To visit centres which have a strong and established focus of caring for dying children at home as well as those that specifically target adolescents – UK, Ireland.

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Signed Judith Frost Dated 26 June 2007
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INTRODUCTION

When I first heard of and considered applying for a Churchill Fellowship, it seemed like a dream that could hardly become a reality. In June 2006 I was elated to receive the call confirming that it was indeed a reality and I was to have the wonderful opportunity of travelling to the United Kingdom and Ireland to study services that provide palliative care to life limited children in the community. Paediatric palliative care is a burgeoning specialty in Australia. I was greatly looking forward to discovering ways to enhance Australian practice by observing centres that are long established and to gain ideas for development in the years ahead.

I thankfully acknowledge the generosity of the Winston Churchill Memorial Trust in making this trip possible. The positive support and enthusiastic encouragement I received from the whole Churchill Trust added enormously to the anticipation of what was ahead. I also greatly appreciated the opportunity to meet past and current Fellows whose generous sharing of their reports and intended experiences added to the excitement of the fellowship.

My grateful thanks also extends to Dr John Collins and the whole Pain and Palliative Care Service of the Children’s Hospital at Westmead, who supported me every step of the way to ensure this trip would be it all was planned to be and more. I cannot thank them enough for being a team I was proud to promote to so many new peers and friends I have gained from this extraordinary experience.

Child Death Helpline Counsellor, Great Ormond Street, London
This fellowship, examining community paediatric palliative care in the United Kingdom and Ireland, took place from 5th March to 20th April 2007. During this time I observed many different service providers including hospitals, hospices, community nursing services and supportive organisations such as counselling services and fundraising groups. I was also able to attend a Conference in York which was a meet of major paediatric palliative care specialists throughout the United Kingdom.

**HIGHLIGHTS**

- **Child Death Helpline** – London. Well organised national telephone service for bereaved parents, siblings and grandparents, run by fully trained volunteer bereaved parents.
- **Bereavement Counselling Service** – Helen House, Oxford. Two year programme with services for bereaved individuals, couples, siblings and larger groups. Well organised staff care all led by bereavement counsellor.
- **Palliative Care Nursing Coordinator** – Oxford. Karen, the Palliative Care Coordinator organises individually designed ‘packages of care’ in collaboration with all involved.
- **Rachel House Hospice** – Kinross, Scotland. A benchmark, in my opinion for hospices. Outstanding were volunteer programmes, activities planning, meals, bereavement support, staff support and outreach training to other centres enhanced by strong emphasis on communication.
- **Acorns Hospice** – Birmingham. Two stand-out innovations of this hospice. Adolescent programme maximising abilities of young people including film making. Secondly, an exceptional multicultural programme designed to encourage access for families from all cultures.
- **Irish Hospice Foundation** – Dublin. A dedicated key group committed to ensuring funding that will support developing services for children in Ireland.
- **Barretstown Castle** – Kildare. This castle and a team of dedicated volunteers ensure that life limited children from all over Europe attend camps for the experience of a lifetime.

**DISSEMINATION AND IMPLEMENTATION**

- Dissemination of this information will be through talks given to providers of paediatric palliative care – locally and in a yearly conference that is attended by many health professionals involved in the area from Australia and New Zealand.
- Informal discussions and presentations to peers.
- Publication in hospital and palliative care newsletters.
- Making a more comprehensive report available to interested palliative care practitioners – this has already been requested by other states.
- The growth of paediatric palliative care to maximise family care is enhanced by implementing strategies that have proved successful elsewhere. Main areas of change include enlargement and expansion of bereavement services, adolescent services and appreciation of multicultural issues.
- Shared care that involves education and collaboration with community services eg GP’s, ambulance and other services that will support appropriate end of life care.
- The development, using the resources gained from the UK, of care pathways that are widely disseminated to community health care professionals, community organisations involved with a child eg school, and hospital staff. These pathways particularly relate to end of life care and the format modified to an individual’s need.
- Future goals would also be transitional care development from paediatric to adult services – a new and developing service throughout the UK and also in Australia.
FELLOWSHIP PROGRAMME – March / April 2007

5th – 9th March – London, England
- Symptom Care Team, Great Ormond Street Hospital – Julia Whatley
- St Pancras community palliative care team - Bernie
- Child Death Helpline - Rosie

10th – 16th March – London, Oxford
- Helen House Hospice - Clare Edwards
- Douglas House Hospice - Clare Edwards
- Bereavement Counsellor – Marie
- Richard House Hospice -
- Oxfordshire Palliative Care Nurse Coordinator – Karen Bromley

17th – 23rd March – Cardiff, Wales
- GWENT County Palliative Care Nursing – Pat O’Meara
- Cardiff University Hospital – Oncology Unit
- Dr Richard Hain – Palliative Care Specialist

24th - 30th March – York, England and Scotland
- Rachel House hospice, Kinross – Sue Hogg
- Royal College Paediatrics and Child Health palliative conference - York
- Robin House Hospice, Balloch
- Royal Hospital for Sick Children, Edinburgh – Oncology Outreach

31st March – 6th April – Birmingham
- Acorns Hospice, Selly Oak
- Footprints palliative care nursing team

7th – 13th April – Ireland
- Sunshine Children’s Home, Dublin
- St Luke’s Hospice, Rathgar, Dublin
- Our Lady’s Hospital for Sick Children, Crumlin

14th – 20th April - Ireland
- Jack and Jill Foundation, Dublin
- Royal Belfast Hospital for Sick Children, Belfast
- Irish Hospice Foundation, Dublin
- Barretstown Castle, Kildare
Arrival and the UK Spring - Sunday 4th March
After a day’s rest, some friends provided a fitting start to this trip by giving me a sightseeing tour of Blenheim Palace, Woodstock – the birthplace and burial ground of Sir Winston Churchill. It is said that Churchill’s mother was visiting the palace for the weekend, had a fall whilst out walking and that Winston Churchill was consequently, and unintentionally, born there two and half months premature.

Throughout the afternoon, the many downpours provided a very damp appreciation of the beauty of the magnificent grounds. Nothing however, could hide the outburst of the spring trumpet daffodils which carpeted the entranceway. A visual demonstration of Wordsworth’s ‘Daffodils’, there truly was...“a crowd – a host of golden daffodils...” As the next two weeks went on into the warmest April in years, the spring flowers were on display in every possible square inch of ground around the towns, along the country roads and in many beautiful gardens.
Week 1: Monday 5th-9th March – London

Background - Paediatric Palliative Care in the United Kingdom
The National Health Service in the United Kingdom has recently undergone a major review of all paediatric services (including paediatric palliative care) with the goal of developing a more coordinated, shared and efficient provision of care. That progress has been made in these was evident by the recurring themes I identified. There are three major institutions that spearhead paediatric palliative care throughout the UK. They are Great Ormond Street Hospital, London (GOSH); The Children’s Hospital for Wales – Cardiff University Hospital, Cardiff and the Royal Liverpool Children’s NHS Trust Alder Hey Hospital, Liverpool.

