

Winston Churchill Fellowship Report 2006

Title: Children's deaths: Home care and professional education -
Executive Summary

This executive summary is a shortened form of the Winston Churchill Fellowship report submitted following my 2006 Fellowship. The full report is lodged with the Winston Churchill Memorial Trust. I am happy to supply a copy of the full report to interested readers.

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Introduction and background to the Fellowship

I have had a career working with and for children in a variety of situations, most of these have been as a children's nurse within health care settings. During this time I have worked alongside numerous children and families experiencing a range of profound and multiple losses. This engendered an early interest in the factors and processes involved when children manage their losses, specifically as those relating to loss through death and bereavement. In more recent years I also became interested in exploring how professional children's nurses cope with loss, and how they are academically prepared to work with children's losses.

The experience of 'loss' is common to us all. Children are socialised into loss experiences from a very early age; loss forms part of every child's daily life. Most every day losses of course are minor, and children learn a variety of positive and negative strategies and schema to manage them. However some childhood losses are profound; these include those arising through abuse, family break up, life threatening and life limiting illnesses, death and bereavement through death.

There are two main themes of bereavement loss that children experience. The first relates to the losses associated with bereavement, grief and mourning that a child experiences when someone close to him or her dies. The second theme relates to those children who live with a life threatening and/or life limiting illness, for example cancer or HIV/AIDS. It is difficult to ascertain accurate figures for the numbers of affected UK children. However in the average school class of 30 children, at least one will be bereaved by the death of someone close to them. (Stokes 2004). It is estimated that there are 150,000 children in the UK at any one time who are living with a life threatening and/or life limiting illness. (ACT 2003).

We know that profound losses can adversely affect children's health and welfare in the short and long term. We also know that with good, loving support, children will grieve and mourn and can (in their own time) assimilate their losses into their lives and safely move on.

The speciality of children's palliative, end of life and bereavement care is complex and diverse, and is rapidly diversifying in response to developments in therapies and research. In recent years there has been a resurgence of interest in death and bereavement within UK society (Seale 1998); this has engendered interest in the needs and welfare of grieving and bereaved children. Academic preparation for key professionals has probably not kept pace with these other developments. For many years I have been aware regarding the paucity of UK academic death education, specifically as it relates to the teaching of childhood loss, death and bereavement is undertaken within most undergraduate and post graduate health care programmes.

Since 1989 I have been centrally involved in delivering 'death education' with undergraduate and post graduate children's nurses and other health

professionals at the University of the West of England, Bristol. Some years ago I devised a pre-registration 'Death Education' curriculum for use with the undergraduate students at my university. I also facilitate a generic post qualifying academic module entitled 'Children's Palliative Care'. This is offered to qualified and experienced professionals who are involved in the care of children living with palliative care and dying and bereaved children.

As an educationalist and children's nurse I have two main responsibilities. Firstly I am responsible for the quality of care that is delivered to children. Secondly I am responsible for good quality academic preparation for student and professional children's nurses, and other health care workers. Children's nurses are the professional group who spend the most time caring for dying children and those in receipt of palliative care. (Yoder 1994). Other professionals of course are involved; their roles however are mostly less intense, and can be more peripheral. Despite the differences with levels of involvement, what is clear that all professionals who care for dying and bereaved children experience a range of professional and personal losses; for some these can accumulate over time. The ways in which professionals are educated and enabled to attribute meaning to these experiences seems to be a crucial factor in good quality care and in preventing burnout. (Papadatou 2002, Maeve 1998). Access to professional support and supervision seems to be an important factor; however what constitutes good and appropriate support remains uncertain.

In Western societies children's deaths are exceptional and always viewed as unjustified. Customs and practices surrounding end of life care for children will vary in response to each country's cultural norms and values. In the UK when a child's death is 'planned', s/he is most likely to die at home. When a UK child dies in hospital the most likely venue is the Children's or Neonatal Intensive Care Unit; most of these deaths are to a certain extent also planned and controlled. (Garros 2003). One example of a culturally sanctioned UK practice relates to the small number of parents who choose to take their child home with them from hospital after death. I recently undertook a research study exploring this practice; my sample was a group of children's intensive and neonatal nurses. I wished to discern their knowledge and experience regarding the practice. In the past I have also undertaken research into what constitutes good quality death education for student children's nurses.

Planning my Fellowship – Early on in the planning stage I identified 3 specific topics relating to children's end of life care, that I wished to explore in more depth. These were -

1. What constitutes good support for hospital based professionals who care for dying children?
2. Current practices relating to working alongside parents who take their child home with them following a planned hospital death.
3. Death education for children's nurses.

