We then follow students into

their countries of choice, on invitation, to support them in setting up clinical services that can grow to have teaching programmes at all levels - from village carers to postgraduate and undergraduate doctors.

The annual Anglophone and Francophone programmes consist of a five-week schedule. The first two weeks are classroom-based, where they learn the basics of African Palliative Care (APC) while sharing their experiences in their own countries. Over the following two weeks, they go on mobile rounds to the homes to learn how to manage those too weak to attend clinics, how to assess home environments and to meet with the families. The last week consists of the training of trainers so that they can train others upon their return home. Upon completion of the programme, these initiators, consisting of doctors, nurses, pharmacists and social workers, become part of our alumni, and we keep in touch online.

IP takes up only a portion of my time. I am also sought out for advice regarding our running of this "model", especially as we have had several different chief executive officers (CEOs) since I first handed over the leadership in 2003. Our present CEO is Dr Eddie Mwebesa, a home-grown palliative care physician, who is a great teacher, speaker and clinician. He is now learning the hard way on how to be a manager and we all assist him together.

Receiving up to 100 emails a day has been a challenge and I am not always able to keep up. I have been asked by



our foundation to ensure that legacy documents are written, for when I "pop my clogs". Thus, I am working closely with Autumn Fielding, an advisor and legacy document writer. Autumn helped me in the writing of my book Audacity to Love in 2010. She also provides support for the foundation and the foundation's website (http:// www.annemerrimanfoundation.org).

All this, plus speaking at conferences to promote our ethos, attending board meetings, and bringing advocacy to donors and fundraisers, keep me very busy.

APC¹ first started in 1989. I was still in Singapore when I was asked to take the post of medical director at the new Nairobi Hospice. When I visited Nairobi, I found that the hospice provided its services in a wooden hut and had only three dedicated staff. The poor patients were given only paracetamol for pain control, whereas the rich, who could afford to pay, sometimes had access to codeine. I could not join them unless we had affordable oral morphine, as what we had made in Singapore. Six months later, they wrote to tell me that they had the government's permission to import oral morphine powder. Thus,

the affordable formula from Singapore got to Africa!

While in Nairobi as the medical director, I wrote an article describing our work, for an edition of Contact.2 Edited by Dame Cicely Saunders herself, my article described one of the many patients whom we had helped and demonstrated the difference that we were making. Letters came in from seven different countries in Africa asking me to help them with the suffering in their own countries. Realising that it was not just Nairobi but all African countries that needed palliative care, I left Nairobi Hospice to start an organisation with the vision to provide palliative care for all in need in Africa. We started by selecting an African country in which a model that was affordable and culturally adaptable could be developed from, so that it might reach all of Africa.

Hospice Africa UK commenced in 1993 and HAU, the model, began the same year, following a feasibility study in four countries. The vision of HAU was, and still is, "to bring peace to the suffering of Africa, through providing and facilitating affordable, accessible and culturally appropriate care in Uganda and other African countries".

This was the beginning of APC and our goal to follow our vision. When HAU was established in 1993, we were only the fourth of 53 African countries (now 54) to have palliative care. The initial two were in the richer countries, Zimbabwe and South Africa, followed by Nairobi Hospice ten years later, in 1988, through the vision of Ruth Wooldridge. Now in 2017, 37 countries have supportive palliative care in some parts of their country, while only 20 have affordable oral morphine.

The importation of morphine is still being blocked by governments, but a solution has been found; morphine for all in need in Africa is made at HAU in Kampala. The formula is one that was devised in Singapore in 1985 and this has opened the gate to palliative care in the poorer African countries.

The Palliative Care Association of Uganda commenced operations in HAU in 1999, and in 2003, the seeds of the African Palliative Care Association (APCA) were sown in HAU. In 2005, APCA became independent and registered. Both of these organisations work together with us in Uganda and other African countries.

The teaching of undergraduate and postgraduate doctors commenced in 1994 in Makerere University, and has completely changed the attitudes of healthcare professionals. In 2008, after two years of intensive advocacy work and planning by HAU, the Palliative Care Unit was commenced under the Department of Medicine at Makerere University.

Our Institute of Hospice and Palliative Care in Africa (IHPCA) has grown since 1993. IHPCA continues training programmes in all of Africa, up to the degree level, and plans to commence Master degree programmes in 2018.

GLG: I remember you first came to Singapore in 1984. Tell us more about that part of your experience in geriatric care in that era.

AM: I was invited to join the Department of Social Medicine & Public Health in the National University of Singapore (see historical note) by Prof Phoon Wai-On because of my experience in geriatric medicine, coupled with my recent Master's degree in International Public Health. I am a clinician at heart and was frustrated to be restricted to working without patients. But I soon made up for that! With ongoing research into Parkinson's disease and incontinence among the elderly, I was able to have weekly clinics. The support I received from colleagues to help the elderly at that time was invaluable.

Working with St Joseph's Home in Jurong and other homes run by religious organisations brought about a new perspective on how having good institutional care was possible in Singapore. I also visited some of the private homes for the elderly and although some were good, there were also some that were really bad.

