

The Rosalie Shaw Oration

ANZSPM Conference 2016

Revisoning Palliative Care

I thank you for recognising in this way the many years I have been working in palliative care. However I am very mindful of all those who have supported me over the past three decades. It is only through their commitment, loyalty and tireless effort that I have been able to continue in this work.

It is a great privilege to be asked to give the oration at this conference and, in reflection as I prepared this talk, I realised that this was an opportunity for me to re-examine my personal inspiration and vision for palliative care.

1963 was the year I started nursing training at St Vincent's Hospital in Melbourne. It was there that my passion for caring was nurtured. I was inspired by the example of the nuns and, in particular, by Sister Mary Francesca Healy who had started and oversaw the Home Care Extension Service. The Home Care Extension Service was what we understand today as a palliative care community program combined with a district nursing service. I was rotated there in 1965 and, like all the other nurses who worked there, was mentored by the wise and compassionate Sister Francesca. Later, as a medical student, in order to support myself, I worked with the service as a nurse every weekend for five years. It often feels as though I have been doing this work for 51 years.

It was not until my second year in medical school that my dream began to take shape. A dear friend died suddenly just before my second year exams and I was thrown into grief. Despite my distress I was aware that this was a seminal experience for me as a future doctor. I had joined the company of those who mourned. I now understood that tears started unexpectedly and stopped as suddenly, that there was the need to talk repetitively about the experience even though that my friends' eyes glazed over as their patience exhausted and their compassion diminished.

I was given the book *On Death and Dying* by Dr Elisabeth Kubler Ross and this led me to the work of Dr Cicely Saunders at St Christopher's Hospice. By my fifth year I knew that this was to be my calling. I searched for a suitable placement for my six week elective but could find no one who was interested in care of the dying. I went to Hobart where Dr Norelle Lickiss was Professor of Medicine but at that time she was showing no interest in this area of medicine. It is ironic that she was later so important for the establishment of palliative medicine in Sydney's Royal Prince Alfred Hospital.

In my intern year I heard that Dr Cicely Saunders was coming to Perth to give the keynote address at the Royal Perth Hospital Post-Graduate Education week. I was able to get leave to attend and after her lecture I hastened to introduce myself and tell her how enthusiastic I was to do this work. I expected her to invite me to come to London to train with her team at St Christopher's. Instead she dismissively told me to "just go and do it". As I knew of no one in Australia who was doing it I decided that, when the time was right, that is exactly what I would try to do.

Four years later I was able to do this but first I had had to agree to pass the initial examinations towards the Fellowship in Medical Administration (FRACMA). This was so that the Medical Superintendent could appoint me at Assistant Medical Superintendent. At the time this seemed to an unpalatable carrot but there have been many times since when I have been grateful for what I learned in my studies towards the FRACMA.

In January 1981 we announced that there was now a Palliative Care Unit at Hollywood Hospital (then RGH Hollywood). Although there were inpatient hospices in most capital cities, this was the first hospital based palliative care unit in Australia. Another was to be opened by Dr Brian Pollard in Sydney's RGH Concord later that year.

My vision was to provide more compassionate and more appropriate care within mainstream medicine. Initially this was within a consultative model but it was not long before I began to accrue beds and developed a community outreach with a dedicated team of nurses, doctors and allied health professionals. My vision was certainly not to birth a new specialty with a division between specialised palliative care and those practising the palliative care approach. Nor did I imagine that palliative care would extend its reach to negotiate for early referral whenever a poor prognosis was identified.

I was influenced at that time by Dr Thelma Bates, a radiotherapist at St Thomas' Hospital in London. An article published in The Lancet in 1981 described the Terminal Care Support Team that had been set up in St Thomas'.