With these topics and many others in mind, I eventually evolved a set of learning objectives that I wished to address during my Fellowship. I was

mindful regarding the Fellowship's crucial advice about being realistic, and not attempting too much.

I initially used e mail to contact a number of individuals, centres of excellence, and universities in the USA and the Antipodes. I had identified these mainly from their published research. I selected the USA because I was aware that much of the current evidence emanates from there. I had also identified centres of excellence in New Zealand and Australia, where many sensitive end of life and after death practices relating to children were emerging. In order to standardise my requests with each initial contact I attached a letter of introduction, and a set of my proposed learning objectives. (see appendix 1). The whole process required an early start, tenacity, good record keeping and persistence. My experience was that many individuals failed to respond; others took several weeks. It was necessary for me to repeat the process many times, and seek out other potential venues, until I had arranged a prospective itinerary that I could submit as my final objectives to the Fellowship for ratification.

Final Objectives – I wished to use the opportunity afforded to me by the Winston Churchill Fellowship to travel to centres of excellence abroad in order to -

Explore and debate with professionals what constituted best practice in hospital based end of life care for children.

- Explore and review policies and practices regarding parents taking children home after a hospital death.
- Explore what constitutes best practice in support for professionals involved in hospital based end of life care.
- Discuss and debate end of life care as it applies to children with a range of professionals.
- Review, explore and debate death education curricula.
- When possible seek out, explore, compare and contrast local provision for after death care for children, and local and some specific religious customs and practices.
- Share and debate current UK practices in end of life care, and (when appropriate), my research findings.

Johns Hopkins Hospital and University, Baltimore, Maryland, USA. - This hospital is situated in a poorer area of Baltimore, and comprises a large inpatient facility that offers many specialisms including a children's inpatient unit of 250 beds. The university had arranged a skeleton programme of visits for me to undertake with named professionals. I had previous knowledge of one particular specialism - The Harriet Lane Compassionate (Palliative) Care Programme based at Johns Hopkins Hospital, and I was keen to find out more about it. Once there I also arranged to meet and talk with senior nurses and other professionals who were actively involved with hospital based children's end of life care. I met with the Family Care Co-ordinator - a senior children's nurse who advises and advocates for families regarding their rights and needs while their child is in hospital. She described current US custom and practices in end of life and after death care for children, confirming that almost all US

children's deaths occur in hospital, and can be very public. Families can spend a limited amount of time with their child after death; they usually undertake many of the recognised after death care and rituals including washing/dressing/hand prints and casts, photos, hair locks. They can be given some of their child's hospital equipment, for example their oxygen mask, to keep as mementos if they so wish, in the same way as the UK. Children are not taken home after death. US children who die at home are taken to the funeral directors very soon after death. The US custom and practice is that funerals occur within 3 – 4 days. Most children are buried; cremation is becoming more common for adults.

The Hospice at Home Service comprises a multidisciplinary team (MDT) of professionals who deliver a generic palliative care community service. The team comprises a Doctor with a special interest in children's palliative care, a children's hospice nurse, generic social worker, hospice volunteer coordinator, and chaplain. Medicaid/Medicare funds most palliative care for children and adults. They stipulate that a volunteer coordinator and chaplain have to be part of the MDT. My observations of the team were that a very powerful (Christian) religious influence pervaded. One mother had been told by her own church pastor that her child's relapse was due to her own sinning and bad behaviour". The Hospice Chaplain explored this with the mother, and had helped her to find a more supportive Church.

Challenges often occur when inappropriate care is given to some children when a crisis or the end of life phase is reached. Examples of children being taken inappropriately to the emergency room and resuscitation instigated in the absence of written "Do not resuscitate" instructions even if it is obvious that the treatment is futile, and the child is dying. The children's community nurse had a 'child only' case load; this is not normally the case as generic case loads predominate. She has no clear policy guidance either nationally or locally to work from, and there are no residential hospice facilities for children. She does not undertake any practical care. Her role is to meet with the family to discuss and plan, and to act as a listening ear. She devises package of services. Parents undertake the practical nursing care; when needed agency nurses are utilised, especially if the care is complex. The Social Worker's role is to work very closely with the children's nurse. She does undertake some lone visits to families. She shares some of the nursing responsibilities, including advising families to adjust strong medication following advice from the children's nurse. She ensures families access the benefits and financial support they entitled to. Hospice Chaplain role involves undertaking an individual 'religious' assessments for each new referral. She contacts each family regardless of religious/cultural background and explains her roles and responsibilities; she offers to support/comfort/give religious input.

