

Submission to Parliamentary Inquiry into Palliative Care

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Preamble

This submission is based on my personal experience with palliative care. The first part of the submission incorporates a talk given at the Palliative Care Week Service in St John's Cathedral in May 2012. This is followed by further expansion of the themes developed in the talk.

Introduction

Palliative care took on new meaning for me in January this year when my daughter Louisa died in a hospice in England. She was in the full bloom of a vibrant life and successful academic career when her illness took its toll. Well aware of what lay ahead, she and her partner, Nathan, had been married just seven weeks earlier on her 44th birthday.

In this submission, I have set that personal experience in the larger context of my journey with palliative care over the past 19 years, particularly through my involvement with Hopewell Hospice Services on the Gold Coast and with Palliative Care Queensland.

If you are in a new place and trying to get oriented to a strange landscape, it is helpful to remember that a compass has four major directions: North, South, East and West. If you look in just one direction, and turn your back on the others, you will have a limited awareness of your new environment. If your friends ask you about the experience of being there, your report will miss a great deal of potential information.

Since Hopewell started, I've come to understand four distinct perspectives that can help with this charting of palliative care:

- a) At the heart of palliative care is a person whose end-of-life journey can be analysed in terms of a specific diagnosis and **objective** data, which is the primary focus of medical treatment.
- b) At the same time, the person has feelings about coming to the end of life and ways of trying to make sense of their situation. This **subjective** dimension is also a key to comprehensive palliative care and the search for quality of life.
- c) In addition, that person is part of a social network, which includes family members that are sharing the experience, as well as the larger **cultural context** in which they live.
- d) Part of that context is the **health system** and the extent to which it funds effective palliative care services.

Exploring Palliative Care

My journey with palliative care could have started in 1984 when my father died with liver cancer. Unfortunately, there was no mention of palliative care at that time. As a family, we said he was 'slowing down' but we and even his GP did not pick up clues to the onset of cancer until it was too late. He spent his final days in a country hospital, where he seemed to be 'parked' in an out of the way section, and where my mother provided most of the care.

Then, in 1993, my present wife, Deirdre Hanna, was serving as an Anglican Lay Chaplain in the Gold Coast Hospital where she spoke with people coming to the end of life, for whom being at home was not possible.

She had read of Dame Cicely Saunders, sometimes referred to as "Founder of the Modern Hospice Movement" for the establishment of St Christopher's Hospice in London, and had also read "On Death and Dying" by Elizabeth Kübler-Ross, so was familiar with her role in helping establish hospices in the USA.

From the 1960s these two remarkable women had brought to life the vision of what became known as "palliative care".



In Australia, people such as Professor Ian Maddocks from Adelaide, the first Professor of Palliative Medicine, were pioneers in bringing the vision to this country.

The Hopewell Experience

Deirdre, in her own visionary way, decided we needed a hospice on the Gold Coast to provide home-style accommodation for people unable to be at home at the end of life. As a result, in October 1993, she called a meeting of friends to discuss the idea. This led to the formation of a planning group, which in March 1994 became incorporated as Hopewell Hospice Services Inc.

Then in June 1994, we found a property known as Glory Farm on Hope Island and there we provided holistic palliative care for several hundred people over the next nine years. At the same time, the Ipswich Hospice started, and people in Toowoomba were researching starting a hospice.

In 2002, a developer who wanted our property to complete a land package, provided funds to assist creation of a purpose-built eight-bed hospice in the Allied Drive Community Precinct at Arundel. The new Hopewell Hospice opened in 2005 as a licensed, accredited private health facility that continues the original vision of holistic palliative care in a home-style setting.

During these years, I have gained considerable insight into the philosophy and practice of palliative care, and each year we have provided courses in Palliative Care Education for the Gold Coast community. This was also assisted in 1995 by sharing with Deirdre in her Churchill Fellowship travels to study "Spiritual Care of Cancer Patients."

As well as insights into palliative care, this journey provided Deirdre with the vision that led to the development in 1996 of the Paradise Kids Division of Hopewell Hospice Services to provide Grief, Loss and Illness Support for children and their parents.

Holistic Palliative Care

To refer to the four perspectives mentioned earlier, I recognise that good palliative care includes careful attention to the physical assessment and diagnosis of the person with the terminal illness. This **objective** data is basic to effective pain management and ensuring physical comfort of the client. The very term "palliate" means to provide comfort to someone who is suffering.