Thelma Bates wrote: *"There are three main advantages of such a terminal care team: inexpensive to run compared with a purpose built hospice, great teaching potential, brings the principles of hospice care to patients at home and in hospital at an earlier stage than previously thought possible... Teaching medical students ... not as another discipline, but rather as a skill to be applied in any situation involving patients with limited life expectancy."*

She went on: *"It is not suggested that other teams should imitate this model; each team should evolve out of local circumstances."*

I saw palliative care as a way of demonstrating how care at any stage of life could be given with competence and compassion. I thought that it was imperative that this modelling take place within the hospital environment, not be outsourced to a custom-built building separated geographically from where standard medical care was being given. By contrast, I saw the hospice model at that time as focussed on creating a "nice place to die".

The other influence for me at that time was Dr Balfour Mount, a urologist at the Royal Victoria Hospital (RVH) in Montreal. I first heard about the PCU at this hospital

through the Canadian sister of a patient of mine. She had brought me a copy of the RVH's palliative care manual which served as a very useful guide in the early years of the PCU at Hollywood Hospital.

After participating in a group discussion of Kubler Ross's book *On Death and Dying*, Dr Mount had initiated a study into care of dying in the Royal Victoria Hospital. When shown the findings of the study he was so concerned that, in 1973, he set up a dedicated ward within the hospital and coined the term "palliative care". This was the term I chose to use for the unit at Hollywood Hospital.

The values of the pioneers of palliative care were in line with those of Dr Cicely Saunders in her writings: namely, the importance of symptom relief using careful assessment and regular oral medication; the concept of suffering as "total pain"; the importance of maintaining dignity and enhancing quality of life.

Those were heady years. There was opposition, especially from geriatricians who accused palliative care as invading their territory. But there was a groundswell of support as community services such as the Silver Chain Hospice Service were established, and independent hospices such as the Cottage Hospice were planned. Conferences were held and textbooks on symptom management began to appear.

I was sent overseas first to St Christopher's, then for an extended period to Wheatfields Hospice in Leeds, and from there to Canada and the US to visit the PCU in Montreal and the Connecticut Hospice, the first American hospice that had been established in 1974.

I was fortunate to be working within a public hospital setting. Although resources were scarce, it was possible to lobby for more staff and more beds as our reputation grew. A dedicated core team of nursing staff led by Ellen Nightingale provided excellent care. The focus was always on the person, whether patient, family member

or staff. Our goal was make things a little better in whatever way we could. In order to build the cohesion of the team, I fought to retain staff including porters and cleaners who were also included in our morning handovers. These meetings were seen as mini teaching opportunities where knowledge and values were embedded in the sharing events of the past 24 hours.

In 1985 we were given a grant of \$2 million, a terrifyingly large sum in 1985. It was designated for refurbishment of a ward of the hospital and staffing for the PCU for two years. I deliberately chose a ward area in the centre of the hospital and with a gifted government architect, Brain Adcroft, set out to create a beautiful and functional space enclosing a large garden area. There was a sitting room with a kitchen dresser and a dining room table, another with a chinz covered sofa bed and armchairs for private discussions or overnight stays for relatives, floral curtains to the floor and beautiful pictures on the walls of the corridors. There were no single rooms but we had moved away from the pavilion style wards in the rest of the hospital. It was a show piece and attracted surgeons and physicians to use our meeting rooms, and to lobby for upgrade of other areas of the hospital. The new unit was opened in 1987. By that time the Cottage Hospice was about to open and the Silver Chain Hospice Service had expanded into several bases across Perth.

Symptom management was important but it was seen as only as a component of care. A comfortable bed, clean hair and nails, gentle bed baths, a warm drink and a hand to hold when darkness threatened: these were more effective than breakthrough opioids. We were restricted in the medications available. Immediate release morphine mixture, NSAIDs, oxycodone suppositories. No slow release medications, no patches, not even a syringe driver until the mid-1980s. But I often think that our pain management was more effective than what we often achieve today.