Organisations visited
In order to gain a global picture of paediatric palliative care throughout the UK and Ireland, I visited as many and varied providers as possible. These were:

1. **Major tertiary hospitals** – which cover wide areas and offer support to local hospitals and community services. As mentioned above they are GOSH, Liverpool, Cardiff as well as Our Lady’s Hospital for Sick Children, Dublin.

2. **Hospitals that provide localised services only**
   - Edinburgh Hospital for Sick Kids; Scotland.
   - Royal Belfast Hospital for Sick Children, Ireland.

3. **Hospices**
   - Helen House and Douglas House, Oxford;
   - Richard House, East London;
   - Rachel House, Kinross, Scotland;
   - Robin House, Balloch, Scotland;
   - Acorns Children’s Hospice, Birmingham;
   - St Luke’s Hospice, Rathgar, Dublin (Dr M. O’Reilly) and the Sunshine Children’s Home, Dublin.

4. **Paediatric community nursing services**
   - St Pancras community nursing team, London;
   - Oxford community nursing team;
   - Cardiff Community Palliative Care team;
   - Diana Community Nurses, Cardiff;
   - Footprints community palliative care, Birmingham and the Jack and Jill Foundation, Dublin.

5. **Other supportive organisations** that contribute to or influence paediatric palliative care services.
   - Telephone counselling services - Child Death Helpline, London
   - Bereavement teams- Helen House, Oxford; Douglas House, Oxford, Rachel House, Scotland
   - Fundraising teams – Helen House, Oxford; Irish Hospice Foundation, Dublin.
   - Allied health workers – Belfast Hospital
   - Barretstown Castle – camp for children with cancer, Kildare, Ireland

Symptom Management Team - GOSH
I was introduced to the Symptom Management Team at GOSH on Monday morning and was to spend most of the week with them. The service has been established for many years providing palliative care for children, both in hospital and at home. They also arrange and support home care for children with cancer and offer medical support to children’s hospices. The team rotates every 3 nights to provide 24 hour on call phone services. Training and education of nurses is by mentorship. The service currently has 3 (2 filled) consultants, 1 registrar, 6 registered nurses and a secretary.
Historically, this service derived from paediatric oncology and therefore, until the last few years, mainly supported oncology families. Four years ago a change in focus, by a system of shared care, was planned to embrace all children needing palliative care. Particularly targeted were children with neurodegenerative conditions, children in intensive care and neonates. Improved support and consultation with GP's has augmented this change. This highly successful approach has simply been “be highly visible and gradually you become part of the process”.

During the weekly meeting, discussions occurred around current patient management. We spent much time comparing practice and solutions to various problems and symptoms. Also this meeting identified an ‘Emergency Care Plan’ for dying children which is distributed to the GP, community nurses and all members of the GOSH team who are either on call or likely to be involved with a patient.

A home visit to a child newly diagnosed with cancer demonstrated that much of the team’s work is still based around curative intent for oncology children. The visit was however valuable in that I was able to observe first hand how connections were made with the local community teams to ensure collaboration and continuity of care. A comment made by this nurse was ‘The biggest luxury we have here is time to talk’ and this comment encapsulates simply what so many families need.

**Lifeforce community palliative care - New Opportunities Funding**

Lifeforce Palliative Care, located within St Pancras Community Nursing, is a service responsible for assessing and planning at home respite for palliative children. Bernie, the nurse specialist, will assess and create a ‘Care Package’ which is agreed to by the Primary Care Trust. This service arose from an initiative using money raised by lottery called the “New Opportunities Funding” (NOF). Grants were given, for 3-5 years, to successful organisations for community health, education and environmental (social) projects for children. Medical backup, and after hours support, is provided by the Symptom Care Team at GOSH.

This intervention has demonstrated a significant cost saving to the health care system - an important consideration in days of economic pressures on the health care. I interviewed some staff who support the palliative care nurse by implementing the care package including a clinical psychologist (who provides staff support), a respite nursery nurse, a youth worker and a play specialist (Jackie) who will assess families at their home and organise up to two hours a week divided between the sick child and any siblings. Timing of visits is flexible to ensure siblings are involved and a carer called a ‘befriender’ will also specifically care for siblings. Staff are regularly rotated to ensure professionalism.

An issue that arose from this meeting, and the UK in general, was the difference between complex care needs of children and long-term palliative care children who survive into their twenties. Whilst there are similarities in need there are certainly many differences. This has definite implications for ongoing health care planning in Australia. A final discovery during this week is that there have been recent law changes in the UK forbidding administration of blood products at home. This practice still continues in Australia and it will be pertinent to pursue this further.

General Practitioner’s have a much greater role in the care of many children, who in Australia, would come to hospital. They have funding to provide any supplies or equipment the family might need at no cost. It became apparent that to increase home care for palliative children supportive education and collaboration is vital in keeping them out of hospital.
Child Death Helpline
A highlight of this first week for me was a visit to the Child Death Helpline. I was enamoured with this service and the prospect of such a service becoming available in Australia. This is a free 1-800 phone-in service from 7pm to 10pm, 10am-1pm M-F, and Wed 1pm -4pm every day of the year. The helpline has two paid staff -the Manager (nurse) and the Volunteer Personnel Trainer. The Manager is also the End-of-life-Care Planner at GOSH.

The Volunteer Manager (a qualified psychologist) is a bereaved parent as are all the volunteers. The Hospital Trust funds this service. Each volunteer works two 3 hour shifts per month. The telephone service runs from 2 on-site UK locations – GOSH in London, and Liverpool Children’s Hospital. Staff travelling expenses to and from are paid by the Trust. There are excellent 3-way translation services for non-English speaking callers.

The volunteers must be 3-4 years minimum bereaved and are subject to an intensive pre-assessment by a psychologist before being accepted. They then undergo a year’s training before going on the phones. Despite all this the service is described as a listening ear, not a counselling service which offers emotional support and confidential talk. The only time confidentiality would be breached is if it would be required by law. A record of each call is however retained for training and statistical purposes and for monitoring and improving the service. Staff are trained in detecting nonsense calls, cries for help in extreme circumstances, and information that they receive that is notifiable by law. Volunteers have compulsory clinical supervision with an independent psychologist every second month with a minimum attendance of four times a year. They also have regular training meetings.

The capacity of volunteers, demonstrated in many other services, to fulfil many of needs in palliative care is extraordinary and I was amazed at the potential scope of the role I saw throughout this trip.

The helpline has just undergone an audit of bereaved families and the results are about to be published. I was privileged to receive an unofficial copy which I can use once published. Many of the issues raised would be helpful in setting up a service in Australia and would go a long way to providing an equality bereavement support that is available no matter where people live. This is the type of service that could easily attract donors, would be relatively easy to set up if the right staff/trainers were available.

At the end of the week I had a very enjoyable visit to the special exhibition of Renoir Landscapes at the National Gallery.