This model of Hospice at Home differs greatly from that offered to UK children. It could be argued that the UK model has become too professionalized, and has moved too far away from independence and self care, and it is important to acknowledge the differences in the cultures and health care provision in both countries. However this hospice model relies heavily on the use of personnel who have a generic professional background, whose interests are not first and foremost child focussed.

Pediatric Bereavement Co-ordinator, Johns Hopkins roles and responsibilities have a powerful religious focus. Her role also includes attending and sometimes instigating audit/review meetings following a child's death. This is in order to give staff the opportunities to reflect/grieve/audit etc. A variety of models for this discussed. It was interesting to note the same problems and challenges for US staff as for UK staff in terms of not attending meetings. This raises the issue that professionals require and utilise a mixed economy of strategies and coping mechanisms to manage professional and personal losses. Papadatou's (2002) professional coping model was discussed.

Harriet Lane Compassionate Care Coordinator's role is to oversee the palliative care service provision within Johns Hopkins. She stated that religious involvement at almost all levels is valued and expected; Chaplains are an integral part of their MTD. Johns Hopkins is also part of the US Initiative for Pediatric Palliative Care. This is an academic initiative for professionals devised by a group of approximately 12 Pediatric health service providers. The objective is to standardise US professional education in Pediatric Palliative Care by offering (mainly) on line post qualifying and post graduate university accredited courses.

It is not the norm to take a child home from hospital after death in the US; if parents wish they can take their child home in their car, it is legal to do this. If they have to cross state lines then the child has to be embalmed. Most professionals are unaware that parents can take their child home, and the option is not routinely offered to a family. When a child dies at home s/he is usually taken to the funeral home very soon after death. The child is cared for at a funeral home, visitation by the family and friends occurs at set times there usually prior to the funeral service. It was suggest that families may/would have trouble living/being in their house if their dead child had been present after death. Two families were cited; one had to move home afterwards. Burial for adults and children is more common than cremation; however cremation does occur especially for mobile families, so they can take their loved one with them. There is a comparatively short period of time between death and funeral 3/4 days on average. There is no specific rationale for this; it appears to be common practice in the US.

Manager - Pediatric Intensive Care Unit (PICU). This was an extremely busy and cramped unit where children are accommodated in 4 bed bays. The unit had a "friendly and happy feel". This manager (tearfully) described to me a most sensitive and humane intervention for one dying child and was due to graduate from High School. The High School Graduation was arranged and held on PICU at very short notice along with 80 of her classmates. She died 16 hours later. Families can be involved in what ever ways they wish when thier child dies; staff will work alongside families at this time. For example they may take photos, hair lock, wash, and dress their child, and be given some hospital equipment. Each family given a hand made quilt that can be used in what ever they wish.

Significant learning

1. The instigation of grandparent's bereavement groups. The bereavement needs of grandparents are beginning to become more recognised in both the US and the UK.
2. Chaplain's roles instigating discussions with parents regarding organ transplantation. Religious views and ideals are highly influential when decisions are made regarding end of life and after death care for children. This was evident in the central roles undertaken by hospital and hospice chaplains regarding life and death decisions, and with family support.
3. Hand made quilts made by volunteer quilters are given to families as a keepsake when their child dies.
4. Review/audit meetings following a child's death. These engendered many excellent opportunities for staff from different specialities to meet and work cohesively in the care of very sick children. They also enabled the staff to acknowledge the good work that they do.
5. The use of the Employee Assistance Programme as one support strategy for all staff.

The Children's National Medical Center, Washington DC. This is a large purpose built children's hospital situated in the metropolitan district of Washington DC. It provides a diverse range of therapies and treatments, and accepts referrals from most parts of the USA. I met with a range of specialist professionals, and others who had an interest in hospital based end of life care for children. Significant learning included observing numerous incidents of excellent practice and care. I was also privileged to meet with some professionals who were passionate and dedicated in the care they gave to dying children. This learning was interspersed with some concerning observations.