But this was a different world from today. Most of our patients had cancer but treatment options were mostly limited to surgery and radiotherapy. Chemotherapy

was only in its infancy. There was an acceptance that life expectancy was probably only months if treatment had failed. This was a younger cohort with fewer co-morbidities such as cardiovascular disease, diabetes and dementia. In many ways these patients, although dying, were not as sick as the patients referred to palliative care today. There was less uncertainty about prognosis and the inpatient unit was for respite, symptom management and care during the dying phase even if this progressed over many weeks. It was rare for us to talk of transfer to a nursing home if discharge to the patient's home was not possible.

By the early 1990s hospice and palliative care services were well established in Perth. In the three years 1989 – 1991 we had run through the Department of Family Medicine at UWA a three month residential course in palliative care. Students came from interstate and from Singapore where support was growing for inpatient and community palliative care services. In 1992 I was invited to go to Singapore to work with the Hospice Care Association, a recently established home care program providing 24 hour coverage of the whole of Singapore with only 1 doctor, 3 nurses (two of whom had attended the 3 month course in Perth), a social worker and an administrator. The Hospice Care Association was set up as a program supported by volunteers - doctors, nurses and lay volunteers. However, the volunteers, many of whom were very enthusiastic, were poorly trained, lacked leadership and were often unavailable when needed.

I agreed to take leave from the PCU in Perth for one year and set forth on this new adventure that was to continue for the next eighteen years. A new challenge lay ahead. What was palliative care in this setting so culturally different from the one I had left behind in Perth? Was it appropriate to attempt to transplant what was essentially a Western Judeo-Christian ethos of care into a non-English speaking predominantly Chinese Buddhist-Taoist-Confucian society where talking about dying was taboo and grief was ritualised during elaborate wakes where the embalmed body was on display for several days before cremation or burial. I found myself asking the question: What is the essence of palliative care? What core values are relevant in this setting when cure is no longer possible and death is imminent? How

to treat pain when morphine is feared as addictive and likely to shorten life? How to answer questions about prognosis when family members stand by blocking any open discussion about disease progression?

Gradually I learned that kindness, respect, genuine interest in the person and their life story earned their trust. I was shown the importance of body language when communication is difficult – quiet stillness and alert attention, the tone and subtle inflection of the voice, the gentle touch of the hand on the forearm. These communicated far more than words could ever have done. I learned how to use interpreters, not professional interpreters but family members, staff or even on one occasion a security guard when I had been called at night to a home where the patient and her husband spoke no English. I always spoke directly to the patient, making eye contact and using gestures I would use if they spoke English. I would then ask the person interpreting to translate my words directly and then to translate the patient's reply, without engaging in any discussion about what being said.

From 1999 when I became the inaugural Executive Director of Asia Pacific Hospice Palliative Care Network (APHN) my world expanded even further. For the next 10 years I travelled in and out of Singapore to 16 other Asian countries teaching and supporting developing palliative care programs in widely diverse cultural and economic settings. Apart from symptom management, the focus of education was on communication – on how to find ways of engaging in discussions about death and dying and about limiting futile treatment despite cultural restrictions. Beliefs about the meaning of suffering, the importance of the family in decision-making, and the role of traditional remedies underpinned many of the ways we interacted with doctors, nurses, patients and their families. But without trusting relationships it was not possible to help. Relationship was the key.

Although in many of these countries medicine was becoming more sophisticated, family structure was still intact and religious and spiritual practices were valued. Doctors had higher status than nurses, and education was largely didactic rather

than discursive. However, there was great concern about the suffering, both physical and psychosocial-spiritual, endured by many patients and a wish to develop staff and services that could address this suffering.

In 2010 I returned home to Australia. My intention was register with the newly form AHPRA and find locum work as a palliative medicine consultant. This was a very different Australia from the one I had left 18 years before.

Society had changed. There was now almost instantaneous access to people and information with internet and mobile phones. Cheaper and easier travel had brought migrants and refugees from a great diversity of cultures. Family breakdown meant that there were “blended families” and many people were now alone and isolated. There was an increasing gap between rich and poor. There had been a movement away from traditional religions that in the past had sustained people when faced with sickness, aging and death.