Week 2: 10th-18th March – Oxford and London

Helen House
Helen House, in its 25th year, is the oldest established children’s hospice in England and has been the benchmark for many others. Helen and Douglas House operate independently but are located nearby each other on the same convent grounds. Some of their issues will be
discussed together and others independently. Helen House provides respite, end of life care and a day occupancy programme where parents can drop them off, go to work and pick them up afterwards. Helen House’s location, in central Oxford, provides a great advantage of accessibility to families. This makes a great deal of difference and is a highlighted issue in Sydney, where the hospice is in Manly and access is difficult, and sometimes almost impossible, for most families hoping to use it. Another advantage of the centrality of the hospice is that it is 10 minutes from Oxford hospital and consultants willingly visit Helen House. A recent grant by the New Opportunities Funding project has enabled extension of Helen House services to be able to provide back up support to community services.

Douglas House is a national facility which is the only UK young people’s hospice that is solely for 16-40 year olds. All other adolescent services are run from paediatric facilities. Until recently the two hospices operated independently but are moving more and more towards shared resources. The team includes nurses, carers, physios, aromatherapists, music therapists, chaplain and fundraising department as well as a family and/or bereavement support team.

**Douglas House adolescent respite**

Douglas House prefers ‘respite’ to ‘hospice’ as most of the young people come for respite yet they must be life limited. Two issues identified by young people were: I) they preferred being ‘guests’ than clients or patients and ii) they sought ways to ask their parents NOT to stay with them during visits. The house is truly ‘5 star hotel’ accommodation with seven individual bedrooms on the ground floor. Each room has en-suite facilities, television, stereo, computer and internet access.

After referral a home assessment is done at home and a care package is created which is reviewed annually. In either house, when a child is dying, there is a care pathway that is individual and is available to all involved in the child’s care. After death, there is a bereavement pathway to be followed. The care packages are different from Australia in that each child’s needs are assessed and the services offered are individual and created by a panel and the family hopefully accept it. Currently in Australia, the families referred all have access to the same services. Worth considering is whether there is a service benefit to the family or a cost benefit to the health care system.

**Transitional Care**

An issue that is embryonic in Australia and the UK is transitional care. It is, however, being addressed at every level of health care in the United Kingdom and many centres are developing standards and pathways for transitional care. Transitional care is the move from paediatric to adult care after a child is of age – usually 18. It is a complex process with many families finding the change extremely difficult and often poorly managed. At Oxford there are even difficulties transitioning from one hospice to another on the same premises –
demonstrating the emotional pressure of this issue for families. Currently there is a crossover period between 16 and 18 years of age. Our goal is to examine the emerging pathways and reviews in order to create the best possible service in Australia. The ACT (Association for Children’s Palliative Care) Transition Guidelines were launched 17th April 2007 in London, Cardiff, Scotland and Ireland, and released on ACT Website. Most important issue was that, in regards to transition, paediatrics and adult services be working alongside each other.

**Education**
There is also move to uphold the statutory right for a child to be educated including those who are terminally ill and services are being asked to answer for what they are providing. Many children that our service has seen have been receiving very little, if any, schooling and if Australia should follow this will impact on care and therefore planning for this is a necessity.

The chaplaincy role is interesting as the Chaplain, Mark works as a paid carer for 3 of the five days. He finds no conflict in this role and believes it actually enhances families’ confidence in his support of them. He often, willingly liaises with members of all religions. I find this quite unique and potentially a way of providing spiritual care in a non-threatening way.

**Fundraising at Douglas House**
The last issue that I found beneficial during whilst visiting Helen and Douglas houses were the fundraising programmes. Searching for fundraising ideas and possibilities is an ongoing part of paediatric palliative care services and there were some great ideas including opportunity-type shops, filled with donated goods and run by volunteers. These abound in the UK and raise considerable amounts of money at little cost. Another innovative and popular strategy in charity work is that of virtual gifts ie ‘buying’ something for a family such as a day’s nursing, a spa session, a school lesson etc. It has been very profitable. They emphasised the need for diversified fundraising and had many other interesting ideas to consider.

**Bereavement Services at Douglas House**
Bereavement care is comprehensively planned at Douglas House using 4 bereavement support staff. Bereavement (or ‘family’) support is provided as long as required and usually at the family home. For the first 1-2 year visits are monthly and then reassessed. During this time ongoing community support is garnered.

I met Marie, the leader of bereavement care for families who have lost a child in Oxford for an afternoon. It was one of the most inspiring afternoons on the trip. Marie has been at Helen House since its inception and has just completed a counselling degree. I have a great deal of information regarding the bereavement services the team provides and believe we can, when funding becomes available, improve greatly on the bereavement care families are offered. Families are supported for a minimum of two years, usually at home. This is because increasing anecdotal evidence is showing that the second year is a much more difficult year for families than the first.
**Bereaved Couples Counselling**

One very successful programme that Marie has developed is the Couples Group, counselling service. This six week programme, once joined, becomes 'closed'. Since beginning these groups there has been 100% attendance. The strategies employed can easily be translated into other environments. For many couples, it is the first time they have actually listened to each other. I found the stories of this work very moving. The sad thing is that it hasn't actually been able to reduce the large number of marriage breakdowns but both parents report immense help. A further intention of the group is that after the six weeks is that it will become self supporting and so far this has been achieved. The team have many excellent strategies for staff support which are enforced in order to stay part of the team. I very much liked her final words to me which were "We can never relieve their grief, but we can offer listening ears whilst they live through their grief".

**Richard House Hospice**

The mid-week visit to Richard House in East London was a little disappointing in that both of the reasons I was visiting there were no longer part of their programme. These were their day care and their multi cultural programme. Possibly due to funding issues. The hospice had refused any money from the New Opportunity Funding grants as they were lottery based and they did not want to offend the many Muslim families they have contact with. The promise of multi-cultural programs and issues was also much less than I had hoped. A remembrance activity that I liked at Richard House was their “Pebble Engraving”. A local stonemason engraves the name of a child who has died and the families can put it in remembrance fountain or take it home as a keepsake.

![Richard House](image)

**Oxford Community Nursing Services**

The Oxford City Palliative Care Team was another team successful in obtaining a grant from the New Opportunities Funding. If such grants were to become available in Australia it would potentially be helpful in providing medical on-call services, or senior community-based paediatric palliative care nursing services. This would mean that families who have difficulty accessing hospices for so many reasons would be able to receive greater support and care at home.

For successful community palliative care services it is necessary that:

- children have their health needs met when it is needed
- the delivery of that care is in the setting of their choice- Home, hospice or hospital
- a partnership exists between multiple agencies to achieve this
- an integrated care pathway shared between each agency
- a range of specialist care providers is available to be drawn on
- continuing education, training, research and development occurs to maintain standards of care
**Shared care in Oxford**

In the Oxfordshire model the community palliative service is accessed via GP’s who have an integral role in the care of palliative care children. If children are to be supported to stay out of hospitals, at a major saving to the community, then the role of GP’s must increase. This will, as already discussed, involve a real commitment to training and education of GP’s.

What the model provides:

- A gradual phasing in of the children community nursing team (CCNT) role offering 24 hour support to any child with a life-limiting illness.
- One of the great initiatives is that there is a single point of contact for information, the Nurse Coordinator (Karen Brombley).
- The Nurse Coordinator liaises with all existing service providers to promote a seamless service.
- 24 telephone and medical backup for the palliative nurses, and if required other health professionals.
- 24 hour medical palliative care assessment and treatment at Helen House.
- Open admission policy to the hospice from CCNT’s.
- Support and advice to professionals in the secondary and tertiary settings regarding palliative care for children.
- A refrigerated room at Helen House is the family wish for a place to be with their child who has died until the burial.
- Bereavement service from Helen House to all bereaved families in Oxfordshire.