1. I was surprised that there appears to be few written policies to inform care at the end of a child's life. Where policies do exist they varied between units; for example the palliative care, and witnessed resuscitation policies and practices. I was able to discuss the current UK status and provision with a variety of professionals. I also offered copies of some relevant UK national policies for professionals to peruse and utilise if they so wished.
2. There seemed to be a lack of cohesion between the specialisms. They had limited opportunities to liaise with each other and work cohesively. Some units were unaware regarding relevant practices and innovations that were happening in other parts of Children's. Some staff seemed unaware regarding professional roles and responsibilities.
3. My observations were that large numbers of newly qualified 'young' nursing staff undertaking complex and challenging roles with minimal support and supervision.
4. The use of 'travelling' nurses is common. As with Johns Hopkins, Children's relies on the employment of travelling nurses on short term contracts in many of their specialisms.
5. I compared the roles and status of Children's PICU nurses with those employed in UK PICUs. In the US a diverse range of professionals

undertake PICU children's care. These include Respiratory Therapists, Social Workers, Child Life Workers, Doctors, nurses, and Chaplains. The child's PICU care may be more fragmented because of this, and the role of PICU nurses appears to be severely attenuated.

6. The needs of brothers and sisters when a sibling is dying are not routinely addressed. The Child Life Workers, (UK equivalent to hospital play workers), will respond to their needs if requested to do so. Nurses do not undertake siblings work.
7. The prominent, and in some cases powerful roles undertaken by hospital Chaplains represents a major difference of approach when compared with UK practice; however their role should be situated within the current resurgence of religious interest and observance in the US. This powerful religious new right influence could be said to be represented and omnipresent at the bedside of every sick child.
8. When a UK child dies in hospital family members are encouraged to be involved as much or as little as they wish. Overwhelmingly family members wish to be very involved with the immediate after death care for their child; this may their final opportunity to care for their child. They are encouraged to spend as long as they wish caring for their child, and they have the opportunity if they wish to accompany their child to the hospital mortuary or home (when possible). At Children's parents are allocated approximately 20 minutes; my view has to be that for most this is woefully inadequate. I could elicit not rationale for this time frame except as it applied to the working practices and needs of the professionals and the unit where the child died. I was informed that the pressure on beds is always great.

Examples of good practice -

1. Use of the Employee Assistance Programme as a strategy for staff support ensures that all staff has access to professional support and supervision if needed.
2. 'Allow Natural Death' (AND) verses 'Do Not Resuscitate' (DNR) policies. This was a powerful new learning experience for me. The concept and practice of AND acted as a stimulus for me to revisit and review my previous perspectives regarding DNR policies. Since my introduction to AND I have reviewed some of the academic evidence, and introduced the concept to professional colleagues in the UK. I believe that AND provides an important vehicle for professionals to move forward with their discourse. I remain concerned regarding Meyer's (1992) use of the word 'allow', is laden. Who is allowing who to make end of life decisions? The inference could be that professionals make the decision and the views of others could be marginalised. 'Enable' natural death may be a more acceptable alternative.
3. I noted some excellent individual examples of good care.
4. The hospital Ethics Committee's routine involvement in challenging situations was an important instrument for staff to access when decisions were difficult and contentious.
5. The increasing recognition that the PANDA team work alongside mainstream 'curative' treatments.

6. When a child is going to die, if possible forward planning with the family regarding the forthcoming death can be a very constructive intervention.
7. The sensitive practice of placing a gold coloured ring on a dying baby's finger, and then removing it and giving to the family as a memento. Many families later make this into a locket.
8. Kangaroo care for some dying babies, undertaken by nurses who opt for to undertake this.

Starship, Auckland, New Zealand - Starship is the name given to the Children's Hospital in Auckland. It is situated next to Auckland City Hospital, and many of the staff work across both areas. The New Zealand population is diverse. Approximately 28% are Maori, and they form the largest minority. In recent years many people also have come from the Pacific Islands and Asian countries to settle or study. Auckland has a population of 2,000,000; this includes large numbers of incomers. In order to find out more about the Maori culture, specifically as it applies to children and death and to prepare myself more fully, I met with one of the Maori curators at Auckland Museum. During my subsequent visit to Starship I met with a number of professionals who are involved in the care of dying children and children's after death care. During the course of my many discussions what emerged was clear concordance with many central policies and practices. My respondents all discussed the centrality of cultural safety, the fact that children routinely go home from hospital after death, and the importance of clear written policies to support and guide practice. Good levels of staff support and supervision was also central to their discourse.

Introduction to Maori culture and practices at the time of death. Death will normally occur at home. When a Maori dies in hospital it is routine for him/her (Tupapaku) to be taken home by the family (Whanau) and remain there for 3 days prior to the funeral. Open displays of mourning will take place. "constant shedding of tears eases the loss they bear". Tupapaku are not left alone, and the coffin is open. Whanau and community including children visit Tupapaku to pay respects.