In addition to this physical care, however, it is essential that there is careful attention to the person's social, emotional and spiritual needs. At any age, facing the prospect of death can create a wide range of emotions that also deserve care. If their life span is being significantly reduced, that can increase the distress. As these **subjective** dimensions are interwoven with their physical state, pain relief will be more effective if emotional and spiritual concerns are also addressed.

As palliative care standards have continued to be raised throughout the years of Hopewell's existence, we have continued to meet the challenge to keep providing more and more documentation and records, an onerous process for a small facility. I believe, however, that such data gathering must not detract from the personal relationships at the heart of the care process.

In addition to the focus on a person with a terminal diagnosis, palliative care has a commitment to care for the whole family and for others that are affected by the illness of a loved one. It was gratifying to receive this commendation recently from auditors of the Australian Council of Healthcare Standards: *All of the staff at Hopewell Hospice are commended on their level of dedication, their application of customer focus and their very dedicated and caring support for patients and families who are seeking a peaceful and supported passage when faced with death.*

Palliative care also has a commitment to educate society, helping change cultural attitudes that make it difficult to talk about death, and that influence whether or not a person has a peaceful death. The theme of this year's Palliative Care Week '*Some things are too important to be left unsaid... let's chat about dying*' is an example of this attempt to improve attitudes within the wider community.

These changes in cultural perspectives on death and end-of-life care will also have an impact on political decisions to ensure that funds are made available at the Federal and State levels for the equitable provision of palliative care services across the nation.

Another Stage in the Journey

Over the years of involvement with Hopewell Hospice, I have provided support to hundreds of dying people and their loved ones, and this has brought palliative care to the centre of my awareness. Palliative Care took on a whole new dimension, however, over the past two years when my daughter, Louisa, was diagnosed with the cancer that led to her death on 20 January this year. In the midst of a highly successful academic career at Loughborough University in England, Louisa was diagnosed in August 2010 with Stage 3 Ovarian Cancer.

This form of cancer is often not recognised in the early stages, even though a simple blood test could have indicated a potential problem if her doctor had been attentive to possible signs of the cancer. The fact that Louisa seemed healthy and was living a very active life may have been misleading until too late.

Throughout her final journey, Louisa showed great courage and we had deep conversations about her prognosis. We lived out the awareness of the Palliative Care Week Theme, that *'Some things are too important to be left unsaid...'* and we had frequent chats about dying. It meant a great deal to her that her mother and I were both able to be with her in England for the final two months of her life. That experience was also deeply meaningful for us.

I was able to draw on my experiences with Hopewell to provide insights that were helpful to her; in terms of her treatments, in sharing about the emotional and spiritual aspects of her experience, and in making plans about her funeral arrangements. This included her request that, as a world citizen, half her ashes stay in England and half be returned to Australia. It reminded me of *My Country* by Dorothea Mackellar:

*Though earth holds many splendours
No matter where I die,
I know to what brown country
my homing thoughts will fly.*

I was impressed with the level of care available for Louisa in England through the National Health Service, and she felt confident with the care she received. Then, for the last two weeks of her life, when her care needs required more specialised support than could be provided at home, Louisa went to LOROS Hospice in Leicester, where she received excellent palliative care from the staff. Historically, palliative care in specialised hospices is well established and supported by the National Health Service, to an extent that has not happened in this country.

Conclusion

After my experience with Louisa, I have a deeper first-hand awareness of the grief of family members dealing with the death of loved ones who have been an important part of their life. The courses in Palliative Care and Grief Counselling that I help teach at Hopewell Hospice and Paradise Kids will cover much the same objective content but will have a new depth of reality for me through my subjective experience.

The journey of finding my way into palliative care continues, and at some future time I, and perhaps all of us, may well expect to be a recipient of palliative care for our own end-of-life journey. I just hope and pray that the care that is provided covers all of the four perspectives that I have listed in this talk, i.e.

- a. Attention to an early and accurate diagnosis of illness, and provision of effective pain management
- b. Care for the social, emotional and spiritual concerns of patients and their networks of family and friends
- c. A culture of care in the wider community that acknowledges the importance of the final stage of life as a significant part of our human existence, and is willing to "chat about dying" and
- d. A health system with adequate resources and vision to make holistic palliative care a reality for all sectors of the community.

Affirmations for Committee Consideration

In this present submission, I draw on those experiences to affirm the importance of palliative care as a significant component of a comprehensive Health Services system. In doing so, I also thank the Parliamentary Health and Community Services Committee for establishing this inquiry; with its implied recognition of the importance of palliative care.