In Australia there is limited funding because the number of children requiring palliative care is smaller and there are limited resources. More research is vital to provide evidence which supports the identified recommendations in this report. In addition advocacy with government for funding to support such research and changes is essential.

Gratifyingly however there is increasing recognition of the importance of paediatric palliative care by the Australian Government. A careful description and articulation of the needs is required by the paediatric palliative care community to ensure best practice. For the last two years the national paediatric palliative care reference committee has begun this journey. Standards are being developed with a paediatric focus.

**Needs assessment - Oxford**

Another recurring theme was that of needs assessments of children done in their homes by community paediatric nursing teams. Karen Bromley, the Oxfordshire Nurse Coordinator, discussed this at length. Currently, we do not have community teams that can carry out this role. Whilst assessment courses are available in Australia, they are not particularly targeted to palliative care. In NSW a training course in advanced child assessment could be developed for adult community nurses who have a desire to gain qualifications in paediatrics and/or paediatric palliative care and to be responsible for taking on a paediatric load. A needs assessment of children who are both palliative or who have complex care needs could be undertaken, a comparative cost analysis done and if we wish to expand services to offer complete care for many of these children at home instead of in hospital an implementation of community paediatric nurses.

The cost effectiveness for the Department of Health and benefits for the families involved could be a definite win-win situation. This could begin with the paediatric hospice nurses in Sydney. As well as upskilling them, if carried out at home, it could help bridge the gap for families who will not come to the hospice until they have made personal contact.
Whilst our population and geographical challenges make it difficult to roll out comprehensive establishment of community paediatric centres in Australia, it is however an achievable aim might be to put a paediatric nurse into each community health centre. These nurses would have experience and skills in acute care of patients in a major hospital, would be familiar with developing care pathways, skilled in complex child assessment and have knowledge of the paediatric palliative care community.

I met with Renee McCulloch, paediatric palliative care physician and Karen Brombley the ‘Community Children’s Palliative Care Nurse Coordinator’ a high level position that must, in order to be accepted, be supported by a medical mentor. Karen’s role is akin to the Nurse Practitioner role in Australia. Karen’s mandate is the lead for children with life limiting conditions and end of life care. She works with existing services to provide an integrated 24 hour home care.

Eighteen months ago the five palliative care teams (PCT) in the Oxfordshire region were amalgamated into one. The goal is better coordinated children’s services and obviously a saving in the reduction of senior level management positions. Karen is responsible for assessing the needs of each child, creating a care package, and ensuring the family receives what they need. This could include social services, allied health care, medical services or respite or all of the above. Dr McCulloch reported that Karen’s skills, experience and previous contact with the palliative care teams has generated a great deal of respect and any package she advises is almost always accepted without question. Costs related to admission to hospital have been dramatically reduced and this system has prevented many readmissions to hospital.

Karen operates from a community base and liaises directly will all involved in the care of a child – including GP’s, allied health and schools. The comparative cost of managing a child at home is £50,000 compared to £200,000 for hospital care. Karen is a key link between all the various services required by a family has not only brought services together it has also provided a more seamless care package for the families.

**Week 3: Monday 19th -25th March – Wales**

**Care Pathways**
Unfortunately I was unable to attend the Liverpool Hospital services as they had clinical problems and cancelled my appointment. This was very disappointing due to it being the third of three recognised tertiary services that provides national direction for paediatric palliative services. I was however, able to meet with and speak to the lead clinician in
paediatric palliative care there at the Paediatric Palliative Care Conference in York the following week regarding the Liverpool Care Pathway for the Dying Child.

This increasingly recognised instrument is being developed for planning end of life care in the UK and is derived from the well established adult pathway. The pathways are a result of an ongoing collaborative programme between GOSH, Cardiff University Hospital and Liverpool to standardise paediatric palliative care services. Despite this, I did sense that the process is slower than imagined and many centres still operate from individually developed pathways. The annual Royal College of Paediatrics and Child Health meeting seeks to collaborate and iron out differences so adherence to standardisation goals increase.

The development of care pathways is a response to the challenge of providing equitable care. Most interventions in the industrialised world are aimed at cure or prolonging life. In 2004 the Australian Government Department of Health and Aging showed in their report that children's palliative services are not equitable to adult. (Paediatric Palliative Care Service Model Review, Final Report; (2004) Canberra, Australian Government Department of Health and Aging). It is therefore very timely for Australian paediatric palliative care to look at initiatives that will support ongoing care of these children and their families.

Because health professionals have little experience, responses to care responsibilities of a dying child can be confronting, distressing and unpredictable. The national audit identified inconsistent care and thus difficulty in making decisions about care. Much literature supports the notion that adequate training of health professionals at all levels will result in increased competent care of the child and their family in a professional manner (Matthews, et al, 2006, p19).

This information has prompted palliative care services at the highest level in the UK to develop integrated care pathways that will provide paediatric palliative care that is standardised and equitable. This care should be available no matter where the child is geographically.

**Cardiff Community Paediatric Palliative Care Nurse**

In southern Wales, Pat O'Meara, is the community children’s paediatric palliative care specialist nurse, for southern Wales and oversees five boroughs. Whilst I was there we concentrated specifically on one borough - Caerphilly in the ‘Valley’ of Southern Wales. Pat’s position resulted from a community nursing service review in 1994 in the Gwent (southern Wales) This palliative care specialist nursing position remains part of the community nursing team and is largely a supportive role to families. End of life support is intense but she does not manage complex symptoms.

As in the rest of the UK, initial funding for each individual child is provided from health, education or social services. In keeping with the national ‘Every Child Matters’ theme, bi-partate funding is sometimes available, depending on the child’s assessment and needs. For example a child with complex medical / nursing needs also needs to go to school.

**Home visiting**

I accompanied Pat on a home visit to a family who live ‘Up the valley’. The colloquial name is widely known throughout the UK. This is a small mountainous area that readily becomes inaccessible because of snow in winter time. The families are poor and often poorly resourced medically, socially and for transport. The towns are well housed and were once well established and busy due to mining but as mining disappeared the majority of services disappeared with them. Community nursing and palliative care are diligent in providing care and resources for these families but are affected through some months of the year by the weather. This is overcome by the provision of one 4WD which means a collaborative effort is needed amongst the staff to rearrange the distribution of care.
The 16 year old boy we met had a severely disabling metabolic disorder characterised by intellectual and physical deterioration as well as constant seizures. His needs included organising respite, facilitating admissions to hospital when needed and general support. He lives with his mother and 18 year old sister and both their partners. The 18 year old sibling was obviously the main carer and most articulate in describing his symptoms / needs over the previous week. The community paediatric palliative care nurse assesses him and brings a report to the weekly palliative care meeting at the hospital where his ongoing management is discussed. Difficulties do arise when children live on the border of Wales and England as disagreement occurs as to whose responsibility the child is.