This led to me writing a book on international geriatric medicine that was published by PG Pub in 1989, with the forward written by Dr Lee Suan Yew. The second edition was promised by a wonderful young lady doctor working in geriatric medicine then. Sadly, she died

after I moved on from Singapore and the next edition never came to fruition.

GLG: You are one of the pioneers in hospice care in Singapore. Share with us that part of your life.

AM: The Singapore nurses, headed by Sisters Geraldine and Mary Tan of St Joseph's Home, and a few dedicated volunteers, including Cher and Siew Kim Florence, first came to me after a meeting in 1985, and asked for some form of home care for cancer patients who were not responsive to treatment and had gone home to await death. When we followed these patients home from the hospitals, we found that pain was no longer being controlled.

Yet from Dame Cicely, we learnt that there were simple methods to control pain so that the patient could stay comfortable till the end of life. This meant taking pure oral morphine regularly, titrated against the pain. Thus, holistic care for patients and their family members was possible when the terror of experiencing severe pain – now considered akin to torture – and it being witnessed by the family, was removed.

Morphine powder was already being imported into Singapore for making the "Brompton Cocktail" which contained not only morphine powder, but also sedatives (eg, chlorpromazine) and other additives. Also added occasionally was the local tipple such as whisky or gin.

The trouble with this was that when the patient became drowsy, it was difficult to tell if it was due to the alcohol, sedative or morphine! Also, sedated patients were still in pain, and a drowsy person cannot function normally.

We asked the pharmacists at National University Hospital (NUH) to make us a pure morphine solution. This was when the formula for affordable pure oral morphine was first produced here in NUH. Oral morphine had only three ingredients: morphine powder, water and a preservative.

Before I left in 1990, we used this on more than 400 patients in the community, with no addiction or diversion observed. Over this period, we taught doctors, nurses, patients and family members how to use it. Gradually, the myths and fears of using morphine were dispersed.

After the Hospice Care Association was established in early 1990, I left Singapore in the hands of a very dedicated team headed by Prof Cynthia Goh who had joined us early in 1985, and she has since led Singapore to the forefront of palliative care in the world.

GLG: Yes, indeed. Prof Cynthia Goh has carried on your good work and taken palliative care in Singapore to where it is today. She also contributed a lot to the development of the Asia Pacific Hospice Palliative Care Network. Based on your professional experience, what message do you have for the world with regard to hospice care?

AM: The difference between palliative medicine and other specialties is obvious. The words "hospice" and "hospitality" both come from the same origins of hospes (Greek) and hospitium (Latin) that mean "hospitality", hospices still reflect hospitality in addressing all the needs of each patient, and see each patient not just as their illness but as people with a life, family and community.





Hospital patients are often stripped of their dignity in order to fit in with the strict bureaucracy of health services and the busy schedule of doctors and health professionals. Hence, there is little hospitality. Shortcuts are taken to ensure that patients fit into a time frame and health professionals must hit the goals dictated by officials, often to make or save more money. This, to me, is very sad.

My message to the world is to ask each carer to be reminded of the aspirations that they had when they joined the caring community. The hospice ethos has three guiding values and those who follow these values form the caring community.

The three guiding values are:

1. Care for the patient and family

Everything – in decisions, in care and in changing the environment for the patient – must be done with this question in mind: "How will this affect the patient?"This question needs to be asked by those in high positions within international organisations, such as the World Health Organization and International Narcotics Control Board, which make decisions and recommendations that directly affect patients, families and communities throughout the world. Additionally,

this should be considered by those in the government sectors, carers, consultants, cleaners and those supporting all that we do. We as carers must recognise and address both the pathology of the body and spirit, as well as other areas of life that affect our bodily health.

2. Care for each other

We should care for each other within our teams, our colleagues and those whom we work with at any level. This brings peace and harmony within teams, enabling the spirit of hospitality to be extended to all patients, families and even strangers. This enables us to go out in peace to provide comfort for the very sick.

3. Support partner organisations

We should recognise that no man is an island. None of us can heal without the support of other organisations, specialties and support services. It is important that we respect and not put each other down in our seeking funds for our own work, and recognise that our patients have many needs and we need one another.

GLG: Thank you, Anne, for sharing with us your work and insights of the time. We look forward to you visiting us again. •

References

- 1. African Palliative Care is palliative care that is adaptable to economies, cultures and needs of different African countries, tribes, etc. It is based on "African solutions for African challenges".
- 2. Merriman A. Living while dying. Contact 1991; 122. Christian Medical Commission, Geneva.

Historical note: The Department of Social Medicine & Public Health, NUS was set up in 1948 and renamed in 1987 to Department of Community, Occupational & Family Medicine (COFM) when family medicine was included as a formal discipline in NUS and taught by COFM. The Department of COFM was next renamed Department of Epidemiology and Public Health (EPH) in 2009 with the departure of family medicine to join the Department of Medicine, NUH as the Division of Family Medicine. Since 2015, the Department of EPH has become the Saw Swee Hock School of Public Health.

Legend

- 1. Prof Merriman and A/Prof Goh Lee Gan during the dinner interview
- 2. Bottled oral morphine solutions for Uganda manufactured at HAU
- 3. Mah-jong group at Day Care Centre in HCA, Singapore, 2017
- 4. Ward round in St Joseph's Home, Singapore, 1987

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