Medicine had changed. Medical technology now prolonged lives with radiological interventions, safe anaesthetics, potent antibiotics and new drugs including chemotherapy agents. Life expectancy had risen and there were now greater numbers of elderly with chronic ill health. More people were dying slowly of organ failure, stroke and dementia. Meanwhile the cost of health care was escalating with the demand in the last years of life for expensive medical care such as joint replacements, ICU admissions, cardiac stents and pacemakers.

There had also been an amazing development of palliative care worldwide. By that time there at least 12 peer-reviewed journals and hundreds of textbooks on palliative care. Palliative medicine was now a sub-specialty in more than twelve countries and interest was developing in paediatric palliative as a further subspecialisation. Most major hospitals had palliative care teams and community palliative care programs now partnered with district nursing programs in metropolitan and rural areas to

provide care in patients' homes. There was a bewildering array of medications and formulations available for symptom management.

Public expectations had also changed in the past two decades. Many people now expected that disease could always be treated or life extended even if the disease could not be cured. Death was seen as preventable. The words "palliative care" evoked fear as a harbinger of death and were often confused by the public with euthanasia or physician assisted suicide.

But I saw many changes in the way palliative care was now practised. Despite having a plethora of drugs available, many patients still had unsatisfactory pain control. The focus on physical suffering (symptom management) was at the expense of caring for the person. There was little interest in exploring the personal narrative of the patient. Despite an abundance of resources available to patients and families, relationships with staff were shallow. Organisation structures and schedules discouraged continuity of care, especially when so many staff worked part-time.

Despite the hospice mantra that the team is the basis of care, there was often an absence of team work. Doctors and nurses were critical of each other's role: palliative care doctors were competing with and excluding colleagues rather than encouraging the sharing of knowledge and skills. Inpatient units had become places for symptom management where, soon after admission, questions were being asked about discharge plans. If home was no longer an option, this meant discussion about ACAT assessment and the search for a residential facility, aka a nursing home.

Staff were overburdened with documentation and data collection at the expense of time spent with patients. Administrators seemed unaware of the stressors created by management and seldom left their offices to "walk the factory floor". Basic nursing care in hospitals was often inadequate. Hair was not combed. Mouth care poor. Bed clothes rumpled. Patients restless and uncomfortable. Agitation was interpreted as a

need for a breakthrough dose of medication, rather than a call for comfort and a kind word of reassurance. Many communication courses were available but what was taught may have made communication more mechanistic rather than compassionate. Those who had participated in these courses often had difficulty transferring these skills into real life situations.

I began once more to ask: What is the unique contribution of palliative care? What do we actually do that makes a difference in the lives of our patients? Why do our colleagues refer their patients to us? Even more importantly, why do our colleagues not refer patients to us and why does the mention of palliative care strike fear into the hearts of patients and their families?

How have we failed to engage respect and confidence in our skills? Do we need to re-examine the way we present ourselves as palliative care professionals? It is important that our trainees are now qualify in another specialty before enrolling in palliative medicine training. But, in our efforts to be seen as credible medically, have we adopted the very model against which the palliative care movement was protesting? Have we become “symptomatologists” conducting traditional ward rounds with a team of doctors standing around the bedside focussed on the results of scans and blood investigations rather than on the bewildered patient in the bed? Do we ensure that one or more members of our team engage in meaningful relationships with each patient in our care?

Does our use of phrases such as “palliate”, “comfort care”, “journey”, “quality of life”, “a good death” repel our colleagues? Would a change of name to “supportive care” help our public image or would this too become a pejorative term associated with death rather than with enriching life within the framework of uncertainty? Is it time to rethink whether we need inpatient beds in our public hospitals? Has the consultative model failed? Do we need to create “centres of excellence” where we can demonstrate how we can transform the experience of the distressed patient?