The next day I visited the major tertiary hospital, the Cardiff University Hospital to consolidate a referral from the Oncology Outreach team. The oncology team had not supported the involvement of this young man with the community palliative nurses because that was seen as contrary to the curative intent of management. An ongoing problem, worldwide, in paediatrics is that it remains difficult to convince many physicians and teams that it is useful for the family and the palliative team’s early involvement. For this child it resulted in his referral to palliative services being made on 24-48 hours before his death. The difficulty for families is having a completely unfamiliar face providing care in a time when they are vulnerable and needing support.

Pat has worked very hard to build bridges with the hospital and bring the many teams together in an attempt to facilitate earlier referrals. She regularly meets with, for example, the oncology outreach staff, too discuss patients and attends their weekly meeting as often as possible to gain information about potential referrals and help ensure that all potential care needs are planned for and implemented before discharge. Her determination has been quite successful and things are slowly changing with the support of the oncology/palliative physician.

Finally we visited two other patients who were being cared for by the CPCN at home and who were in hospital for various reasons. We sat and had long talks with the families about any issues that had been occurring and their child’s condition. This very productive time provided a clear overview of domiciliary paediatric palliative care in Southern Wales. We stopped to admire Caerphilly Castle – the very old and big castle which dominates the centre of Caerphilly. It must have been magnificent in its time.

I had tried to unsuccessfully contact Macmillan nurses but discovered that these paediatric palliative care nurses have changed to adult services only in Wales. This is due to the NHS changes and resultant increased paediatric community nurses.
We visited a Welsh school to discuss schooling of a child with complex care needs. This visit reinforced the value of having a specialist paediatric palliative care nurse who can help others identify problems before they escalate to a state of requiring hospital admission.

**Cardiff University Hospital**
I also met with Dr Richard Hain who is the sole paediatric palliative care physician in Wales. University Hospital and has a dual role of providing on-call oncology physician on a regular basis. Dr Hain played a major role in the development of ACT Care Pathways.

His role includes running a weekly palliative care multidisciplinary meeting which I attended. He also provides hospital-wide support for children who have palliative care need or has pain issues. He is the sole physician support for the local paediatric hospice – Ty Hafan. There is no medical team at the hospice and they do not care for children with complex medical needs. He does a weekly visit and 24 hour phone support. In attending rounds of palliative care inpatients I gained a perspective on the five boroughs of South Wales covered by the service. The oncology team take primary responsibility for the oncology patients and often involved the palliative care community services only very late in their end of life care. All of this is quite similar to the Australian population. The main gain from this visit was examining the care pathways again and, of course, networking and linking up with the different services across the UK.

The second gain of the day was the sorting out a child with complex needs, pain issues and end of life issues. This proved to be interesting in that several teams were involved with the care of this child. Eventually everyone got together and agreed on a management plan based on current symptoms. The community palliative nurse felt isolated working alone in the community and needed validation of her role in the care and I was able to support her in identifying that a pivotal person, with links to all teams involved is absolutely vital to the ongoing competent support of these families.

**Week 4: 26th March  1st April Liverpool and Scotland**

**Rachel House and another Churchill Fellow**
The Children’s Hospice Association Scotland (CHAS) is the main Scottish charity that supports children’s hospices. Rachel House is one of two paediatric hospices in Scotland, offering specialist palliative support. It would, in my opinion, be the benchmark for hospices. I was welcomed very warmly by all staff and met primarily with Sue Hogg, Deputy Manager who was herself a UK Churchill fellowship recipient. We had a very enjoyable and thoroughly supportive time discussing palliative care services.

Rachel House operates under this charity and have impressive services. These include respite, emergency/terminal care, home support, bereavement care, social work, physio, occupational therapy, play therapy, complementary therapy, medical input (GP local on sessional basis), on call weekends and 260 weeknights per annum. Also there are sibling groups, bereavement support groups and in house is run by registered nurse teams and support staff for clinical care, activities staff, chaplain and counsellor.

Rachel House had several activities which were of great interest to me.

1. Telephone support (24 hour) including bereavement support.

2. Staff support in monthly meetings followed by relaxation sessions run by a volunteer complementary therapist. A counsellor is also available weekly and provides formal and informal support to staff as needed. Personal development plans are well supported
financially including study days, degrees and diplomas. The lead GP is undertaking a diploma in PPC. They have excellent on-site education facilities and education is promoted vigorously. Rachel House closes for training twice a year.

3. Of interest, Rachel House has two chaplains and despite having families from many cultures it is reported that no one feels threatened by the fact that the chaplains were of Christian faith. These chaplains have contact with spiritual leaders of all faiths and readily contact them for guests when needed and offer to contact them on arrival. They are seen as an integral part of the service and are as welcome as any to interact with families. The chaplains run a ‘reflection time’ each day which is not religious.

4. Unlike other hospices, including our own, the parents’ quarters are separate from the children and very comfortable. This supports the notion that it is acceptable to spend time away from your child.

Volunteers
5a. Cherry, the Volunteer Coordinator discussed volunteer duties which include driving, public speaking (trained), attending functions to receive cheques, babysitting for siblings. Volunteers are formally recruited eg, by the internet, public speaking, word of mouth. One major volunteer responsibility is to be a ‘Bereavement Befrienders’ (a listening ear) which is telephone support. Care team members and social workers who specialise in bereavement train the volunteers over six weeks and is reported to be very successful.

b. The fantastic team of activities volunteers plan a whole weeks activities based on which children will be there the following week including trips out, themed weeks, etc. This kind of activity promotes a real focus on individual needs of the children and families. Any combinations of team will be involved. Volunteer drivers collect families without transport. Minibus training is given by a volunteer trainer.

c. Young Volunteers (16-19 years old) are called ‘young befriender’s and are trained by social work to visit and provide youth support. They come from local high schools and the programme is so popular there is now no need to recruit. Have 25 young people at a time.

d. Public Speaking Volunteers are trained to do anything that requires talking, receiving donations etc. When applying they receive an hours information session, then a formal interview followed by an induction day and yearly training support. There is a very high retention rate.

Outreach
6. Rachel House runs an outreach training programme which is at Inverness in the Scottish Highlands. This, again is funded by a New Opportunities Funding grant. It is aimed at training home carers (not nurses) for the highlands region. Since these families are often too remote to travel down to Balloch to stay at the hospice, locally trained ‘hospice staff’ go to them. There are all sorts of care and support activities carried out by these staff members. They have training sessions at Rachel House and two Rachel House staff go up there twice a year to provide on-site training.

Bereavement
7. Bereavement support is run by two social workers – who split their time into half bereavement and half social work. One of the social workers is dedicated to work with young adults.

An excellent innovation is a ‘bereavement pack’ containing several brochures which are left lying around the house. Families will pick them up anonymously but not accept being given them in case they jinx their child into dying. These packs have loads of brochures covering
anything from grief reactions, to planning funerals, to information on how to answer difficult questions by children.