1. I affirm the importance of education is the specialist field of palliative care in the education of doctors and nurses, in regard to the diagnosis of illness, the transition from curative treatment to palliative care and the use of appropriate pain medications.

- Too often I have heard of delays in the diagnosis of treatable illnesses that put people beyond the stage when effective treatment is possible.
- Too often I have heard of people left in severe pain because of fears associated with the use of opioid medications, the concern that someone close to the end of life might become addicted or through lack of training in appropriate and available pain medications.
- Too often I have heard of people in Residential Aged Care Facilities receiving inadequate care because staffing levels were too low to meet the standard set for providing palliative care.
- Too often I have heard of people pressured to continue attempts at curative treatment when transition to palliative care would have provided better quality of life. On this issue, research in Canada indicated that people receiving palliative care actually lived longer than a comparable group receiving curative treatment, as well as having better quality of life.

2. I affirm the importance of developing a partnership between the Health System and locally based NGO services.

- As 'being at home' at the end of life is the expressed desire of most people, it is important that there are services in the community to help make this possible. This is also of benefit to the Health System as family members carry most of the load of providing care at less cost.
- It is not always possible, however, for palliative patients to remain at home. Some live alone and lack family support. Others have care needs that are beyond the capacity of a family to provide.
- Having a hospice in the community provides an alternative to either hospitalisation or admission to a residential aged care facility. In addition, hospice care is much more like being at home than either of the other alternatives. While providing excellent nursing care, hospice life is less regimented than being in hospital, and is less costly for the Health System. Hospice care has better staffing levels and more specialised staff than is available in Residential Aged Care Facilities, and thus provides a superior level of palliative care. Hospice care can also provide for a wider age range than aged care.
- We developed the NGO service known as Hopewell Hospice Services as a community response to a need within the Gold Coast community. Fortunately, the Minister for Health at the time was willing to make an annual grant to help sustain the service, and this has continued.
- Similar community based hospices have been developed in Ipswich and Toowoomba, and they also make a valuable contribution to palliative care services in each local area.
- Unfortunately, as different Health Ministers were in place as each Hospice was developed the levels of funding provided from Queensland Health are not consistent but as 'historic funding' has remained the same over the years. Thus, Hopewell Hospice, with eight beds, receives less funding than others with six beds, although we are also glad to receive some help, which is about 20% of running costs. There is concern, however, that with the move to allocate most funds at the Health District level, even this support could be at risk.
- To maintain the partnership between the Health System and the Hospices that are already established requires continuity of financial support. Such support also needs to be available to encourage other communities to establish Hospices as a component of palliative care services, without detracting from the support currently being provided.

3. I affirm the benefit to the Health System and to the local community of encouraging the development of community based hospices

- In Queensland, there has not been the same level of recognition of the contribution to be made by community based hospice services, as has been the case in New Zealand and Great Britain. This has made it difficult for other communities to follow the lead of the Gold Coast, Ipswich and Toowoomba in developing hospice services, even though we have been approached over the years by a number of interested groups for advice about starting a hospice in their local area. Without the co-operation of the

- Working in co-operation with local communities in provision of palliative care is of benefit to the Health System. Having a Hospice in the community raises the profile of palliative care, both in terms of the families assisted and through the involvement of significant numbers of volunteers. These volunteers receive training and have the opportunity to serve their community. Facilities run by the Health System have difficulty achieving a similar level of volunteer participation.
- The care provided in a Hospice setting takes full account of the psychosocial and spiritual aspects that are recognised as being an essential part of palliative care. Having a smaller number of beds makes it possible to generate a sense of community among the residents, their family members, the staff and the volunteers in a way that is not possible in larger institutions.
- Hospice care is particularly effective in all the following aspects of care as identified by the World Health Organisation:

Palliative care:

- *provides relief from pain and other distressing symptoms*
 - *affirms life and regards dying as a normal process*
 - *intends neither to hasten or postpone death*
 - *integrates the psychological and spiritual aspects of patient care*
 - *offers a support system to help patients live as actively as possible until death*
 - *offers a support system to help the family cope during the patient's illness and in their own bereavement*
 - *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
 - *will enhance quality of life, and may also positively influence the course of illness*
- Based on Hopewell's experience of providing social and emotional support to residents in the Hospice and their families, and the obvious benefits this provides, we have established the Hopewell Outreach Service to provide similar support to families caring for a loved one at home during the palliative phase. This involves providing a friendly, listening ear to supplement the role of the Nursing Services.