Tangahanga is the name given to the funeral celebration. This means *Tanga/cry Hanga/for that person*. The Marae is the name given to the traditional meeting/funeral place; this may be a carved wooden meeting house. The Tangahanga usually takes place 3 days after death. This is the cultural norm, and occurs when Tupapaku and wider community (Whanaungutanga) have assembled. The wider Maori community share a responsibility to assemble for Tangahanga.

At Auckland City Hospital and Starship I met with the three designated Maori staff/Kaiwhakahaere, whose focuses is the spiritual and cultural needs of Tangata and Whanau. They work as advocates for the needs of the Maori population, and peoples of Maori descent. They explained that New Zealand is a bi-cultural population and society, mainly Maori and European. Maori needs must be seen to be equally represented and advocated for. "Culturally Safe" practices are advocated, for example Maoris never sit on a dinner table

and they always take shoes off before going into a home. Organ donation and recipients are not acceptable within Maori culture.

Kaiwhakahere roles are to support families and children and to advise staff regarding cultural norms and values. Within Maori culture the child belongs to the Whanau and the Whanaungutanga. They work with Maori families when their child is in hospital to ensure that they know their parameters, and what are acceptable behaviours and actions while their child is in hospital. They offer a variety of services and advice to staff and Maori families including support during witnessed resuscitation. When a patient dies the room is blessed (Karakia) prior to another patient's use. Although this is not a Christian blessing the Chaplain unusually performs this prior to the room being cleared and prepared for the next patient. Nurses and other professionals undertake the blessing if a Chaplain is unavailable. The blessing is an essential and integral part of the process of saying goodbye to the deceased patient and releasing the spirit of that person/Tupapaku, prior to another patient using the room. The process is also viewed as an essential component of care from a professional perspective. This closure time is important in helping staff to manage their many professional loss experiences.

Significant learning

1. The centrality of 'Cultural Safety' policies that guide and affect all professional health care. The New Zealand ethos to life and health generally is more spiritually based. Holism probably means more in New Zealand than in the UK; cultural safety is a vital part of this.
2. The deaths in hospital of children are well managed, and supported by much clear policy guidance and sensitivity to cultural needs. It is routine for children to be taken home after death, professionals are prepared for and support families with this practice. The large numbers of children taken home in this way in New Zealand is probably influenced by the Maori tradition, the practice is now also routinely undertaken by most New Zealand families.
3. The PICU bereavement team are highly organised and effective. They demonstrate an excellent example of high quality end of life care for children.
4. "New Zealand children do not need children's hospices". Differences in health care provision and demographics means that the UK model of children's hospices would not be appropriate. There are differences in appreciation of the role of hospices; in the UK their main purpose for children is respite, a secondary purpose is end of life care. However New Zealand professional associate hospices only with end of life care. It is unclear how the respite needs of New Zealand children are met.
5. Staff support is taken very seriously and is well managed. The extensive use of the Employee Assistance Programme as a means of professional support and supervision is one example of this.
6. "Pop up" palliative care services for children throughout New Zealand. Palliative care services are provided by local professionals with the technical and professional support for the Starship Palliative Care Team.

7. The length of time between a child's death and funeral (3/4 days) is probably informed by current custom and practice only.
8. The use of travelling nursing staff. Many units employ foreign (especially from the UK and Australia) nurses on short term contracts. These personnel are required to fill the shortfall in New Zealand qualified nurses, many of whom go abroad once qualified. They are encouraged and welcomed to come back to work.

Princess Margaret Hospital, (PMH) King Edward Memorial Hospital, (KEMH) Perth, Australia. PMH and KEMH are the two regional providers of care for children in Western Australia. The geographical area is huge, covering several thousand square miles. Children are admitted to PMH for treatment of a wide range of medical and surgical problems. All complicated obstetrics are managed at KEMH. A neonatal unit (NICU) of 100 cots provides care for all babies requiring their services from the across the region. I arranged to meet with a range of professionals who were involved with children's end of life care. I had anticipated seeing some similarities between the service provision in New Zealand and Australia; in the event these were limited.

Significant Learning –

- The use of a generic nursing service (Silver Chain) for the home management of end of life care for children and babies and Western Australia. This provision is relatively new, and so far the service has not been audited. However vast distances covered by the service make it unrealistic to utilise the provision of qualified children's nurses with expertise in children's end of life care, even if they were available.
- The central role of the Occupational Therapists who work with children diagnosed with cancers and those children who are in receipt of palliative care is in my experience unique.
- The use of hand held computerised patient record keeping is a vital strategy in ensuring good communications between the Silver Chain nursing team.
- The 'relaxed' Australian way of managing funerals, and the use of modern technology that enables friends and relatives abroad to be involved.