Intensive support around time of death is provided by multidisciplinary team and all staff are trained to work together to support bereaved families. This means needs can be identified by any member of staff when bereaved families visit. Contact is initiated within 6 weeks after death. Sometimes kitchen will pack up packages of food and sent out with volunteers to homes. Many different support services and groups are offered to families.

Of interest was that the Australian Catholic project from the McKillop Foundation, Seasons for Growth' is run by two workers at the hospice trained in its use. They run adult and child activities on the same theme but separately. The hospice promotes and supports this programme.

8. Social workers have the role of assessment (again at home) and providing support to all family members by linking them to appropriate services in the community and following them to ensure they receive all necessary benefits and advice. They also provide emotional support particularly in the areas of anticipatory grieving and sibling coping as well as advice on legal issues and schooling.

**Royal College of Paediatrics and Child Health Conference (RCPCH) – York**

During the week I travelled to York University to attend the palliative care day of the annual Royal College of Paediatrics and Child Health conference. I found this day informative as the palliative care specialists of the UK got together to discuss and plan the changes and future of paediatric palliative care.

An interesting lecture was presented by one of the physicians from GOSH. She presented five case studies of complicated management issues in palliative children. There was a discussion on advance directives – what to do when a child dies - and the difficulties that had arisen in the implementation of these.

The second lecture was by the Head of Care at GOSH Symptom Management Team, Finella Craig, describing the history of the service and presenting statistical information. A very interesting part of her talk was the presentation of a survey of GP’s on their understanding of palliative care. There were many lessons to be learnt from the responses.

As already mentioned there was discussion around the Liverpool care pathway which is almost at the end of its first year pilot with a report pending.

A Department of Health Official discussed their review of palliative care. Their interest and emphasis was on networking and support of regional families. They also generated discussion on defining assessment of levels of symptom management.

Finally, the national palliative care group are working towards developing an educational curriculum for all levels of palliative care. The two major questions/issues the Department of Health were asking in relation to this were related to expectations at the end of training and definitions of competence as well as clearly identified progression on competence levels.
**Robin House Hospice**

Robin House in Balloch Scotland (on the shores of Loch Lomond) is similar to Rachel House and modelled on the same but only open for last two years. The greatest physical features were the large hydrotherapy pool and huge playroom.

![Robin House playroom](image)

here is impressive volunteer support with some just coming to do baking so there is always have home cooking. All staff and families eat meals together.

**Edinburgh Hospital – community palliative care**

Finally this week I visited the Royal Hospital for sick children, Edinburgh. This has a community outreach service of 32 staff with one dedicated palliative nurse whom I met with. She has 9 children under her care. Once again each child receives an individual ‘package’ which could range from 18 hours day care to 70 hours night nursing per year. If a child is dying they can have 24 hour, 7 nights a week service in the home. This is a great service and I spent a day visiting children in their homes and discussing symptom management and various respite services available to these families. It was great to talk with parents to gain their perspective on the services available.

**Week 5: 2nd to 6th April - Birmingham, England**

**Acorns Hospice**

I visited Acorns hospice in Selly Oak, Birmingham, one of three hospices under the same umbrella. The other two are located at Walsall and Worcester. They all operate slightly differently but attend combined weekly meetings. Acorns was the 3rd hospice opened for children worldwide. At Selly Oak, they have 20 nurses who work from the hospice in the community. This is very different from Australia. Again assessments are done at home and the assessor will bring the family for a visit.

I interviewed many of the staff including activities coordinators, music therapist, physiotherapist but will highlight some of the speciality staff.
**Acorns adolescent worker**
Jamie is the dedicated adolescent worker. He has a Masters in bereavement but this is not in his job description. He currently cares for 43 families and the young person will see him about every 4-6 weeks. The main emphasis he makes is to ‘walk sideways’ with adolescents for example, playing playstation, which he asserts achieves a lot more than just talking. For group work the young people are divided into 10-13 year olds, 13-17’s and 18-25’s.

Important issues:
- The young people want to talk about teenage issues not palliative issues except during focus groups based on an issue.
- The young person is always included in discussions about them.
- Development of services always includes young people
- Have created, with the young people leading, a film called Dis Life about sexuality and relationships. This film won a national award and is available on the Acorns Website.
- Liaising with in house staff as young people are always pushing boundaries
- Production of a newsletter – mostly by young people themselves
- Adolescent information brochure which as well as giving information on activities and groups etc it clearly defines house rules re the law and alcohol, drugs etc.

Selly Oak, like Rachel House, has a huge volunteer staff 174 of which 85 are under 25. The volunteers are also picked to reflect the local ethnic mix. Some sibling groups are run entirely by volunteers and some are trained by Royal Lifesaving to be ‘lifeguards’ at the hydrotherapy pool.

**Acorns multicultural Care**
Hardav Notta is Acorns multicultural Worker. Approx 50% of clients at Selly Oak are from NESB. They were initially reluctant admissions and the team worked hard to search out barriers. They discovered the need to ‘see the hospice’. Secondly find ways to overcome guilt issues relating to personal responsibility – especially from the wider family rather than personal belief.

Acorns have made a deliberate attempt to create a multi culturally sensitive hospice. This includes banners welcoming visitors in all languages; special shower for pre-prayer and disposable washing jugs in the public bathroom; little arrows in the rooms, discreetly hidden, that point to Mecca. This was done in collaboration with an Imam to ensure accuracy. This is especially important in the ‘cold room’ where a child can be kept after death until burial where prayer towards Mecca is vital. The trustees of the hospice include members of the Asian (ie Asian middle-east, and African backgrounds). Large Afro-Caribbean group of patients. Multicultural workers – all offer living and deceased work and will follow up a family for up to 7 years if necessary. The average is 2-2 ½ years with approximately 40-60 families at a time. T

he highly visible artefacts cupboard, for each major religion, has multiple artefacts including prayer tapes, CD’s and holy water, Prayer or Scriptures and prayer mats. They have no particular chaplain but try to get families in contact with local Christian, Muslim, Jewish, Sikh and Hindu religious people.

There are many other multi-cultural friendly activities and I particularly noted that all the cooks are trained in real multi cultural cooking and there are always genuine meals available that are culturally appropriate. There is a welcome video in five languages as well as a supply of dress up clothes and musical instruments from other cultures.
I gratefully received a copy of the Multicultural Information handbook. A very detailed text covering artefacts, hygiene, food, models of care, bereavement, cultural do’s and don’ts and some frequently used words.

Dianne, the African Caribbean Liaison Officer, was employed because of the realisation that African Caribbean families were not coming to the hospice. Dianne, who is an African national and social worker with child protection / family work background, was employed to review the services community for one year.

She identified some interesting issues including:
- The publicity material was completely Eurocentric
- The need for a data base
- The need for an increased number of black volunteers
- The need for genuine meals which are inclusive and not a special exemption.
- The need for a dedicated African Caribbean Liaison Officer who understood cultural issues.

There is now a considerable increase in the number of African Caribbean families and Dianne is employed full time to support their care.

**Sibling Care**
Acorns has for the last 9 years, had a sibling worker who offers families up to 90 hours home support per year. The role is split between in house and community and trained volunteers are an integral part of the service. A volunteer must have worked as a befriender in house before they can become home sibling worker. There are 40-45 groups a year over the three sites. A magazine called BASIL (Brothers and Sisters in League) supports siblings and is put out by older teenagers with volunteer support.