More funding is always welcome but funding without vision will only replicate the problems that already exist. For three decades we have been trying to convince our colleagues and the public that we have skills that can enrich their practice of medicine and nursing. We have failed. Many of the doctors on the wards and in the community are still unable to use opioids appropriately to relieve severe pain and they are unaware of the services available to assist them in care of the patients at the end of life.

We and they are unprepared for the tsunami of patients who are now demanding better care. We, the palliative care professionals, cannot care for all patients from the time of diagnosis of a life-limiting condition. Others have to assume this responsibility. But how will we feel when other specialties begin to train their own palliative care specialists as yet another subspecialty, as is already being mooted in the US where a three year training for palliative oncologists is being discussed?

I do not believe that referrals are made solely for symptom management, for advance care planning or for access to services and equipment outside the hospital setting. Our colleagues care deeply about their patients but they are trained to diagnose and to treat disease. They find communication about the end of life very difficult. This is why they ask us to help. They recognise that we have the courage to bear witness to suffering.

Why then do we cringe from declaring to our colleagues that this is why we are practising palliative care, that this is what makes such a difference to the patient experience at the end of life? Are we afraid to model what we do so well? Why are we not demanding that bedside comfort is paramount, that competent 24 hour support is provided in the community, that more appropriate beds are available for end of life care?

Professor David Haslam, Chair of the National Institute of Health and Care Excellence (NICE) wrote in 2015, “As patients and as relatives we know when care is delivered with compassion and when it is not. ...I am potentially a very frightened patient.” I too am potentially a frightened patient.

Should we be asking whether it is even possible to practice palliative care in the health care system today where the emphasis is on what can be counted? I believe it is possible even when resources are scarce. My hope lies with the trainees and consultants who have chosen this specialty. I have worked with many of you over the past six years. You have inspired me with your commitment, your intelligence and your compassion. It has been a joy to work with you. This morning I have asked the questions. But it is you who must find the answers to these questions.

It is a privilege to do this work that touches deeply into the mystery of what it means to be human, what it means to live for this brief span, to suffer and die. Symptom management is important but the relationship we establish with the patient is more important. Symptom management is “doing” - is what we do. Communication is “being” - is how we bear witness to suffering: by listening, by showing respect, by kindness. There must be the intention to be present, to create a bubble of attention. Putting aside assumptions and our desire to “fix things”, this time is this person's time, even if for only a few moments of time. Dr Cicely Saunders wrote of “the search for the quietness of Presence, the still waiting with another person.” Presence describes the quality of this communication.

This does not require more time or more resources, although more resources are needed. What is required is a different focus, a cultural change. It requires that we look deeply into our own fears and prejudices, that we explore the values we hold about the sanctity of life and the uniqueness of each person's life story. It takes

courage to go into these dark and difficult relationships with compassion, skill and humility.

We do not need to revision palliative care. Instead we need to reclaim the vision of those who came before. In the year after I established the palliative care unit in Perth I heard that Sister Francesca was very ill with motor neurone disease. I flew to Melbourne, not only to say goodbye, but also tell her what I had achieved and to acknowledge the inspiration she had been for the Palliative Care Unit. I told her of the challenges and, in particular, of the hospital politics that I was encountering. She was no longer able to speak but wrote on a pad: "If you keep your eye on the patient you can't go far wrong." These words have often been a lode stone to which I have turned when decision making was difficult. At times when there are organisational or personal pressures we need to be reminded that the patient is central to all that we do.

Kahlil Gibran, a 20th century American-Lebanese poet, wrote about the intensity of focus that can transform the work experience, whether as a weaver, a carpenter or as a gardener. In *The Prophet* he wrote:

"It is to weave the cloth with threads drawn from your heart, even as if your beloved were to wear the cloth.

It is to build a house with affection, even as if your beloved were to dwell in that house.

It is to sow seeds of tenderness & reap the harvest of joy, even as if your beloved were to eat the fruit.

*It is to charge all things you fashion with the breath of your own spirit,
and to know that all the blessed dead are watching."*

Palliative care also sows seeds of tenderness and reaps a harvest of joy. We are greatly blessed.