Fellowship – Overall Significant Learning

Children's Hospice provision: The UK provision of children's hospices is well established. In my discussions with professionals in the USA, Australia and New Zealand, many expressed opinions that children's hospices were unnecessary in their countries. These discussions caused me to reflect on the children's hospice UK model and ethos of provision. UK Children's hospices are designed to offer respite care and (exceptionally) end of life care to children who have a diagnosis of a life limiting illness. (ACH 2005). They probably 'work' in the UK because the demographics, geography, and the health care funding systems are mostly responsive to this. Professionals in New Zealand and Australia were sure that the UK system of children's hospices would be unworkable there, and that children's hospices are unnecessary, because the management of dying children is very different. The huge geographical areas and rural populations would make the provision

of children's hospices unworkable they believed. However their arguments were focussed on the provision of hospice based end of life care for children, rather than respite care. It was unclear how this was met; however it seems that most respite care is also provided within the home or local community.

In the UK only a small minority of those children who require respite provision receive it. There are many thousands of UK children with a range of health care and disability needs who cannot access hospice facilities because their diagnosis does not fit their stringent inclusion criteria; this is an important equity issue for UK children. When I reflected on this I came to conclusion that UK children's hospices may risk becoming dinosaurs. Children who require respite provision and their families (whether or not their child has a life limiting diagnosis) require a mixed economy of provision and services if they are to effectively care for their child (mainly) at home. The provision of a local children's hospice may be unrealistic.

Staff support and supervision: In each country I visited the Employee Assistance Programme (EAP) as a mainstay of support and supervision was extensively used and endorsed within all of the hospitals that I visited. All staff can access EAP, and all are entitled to a free but limited range of counselling/support/advice. Good quality support and supervision for professionals who care for dying children is a theme that regularly appears within the research evidence, mostly in the context of preventing burnout, excessive sickness, and reducing job turnover rates. This high level of provision suggests that these employers acknowledge the importance of good quality and timely support and supervision for their staff. What also emerged was the importance of mutual support (Papadatou 2002). Without exception all of the staff that I met with endorsed this as a crucial support strategy.

Allow Natural Death (AND) verses Do not Resuscitate (DNR) policies: I first encountered these radical policies and ideas at the Children's Medical Center, Washington DC, and later in New Zealand and Australia. The ethos of this approach to change in policy and practice will probably take some time to be professionally acknowledged and developed before I believe becoming established within mainstream end of life care for children in the UK and other Western societies. My belief is that AND has the potential to offer a more humane and sensitive approach to end of life care for people at whatever age. I believe the use of AND has much potential in assisting professionals and families with the difficult decisions that have to be made when a child is dying.

Teaching children's palliative and end of life care: Teaching children's palliative and end of life care, death education and associated subjects is mostly undertaken by individuals who (like myself) are self-selected. Teaching this subject can be academically 'lonely'. This is probably because colleagues although supportive, generally do not share the same depth of interest and knowledge. I found it extremely useful during my Fellowship to commune with like-minded professionals who are also at one with caring for dying children and teaching about it. This was a significant learning experience for me. I was also able to forge contacts and supportive networks through this process.

Room blessing practices/Karakia: The policy and practice of room blessing following the hospital death of a child in New Zealand was one of the most profound learning experiences for me. I was deeply moved by witnessing the sensitivity, care and respect afforded to this most dignified practice by the hospital chaplain who undertook it. Although not in itself a Christian blessing, my observation on this occasion was that many elements of Christianity were evident, as was careful respect for cultural safety policies. I noted also the importance of the practice for the professional staff, especially the nurses and doctors. The Karakia/room blessing offered them the opportunity for some 'closure' with the child who had died. Another crucial factor was the time element; the room in which a child has died is not cleared and prepared for another, until completion of the Karakia/room blessing. This means that the staff will have a period of time before they have to reinvest their professional energies with the next child. This practice may represent a further strategy to support PICU/NICU staff who often care for dying children.

Length of time between death and funeral: In the 3 countries that I visited the length of time between a child's death and funeral/Tangahanga is 3 – 5 days. This is a much shorter period of time than is currently UK custom and practice. In the UK a period of 7 – 10 days is normal. Practitioners informed me that 3 – 5 days gives the relatives/mourners/Whanau adequate time to assimilate the death and prepared to say goodbye, and that a longer period of time is not needed. One funeral director did not concur with this; her view was that (probably) 3 – 5 days is insufficient, and that some families need longer. The funeral directors that I met with also raised some pragmatic issues. For example the difficulties of having a body at home for 10 days, especially in a hot climate.