Important points about siblings:
- They have found that mixing bereaved and non bereaved children works really well.
- Siblings have to know their brother or sister is life limited to be allowed to join the group.
- If a sibling has just lost a brother or sister will discuss with them how the group would be told and what they will be told as well as discussing with bereaved child re other children’s reactions.
Footprints community palliative care nursing
I spent the last day with the ‘Footprints’ palliative care nursing team which is an initiative of New Opportunities Funding. It filled a gap created when the Diana Children’s Community Nursing teams stopped providing services to children last year. Like all other initiatives resulting from the New Opportunities Funding this money will run out in three years time when they hope it will become independently sourced. The team consists of a consultant paediatrician, a team leader, 3 nurses and 2 carers. The carers offer respite support to parents and families of children aged 0-19 years who have a life limiting condition. Priority is given to families whose child is receiving end of life care and respite depends on an individual family assessment by the team. The team have a clinical psychologist who provides support advice and backup to the team. The respite may be provided directly or may be given by community services in liaison with the Footprints team.

A nurse and social worker, Kerry & Rochelle, from this team took me to visit families with various needs, mostly symptom assessment and management and provision of general support to parents. If the child is in the terminal phase of their illness this support extends to 24 hour, seven days a week care. Currently they have about 80-90 patients. Service is covered 8am to 8pm via a mobile phone. All equipment families need are supplied by the NHS. Included in this day was a sampling of the legendary Birmingham curry. The benefit of the day was first hand experience in how the service operates and how problems are managed.

Week 6 & 7 - 7th -15th April - Ireland

Background to Irish Palliative Care
The week began with a public holiday and everything shut down. Paediatric palliative care in Ireland is a lot less advanced than I had imagined. The usefulness of this part of the fellowship was to meet with the group who are currently planning services so that a national, collaborative and well planned service will be available when it is implemented. There are several different players in this group who have completed a needs assessment and are responsible for driving the planning of services. I met with all the different teams involved in the group. They have carried out their research thoroughly and they were very keen to learn from the Australian experience. We have developed invaluable networks that will be able to offer them ongoing support. One of the difficulties I faced in Ireland was the national nursing strike –’work to rule’ only and therefore was not always able to access appointments.

Sunshine Children’s Home Hospice
The Sunshine Children’s home, although described as a hospice is primarily a respite centre for chronically ill children and a base for home care nurses but it is rare for a child to receive end of life care there. The premises are huge and the potential for development enormous. A paediatric palliative working party are currently planning ongoing paediatric palliative care services in Ireland and hope to turn it into a hospice. A foundation called Laura Lynn Foundation, named after two children who died is linked together with Sunshine Home and there are plans to bring this together. Currently there are very few respite facilities for children and young people in Australia and it was interesting to see that kind of service in operation. Many of the young people are in their late twenties.

Dr Maeve O’Reilly – Palliative Care Physician
The next day I met with Dr Maeve O’Reilly at St Luke’s (adult) Hospice, Rathgar, Dublin. Dr O’Reilly is an adult physician who is the interested in establishing and driving the development and planning of paediatric palliative care in Ireland. She has been involved in undertaking and reporting on a national needs assessment and is part of a core group
developing a plan for implementation of paediatric palliative care services. Dr O’Reilly responsible for guiding the quite significant number of wealthy philanthropists wanting to set up services with no policies, safeguards, needs assessments and so on.

The plans include
1. Needs assessment report – done
2. To create a national database
3. Is to collaborate with the Laura Lynn foundation to ensure the hospice is properly supported with a paediatric consultant.
4. To develop a clinical nurse consultant system. This is three or four nurses, one for each main centre – Dublin, Galway, Cork & the north. These nurses will be responsible for meeting with current services – hospital and community, meeting patients and building bridges, attending meetings. Anticipated problems include underutilisation of services due to fears and prejudices.
5. Create a paediatric palliative care consultant position shared between the hospital at Crumlin, the hospice and in community.
6. Continued respite: Currently the Irish Cancer Society provides night nursing respite for the last 10 nights of life.

Crumlin Hospital Palliative Nurse Specialists
Two nurses who are currently the only dedicated paediatric palliative care community nurse specialists are based at Our Lady’s Children’s Hospital, colloquially referred to as ‘Crumlin’. These nurses are community liaison nurses who take referrals from the hospital and ensure that there are appropriate services available to them in the community. They have qualifications in paediatric palliative care and one of them particularly will be one of the 3 or 4 nationally appointed nurse specialists to lead paediatric palliative care throughout the Republic of Ireland. Throughout the day, as well as touring the hospital and meeting various personnel involved in the care of palliative children many discussions were had comparing the service to Australia. The main differences are that there is no paediatric palliative medical support, as in palliative physician and therefore not a ‘service’ as such but this will change in the next two years. They were still very much looking to us for guidance and networking.

Jack and Jill Foundation
The meeting with two nurses from the Jack and Jill Foundation (Sinead Moore & Sandra Nolan) was a great networking and sharing of information session. The Jack and Jill Foundation was formed in 1997 and currently has 9 nurses, six full time and three part time. These community nurses offer families a maximum of 20 hours nursing care per family per week or 15 hours carer respite per family per week. The main focus of their care is children under 4, who are severely developmentally delayed with some palliation. Some of this care is palliation and they hope to escalate that in collaboration with the national plan. The service demonstrates that there is some palliative care nursing but in a random manner.

The service currently runs basic child care education in three tiers – i) a five day basic course for nurses, ii) a one day conference open to all, iii) a two year higher diploma (under development).

New Initiatives:
1. Creation of database – already happening in collaboration with others as mentioned.
2. Have three nurses with some experience in paediatric palliative care who cover community patients in Dublin.
3. Education

The National Health Service funds individual families (not means tested) with ‘care packages’ but the difficulty has been getting staff to fill the packages. This would be in
addition to what they already receive from Jack and Jill Foundation. Some adult palliative care services will take on children. There are three paediatric units in Ireland and most children who need hospitalisation are cared for in adult hospitals. If a child dies, the family will receive a bereavement visit after a year. The Foundation also runs a bereavement day once a year. There is an isolated sibling bereavement group in Dublin.

Belfast Hospital
A very quick trip to Belfast identified the only paediatric palliative care work in Northern Ireland which is for children with cancer. Any other care is provided by adult palliative care teams. I, along with the palliative care nurse consultant from Crumlin, spent the day with the oncology team.

Community Play Specialist
The definite highlight of this visit was a presentation by the community play specialist, Naomi Spence. The play specialist is in a dedicated community role with priority given to palliative children, covering the whole of Northern Ireland. Naomi developed a business plan and approached a charity for funding for this position herself. She had been previously head of play therapy department. She has just completed a 3 year evaluation which has been presented to the Health Department in the hope they take over funding.