4. I affirm the importance of body, mind and spirit as components in a holistic understanding of human nature.

- The final stage of life can be a valuable time if people are supported in reflecting on their life journey and dealing with what may be called 'unfinished business'.
- As well as being a time where adults and children can find a deeper sense of relationship, it can also be a time for gaining a stronger sense of being a total person, where mind and body come into a closer connection. Often, while dealing with the reality of having a terminal condition, the mind can be critical of the body for not staying healthy and for becoming more frail. This situation may reverse closer to the end of life where often the mind becomes oriented towards dying and the body seems to have a different timetable. When mind and body are unified, accepting the reality of death and allowing the process to unfold naturally, death becomes a peaceful process.
- Opportunities to talk about the process of dying, to receive factual information about what happens at the end of life, and to deal with emotional and spiritual aspects of preparing for death can help greatly in making it a peaceful process. This will also make the medications used for pain management more effective.

6. I affirm that each person is part of a social and cultural context that needs to be taken into account in providing palliative care.

- Palliative care attends to the needs of the whole family, as well as providing care for the person that is dying. As such it must be sensitive to the ages and stages of development of the family members.
- Palliative care is now being offered to varying degrees in many different countries. In each case, it is important to be aware of differing cultural perspectives. For example, it is usual in books on grief counselling to affirm the value of speaking of a deceased person by name to help reinforce the reality of the death and to help with the grief process. In some indigenous cultures, however, it is not acceptable

to use a deceased person's name.

- It is usual to help a person deal with the reality of dying so they can come to terms with the situation and, hopefully, reach an acceptance of that reality. In some cultures, however, a code of silence surrounds the prospect of dying. This can make for difficulties in communication, as often the dying person, even if it is a young child, is aware that they are dying but is unable to talk about it with their loved ones.
- Although some may regard dying at home as the ideal, indigenous cultures that lived a nomadic lifestyle may have a tradition that you have to move to a new location after someone dies. While living in a simple shelter might make this easy, it is more difficult when living in a house, and can complicate the grief process that is so important in such cultures.
- Taking account of the special needs of children, Hopewell Hospice has developed a program known as Paradise Kids to provide Grief and Loss Support Groups for children and their parents in dealing with losses such as a death in the family or family break up. Another component is the Illness Support Program, which provides social and emotional support for all members of Gold Coast families dealing with the long-term or terminal illness of a child. In addition, the Illness Support Holiday Program sponsors a one-week Gold Coast holiday for such families from rural and remote areas, covering the cost of bringing the whole family for a holiday, and during the week also providing counselling support for the parents, the sick child and the siblings.

7. I affirm the Vision of Hopewell Hospice as a valuable model for community-based palliative care

- Hopewell Hospice provides the hospitality of a loving and supportive community, in which skilled nursing care and holistic pain control are combined with the warmth and comfort of being in a home-style environment.
- By providing physical, social, emotional and spiritual care, Hopewell assists those whom it serves in choosing and attaining their preferred mental and spiritual preparation for the experience of death. This, in itself, often leads to an increase in life expectancy by supporting the natural healing forces in each person.
- Hopewell recognises dying as a normal part of life, whether or not resulting from disease, and its hospice services seek neither to hasten that process nor to postpone it. The emphasis, rather, is on making whatever remains of life as pleasant as possible and on encouraging all who are involved to live fully and creatively for the whole of life.
- Hopewell Hospice respects the right of residents to participate in decisions about their treatment and care.
- The Hopewell Team works to enhance the residents' sense of independence and personal choice to the fullest extent possible, within the limitations of their health status and of respect for the needs of others in the hospice community.
- As well as supporting people who are dealing with cancer and other life-threatening illnesses, Hopewell responds to the needs of the residents' families and friends, and encourages their participation in the care process.
- To develop a community sensitive to individual needs, Hopewell's staff and volunteers are encouraged to work as an integrated team, to participate in programs of professional development, and to share in the search for continued personal and spiritual growth.
- Established as an expression of Christian compassion, Hopewell Hospice is an inclusive community that welcomes and respects the personal religious and spiritual beliefs of people of all faiths, as well as those who have no particular faith tradition.
- As a community-based charitable organisation, Hopewell also provides support services and education programs for the wider community.
- As part of the growing network of Palliative Care services, Hopewell Hospice operates within the Standards of Palliative Care Provision developed by Palliative Care Australia, as well as the requirements of Queensland Health.