The use by some funeral directors in New Zealand and Australia of video conferencing, webcams and other technology to transmit the funeral around the world reflects modern lifestyles, as does the place of the funeral – in Western Australia, on the beach, or in the back garden together with the bar-b-que and cold beer. In New Zealand the traditional practices continue to predominate; the Tangahanga/funeral celebration take place in the Marae, this is the name given to the traditional funeral building.

Professional education: At all the centres that I visited the use of on-line learning for professionals was well established. The main impetus for these has been the demographics and geography of the countries. In the UK the more common custom and practice is for professionals attend universities on a regular basis in order to undertake post-qualifying courses; however this mode of delivery is rapidly changing to on-line and other forms of distance learning. It was important for me to have the opportunity to talk with academics regarding how their courses were set up and the associated difficulties and challenges. The on-line End of Life interprofessional MSc in Washington DC offers a blended learning approach. This seems to be crucial in the context of the subject. Professionals have the opportunity not only to network on-line, they can also meet up at an annual 3 day gathering in

Washington DC to undertake important face to face learning, and to garner support and supervision from each other.

Generic community children's nursing services: In the countries that I visited the majority of children who were dying from incurable illnesses were cared for in their own homes by professionals who had no direct expertise or qualifications in children's nursing. In the UK the profession of children's nursing is fiercely protected and endorsed as a specialism by most health care professionals while others hold the view that the specialism is unnecessary. I continue to hold the belief that children have a right to be cared for by professionals who are specifically qualified and competent to undertake this work. I acknowledge that the UK model of health care for children would not work in the countries that I visited, as there is no equivalent professional nursing qualification. In this respect I believe that UK children are more fortunate, because their care is likely to be delivered by professionals with that specific knowledge and expertise.

There are some important and useful elements of care that I observed. The use of hand held computers by the Silver Chain community nursing staff in Western Australia, and the extensive use of video conferencing by the Palliative Care Team at Starship New Zealand, were both examples of professional practices designed to enhance the care offered to children dying at home. The instigation of 'pop up' palliative care services for children who are dying in their own homes is a further example of an imaginative use of limited resources.

Hospital Chaplain roles: I was fortunate to spend time with hospital chaplains at each of my host sites. My experience was that all the Chaplains I met were female. Unlike UK hospital chaplains, their careers were focussed on their roles and responsibilities within health care. Most of them had previously worked in their own parishes. Their strong religious beliefs were very evident, and their powerful roles within the care teams, especially in the US were taken very seriously. This aspect of the model of work by US hospital chaplains differs markedly from the UK, and is responsive to that country's upsurge in interest and affiliation to religion.

Did I achieve my objectives? I believe I managed to achieve most objectives, and in some instances surpassed them. I would have welcomed the opportunity to spend more time with student nurses, and with practitioners undertaking end of life care for children. Despite this I learned a huge amount about practices in children's end of life care, as well as the use of policies, or lack of them, and the technical aspects of caring for dying children. Some of most significant learning mostly came about unexpectedly, for example witnessing the Karakia; and observing the quiet tears shed by a senior PICU nurse following the death of a small baby; and the results of the work of what must be an army of volunteer quilters who prepare the beautiful hand made quilts that are distributed to children and families in the centres I visited in the US and Perth.

Concluding thoughts and suggestions for future Fellows. Undertaking a Fellowship inevitably means that more questions than answers emerge and that there is still much to do. I was able to compare the practices and policies with those in the UK. I am firmly of the opinion that the care offered to children who die in hospital in the UK is very good. Professional staffs here are mostly well educated, and there are many policies to guide good care. Support and supervision for UK professionals remains a contentious and difficult issue. Some of the practices and policies that I encountered during my Fellowship may prove helpful in informing what constitutes good professional support in the future. My advice for future fellows has to be to 'go for it'. This is a once in a lifetime opportunity.