One strong case to support this was that, out of 13 children referred for total body irradiation, 12 were compliant with the procedure without anaestheisa thereby saving the hospital 12,000 pounds per child. The main goal of the position is to prepare children, at home for any procedure they might endure from simple oral medicine taking, finger pricks, to half hour radiotherapy sessions or bone marrow aspirates. She actively seeks ways to involve siblings in this service and will tailor her time to when siblings, and sometimes fathers, who are working, are able to be at home. She aims that the family feel confident and in control supporting the child through the procedure and she is able to back off. Specialist dolls tailored to children’s likes, such as piglet, Scoobie Doo or Tweenies have all sorts of attachments to help the child understand procedures and they keep these after treatment. This has been a very successful service and has great implications for future development of our service.

When a child or teenager is dying, Naomi will visit them 2-3 times a week, for a three hour session. For example teenagers may do gardening, cooking or painting. Again deliberately involve siblings and just beginning to incorporate photography and videos to, not only stimulate interest but, to provide the family with memories. She does not have the time to do bereavement follow up and hospital play specialists will visit siblings for bereavement support.

There is no paediatric palliative care in Northern Ireland, and any specific care that is given is mostly for children with cancer, run by Belfast Hospital’s oncology outreach nurses. Again any home care needed would be by generalist community nurses and general practitioners.

After a child dies the bereavement service includes:

- Care of a dying child is directed by guidelines from the Royal Marsden Hospital.
- Staff routinely attend funerals of children
- Belfast have 10-12 children per year die
- Have a palliative care box to help with keepsakes and mementos
- Bereavement follow up is done by nurses or social workers
- Yearly remembrance service and book held at and Hospital
- Send a bouquet at one year anniversary
Irish Hospice Foundation – funding and education
My second to last visit was to meet with several key members of the Irish Hospice Foundation. The foundation has been running for 21 years. It was a very interesting afternoon. This charitable trust in cooperation with other groups, from the national needs assessment, identified the immediate need to have support to die at home, and of supporting parents to be able to identify needs.

A primary goal is placing senior trained palliative nurses in the community. The voluntary organisations agreed to match any government money given for paediatric palliative care and as discussed all providers have joined forces for this end. The Irish Hospice Foundation are therefore committed to providing funds to enhance anything that will legitimately promote paediatric palliative care in Ireland. This foundation recently funded two senior Irish oncology nurses to spend two weeks with our palliative care team in Sydney.

The foundation runs workshops on grief, loss and bereavement – mostly adult based. The most useful thing to myself was the enormous array of support material they have which is available on request including an extensive palliative care library, pamphlets, diploma and certificate courses, reports and PhD’s and much more.

They are also part of a group forming a proposal for an educational framework to support excellence in “Caring for the child with life limiting conditions”.

Palliative Nurse Education
Once the four Clinical Nurse Consultants discussed above are in place, the next step is education of other nurses. The plan is a three tiered system of

i) A very basic introduction to palliative care – day training, based at Crumlin Hospital. The plan is for 390 nurses to receive this education by the end of the year

ii) A more complex course over 3 weeks aimed at palliative care nurses or paediatric nurses. The course includes one week training, a one week placement at Crumlin (not started yet) and one week supervision. The target is to have run three courses by the end of the year which would result in 60 nurses trained at a higher level than the basic course.

iii) An interim plan for specialist nursing palliative care training. Not yet implemented. This course will eventually go on to palliative accreditation.

Barretstown Castle - Inspiration
My last visit was to Barretstown Castle in Ballymore Eustace, County Kildare and was all about inspiration. This amazing castle is quite astounding in what it offers to sick children and their families. The grounds are enormous and children come from all over Europe to the various events. At Barretstown camps are run for children with life limiting illnesses, their siblings, families and for bereaved families.
The sibling programme caters for children aged 7-17 years. This is particularly for siblings of children with cancer, where the parents are away at hospital so often, family life is completely disrupted and the siblings often end up cared for by relatives with no real holidays, trips, weekends away or cancelled sports event. This can easily generate anger and resentment. These camps are aimed at meeting other siblings, making friends, identifying issues that are common to them all. The camps provide opportunities to give the children one-to-one exclusive time. Another important outcome of the camp is that the children actually learn about the illness their sibling has – information which they surprisingly, often have very little knowledge of. The facilities are all free.

The dedicated, multi-skilled teams of volunteers are inspiring and committed. They range from artists, dancers, sports people, just companions, nurses and the list is endless. In some ways, the concept of a place that is available for camps, that is fully staffed to cope with any medical needs and emergencies this type of programme could be a plausible option to hospices. As an end to an often intense time during this trip, this was a thoroughly enjoyable and also eye opening as to what could be achieved, with the right money, facilities and staff to make life a little easier for these families.

CONCLUSION

The fellowship was everything I had hoped in the breadth and depth of services that I was able to observe. I formed some lasting networks with paediatric palliative care workers in many places. In planning Australian services for families we have a lot of growth to do in care pathways, for siblings and in bereavement care. The role of volunteers and carers can be widened with support in training and education and targeting different groups of volunteers such as high school children.

I believe, however that the symptom management and availability during end of life care that we provide to children and their families is excellent. The examination of services and resulting reforms which revolved around providing standardised services is becoming a reality and this can only mean better service to families and a more efficient use of the resources that we have.
RECOMMENDATIONS

1. **Home Assessments** - Throughout the United Kingdom and Ireland all assessments of children are done in their homes as was demonstrated by almost every service I visited. The benefits of this cannot be underestimated because it encourages families to access services in a very non threatening way. It also allows the health care provider to see the child in the context of family and social circumstances which cannot be truly understood in seeing the family in a hospital environment. This would be relatively easy to implement, particularly for children referred to the hospice. This would create a feeling of familiarity and reduce fears in visiting the hospice.

2. **Care Pathways** - this tool has helped enormously in providing standardised end of life care with equal access to services. It has enhanced collaborative patient management resulting in shared care that is beneficial to both families and the health care system. Our role is to examine the UK pathways and devise a pathway that is appropriate to the Australian paediatric environment.

3. **Fundraising** - a perennial problem with innovations that would require little effort to implement. The easiest being, as mentioned, the popular 'virtual gifts' which I intend to discuss with our fundraising team. Secondly the development of opportunity shops which we could use trained volunteers services to implement.

4. **Bereavement Support** - perhaps the most important recommendation of all. The limitation at present is funding and it is my strong recommendation that it is mandatory that when money becomes available a dedicated bereavement worker is employed who could build a bereavement team. Currently bereavement care is not systematic. I believe that a planned and coordinated service would greatly contribute to the holistic principles of supporting the child and their family and would provide better long term outcomes for these families.

5. **GP Education** - the value of this was demonstrated in discussion with many staff that I talked with. There are already plans underway to increase community education next year and GP’s would be a primary target group. The aim of this would be to support them to take greater responsibility for the care of the families, with the support of the specialist palliative care services. This in turn, would help families to feel safe to stay at home when they might otherwise go to hospital.

6. **Transitional Care** - this area is in its infancy, however this is high on the agenda of health care planners throughout Australia. Palliative care will, I am sure, take a strong advocacy role in the future in this aspect of care. For paediatric palliative care it is something for the near future and my current recommendation is to familiarise ourselves with the pathways being developed in the United Kingdom.