

Submission to the Parliamentary Inquiry into Palliative Care

Prepared by Ms Deirdre Hanna, Founding President, Hopewell Hospice Services Inc.



Deirdre Hanna

As the Founding President, since 1993 and Co- Founder of Hopewell Hospice Services on the Gold Coast, which includes Paradise Kids, I want to support the inquiry into palliative care and home and community services in Queensland.

While working as an Anglican Chaplain and Ecumenical Chaplain in the Palliative Care Ward of the Gold Coast Hospital, I saw a need for a community based palliative care residential hospice that would offer consumers an alternative choice to death in a hospital or dying in their own home, when they were alone or became too frail to have quality of life.

Hopewell Hospice Services Inc. began in 1993 and is now a licensed private health facility offering an 8 bed residential hospice in a beautiful home-style environment. We also offer emotional, psycho-social, spiritual support and bereavement support to residents and their families and bereavement follow up including memorial services to family members.

In 1995 I received a Churchill Fellowship to study Spiritual Care of Cancer Patients and visited over 17 different hospices in UK and USA, including children's hospices. Then, in 1996, I developed Paradise Kids as part of the outreach of Hopewell, to support children and families living with life-limiting or palliative diagnoses or children suffering from grief, loss and illness experiences.

I gained insights into how palliative care and hospice care, including bereavement follow up is very well established in other parts of the world, and I did a 5 day multi-disciplinary course at St Christopher's Hospice, founded by Dr Cicely Saunders, the founder of the modern hospice movement in 1967. Dame Cicely also understood that a dying person is more than a patient with symptoms to be controlled. She became convinced of the paramount importance of combining excellent medical and nursing care with 'holistic' support that recognised practical, emotional, social and spiritual need. She saw the dying person and the family as the unit of care and developed bereavement services at St Christopher's Hospice to extend support beyond the death of the patient. My dream was to follow in her footsteps. The dream was literal, but with the founding of the Association and community support over 19 years, it has become a reality on the Gold Coast.

The Development of Hopewell Hospice

Although the health system aims to encourage those with terminal illnesses to return home, this assumes that family or other carers are available and able to provide the level of assistance needed. Caring for a dying family member is a difficult task - physically, mentally, emotionally and spiritually, especially for frail aged or those who leave loved ones behind to move to the Gold Coast for retirement. There is also a lot of uncertainty at that time, and deciding on what is the 'best' thing to do can cause frustration, guilt, worry and fear. Death is still a 'taboo' subject in many parts of society and this includes the Gold Coast. We have cared for thousands of adults and children over the years, and there is an educational and awareness process to a peaceful and pain free death that happens over time with good symptom management in peaceful surroundings. Like ripples in a well, the recipients of care take this back out into the community.

If young parents are dying in the hospice, the children are taken through the illness support program so that they can deal with their grief issues as they are happening. Grief and bereavement care can prevent illness before it happens and is part of primary preventative health care. Siblings of palliative children are also provided anticipatory grief and bereavement support.

Hopewell is very under-funded for the running of the hospice. This is linked 'historically' to previous health ministers and we receive no funding for Paradise Kids even though we receive many referrals from DOCS. Over the years the community has supported us and we have grown into the needs of the community requiring palliative care and which is ageing and will need more care over time.

We have recently received some funding to run a Hospice Outreach Service into the community but there are onerous occasions of care required for the small amount of funding received.

Paradise Kids

From its founding in 1996, we have provided services to children who are palliative in their own homes or in hospitals through our Illness Support Program.

Paradise Kids, a Division of Hopewell Hospice is situated next to the hospice and is now the largest counselling centre for children in Queensland. We also offer illness support programs to families with a child living with chronic life-limiting illness in the Paradise Kids Illness Support Holiday House next to the hospice so that 24-hour support is available and we are in touch with the hospital before the ill child arrives. The entire family becomes aware of the chronic stress, physical, psychosocial, emotional and spiritual which is placed upon them from long term disabling illness. Over their week's stay, they learn life skills to sustain them on their return home and bereavement care follow up. We offer this to families in rural and remote areas of Queensland and have far more referrals than we have funds to cope with. Referrals also come from Very Special Kids, a Children's Hospice in Victoria. We work in conjunction with the Children's Oncology Ward, the Paediatric Palliative Care Nurse, and Social Workers from Hospitals around Queensland. We train over 90 volunteers a year to work with children and grief issues and many Universities and Colleges place their students as interns with us.

Education.

Hopewell's College of Transformative Education

From its foundation Hopewell has placed an emphasis on education and living well even with a palliative diagnosis. We offer a 26-hour Palliative Care Training Program twice a year, and two 42-hours Children's Grief Counselling Courses annually. We also offer Child-Parent Relationship Training, Suicide Intervention Training and Living Well with Cancer Programs.

This increases community awareness and understanding of dying, grief, bereavement and loss issues so that people can make timely informed choices when one of their family members becomes palliative or has grief issues.

We offer palliative services that are individually tailored to meet the needs of palliative patients, children and families.

Our governance and leadership is strong, with most staff and Board members present for over 10 years. Our Board includes representatives in medical, legal, financial, aged care, educational, spiritual and psychological expertise.

With sufficient funding we could support more patients and community members.

Innovative Service Delivery

We train hundreds of volunteers per annum. In the future, with our excellent name in education and training, and through wider use of the internet, we will be able to provide additional support in people's own homes, via trained multi-disciplinary volunteers, and telehealth Skype counselling and bereavement follow up support to palliative families and children's families, so that distances in remote part of Queensland can be breached and locals can become more educated and proactively involved in caring for one another.

I personally remain involved in all aspects of hospice, palliative care, and children's psycho-educational support, including writing programs for over 400 children per annum dealing with grief and loss issues.

Deirdre Hanna is Co-Founder and Founding President of Hopewell Hospice Services Inc. (1993) Her background includes Bachelor of Theology (B.Th.), Certificate in Transpersonal Psychotherapy and Counselling; Doctoral Student, University of Creation Spirituality; Multi-Disciplinary Certificate in Hospice Care, St Christopher's London; Certificate in Mindfulness Meditation, Massachusetts Medical School Mind-Body Stress Reduction Clinic; Certificate in Spiritual Retreat Leading and Direction; Diploma of Nutrition and Dietetics. Zonta Gold Coaster of the Year, (1994) Winston Churchill Memorial Fellow 1995 (Spiritual Care for Cancer Patients), The City of Gold Coast Women at Work Wonderful 20th Century Gold Coast Women Award, Gold Coast Bulletin Community Service Medal, 2007; Member of the Churchill Fellows' Association; past Member of Ethics Committee Gold Coast Hospital and current member of Monash IVF Ethics Committee.

Deirdre is presently writing a book on the founding of Hopewell and Paradise Kids.