- I would advise you to plan well ahead; and expect rejection and sometimes indifference during the planning stages. Before undertaking your Fellowship it is important to be very well prepared and knowledgeable. Find out all you can about your proposed host institution, and the local area. Be prepared to be very adaptable; my experience was that plans and timetables could change very quickly. Once you arrive at your destination I advise Fellows to be proactive, and actively seek out further local knowledge and learning opportunities. Mostly I received a positive response to these requests; remember that the worst that can happen is that your request is declined. I contacted local Funeral Directors and places of religion, and arranged to meet with some of those professionals. During my time in Washington DC I took the opportunity to visit the headquarters of the Church of Scientology, and I received a very warm welcome. I now understand a little more about their beliefs and practices, especially as they apply to the care of dying children. I also visited cemeteries in most of the cities I visited; it proved interesting to compare and contrast these with those in the UK. There were also some surprising findings. At one cemetery near Perth wild kangaroos thrive by eating the flowers that people place on their loved one's graves!
- Another important aspect to consider is that your hosts are busy people; they have limited time available for visitors. Always be prepared for meetings; I always planned my meeting with professionals. In a notebook I prepared a list of focussed questions ready to ask. I took notes during my meetings and used a laptop to transcribe these each day.
- Be prepared to be totally independent and don't expect to be entertained. Remember that this is a working Fellowship and not a holiday. My experience was that with occasional exceptions, my hosts were busy people who (quite correctly) did not consider it part of their role to entertain or 'look after' me.
- When making initial contact with potential hosts I suggest that as well as asking if it is possible for you to visit, tell them what you can offer. In each of my initial inquiries I told potential hosts that I would be very happy to share my knowledge and expertise about UK practices in children's end of life care; I offered to undertake seminar and teaching sessions, and I offered to present my research. The majority of my hosts took me up on

this, and I believe it is a way of repaying some of the kindness shown to me by my hosts.

- I would strongly advise Fellows to go prepared to share their own knowledge and expertise. My experience was that many of my hosts were interested in the UK perspectives of end of life care for children, and they were interested in current research and practice innovations. Of course it is vital that any responses or potential concerns regarding the host's practices are sensitive and measured. I did encounter some end of life care practices for children during my Fellowship that I considered to be outdated and insensitive. Through discussions with professionals, teaching sessions and presentations, I was able on some occasions to help professionals to reflect on these, and become aware of some more sensitive and appropriate alternative strategies.
- Be prepared to undertake presentations regarding your work, expertise and research. I gave several of these during my Fellowship; they mostly engendered much lively debate and discussion. I took some paper copies of my work, however the most efficient method is to use a memory stick, and arrange to download and run off paper copies when needed. This worked very effectively for me.
- I took copies of some relevant UK national policies, for example the Department of Health (2006) Children's Palliative care policy; I also took a range of the ACT/ACH policies and The Royal College of Paediatrics and Child Health (2004) policy relating to withholding and withdrawing treatment for children. I offered these policies to my hosts in the context of our shared duty of care to children, and our shared belief in the highest quality care for dying children. My experience was that my hosts were very pleased to receive these. They suggested that knowledge of UK policies and practices can only offer them a wider perspective, and that all knowledge and evidence is valuable when policies and practices are being engendered or developed. I was also grateful to receive some copies of local policies relating to children's end of life and bereavement care, and some relating to Allow Natural Death. The drawback regarding taking copies of policies related to the extra weight that I had to carry with me. I had to make allowances for this within my baggage; the policies weighed approximately 8 kgms.

At the end of each visit it is vital to take the time to thank hosts for their time and energies. I wrote individual 'thank-you' cards. I also brought and donated books for children that explore aspects of loss and dying and death. I brought these books locally, and donated them to some of the practice areas that had hosted me. The intention is for staff and/or parents to use these with children. Once I returned home I also wrote an official letter of thanks to the named professional at each centre who had hosted my visit.

Conclusions – During my 5 hectic weeks undertaking my Fellowship I had the opportunity to visit, evaluate and compare some hospital based children's facilities for end of life care. I was fortunate to spend time with a large number

of professionals who were very dedicated to the care of children and passionate about ensuring that when children died, their deaths were 'good'. Other professionals expressed their frustrations regarding the slow pace of change, and their inability to improve and develop the care that children are offered at the end of their lives in hospital.

The Fellowship also offered me a chance to reflect on my current knowledge and expertise relating to children's end of life care, death education and staff support. I believe that my knowledge has been significantly enhanced by undertaking the Fellowship. Some of my most profound learning has been achieved not through high powered meetings with professionals and academics, although these experiences of course have been important; but by the many informal meetings and discussions with professionals who (like myself) are 'at one' with the subject of children's end of life care. These encounters have been crucial to my learning. The topic of children's end of life care is always challenging for professionals; these discussions were a significant part of my learning, and invaluable because of this.

Undertaking the Fellowship also reinforced to me that the current UK hospital based end of life care provision for children is basically very good. We are fortunate to have a range of excellent policies and protocols to inform the care that is given, and many well-qualified and experienced professionals who have an interest in the work.

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