

THE WINSTON CHURCHILL MEMORIAL TRUST OF
AUSTRALIA

REPORT BY

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THE DOROTHEA SANDARS AND IRENE LEE CHURCHILL
FELLOWSHIP

TO IDENTIFY AND INFORM GUIDELINES FOR BEST
PRACTICE PAEDIATRIC HOSPITAL BEREAVEMENT CARE
SERVICES

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Date. 25/9/2018

KEYWORDS

Bereavement, paediatric, hospital, hospice, community

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ACKNOWLEDGEMENTS

Alone we can do so little; together we can do so much

Helen Keller

In 2016 I entered the world of consultancy after identifying a gap in expertise in the care of families following the death of a child in Australia. I named my consultancy *Collaboraide*, a word that incorporates ‘*collaborate – to come together, to work together*’ and ‘*aide – an assistant or helper*’. The tag line for *Collaboraide* is ‘*together we can do so much more*’.

I am indebted to my partner, family, friends, colleagues and mentors who have walked alongside me over nearly two decades, first as I entered the social work profession and then as I found myself becoming an advocate for families who had suffered an immeasurable loss...that of their child. This has not been an easy ride nor should it be. As one of my greatest mentors Brené Brown suggests, empathy means getting down low and close to those suffering. Sometimes this comes at a cost – for the carer and for their supporters. Thank you all for continuing to walk alongside me as I have continued this important advocacy.

To those bereaved parents who shared their pain and heartbreak and trusted me to walk alongside them; you have been and continue to be my greatest teachers. I remain committed to advocating for an Australian health system that ensures bereavement care is core business. No bereaved parent and family should be left to fend for themselves as they leave a hospital without their child by their side.

Most sincere thanks to the Churchill Trust and the Dorothea Sandars and Irene Lee Churchill Fellowship funders who honoured this cause by believing in me. While you have offered great support to me, more so, you have enabled a light to be shone on a devastating area of need. I am confident the learnings, findings and recommendations in this report will strengthen our advocacy campaign to ensure each children’s hospital in Australia acknowledges child death and bereavement care for families as core business and is appropriately funded and supported by the health system.

Finally, to all the new colleagues and friends throughout the world who I met on my travels. I am so very grateful for the time, energy and care you put into sharing your experiences with me. I can see I am not alone in this cause and I look forward to a future where we can continue to share our collective learnings on an international scale.

EXECUTIVE SUMMARY

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HIGHLIGHTS

Bereavement care following the death of a child is a niche sector in Australia. We are a small group of professionals faced with a large task. It was a privilege to meet colleagues working in this area of care in the USA, Canada, UK, Ireland and South Africa. Most shared similar opportunities and challenges in meeting the needs of families following the death of a child and expressed a desire for an international network in this space. I look forward to sharing their learnings and ongoing collaboration on service design and research in paediatric bereavement care.

MAJOR LESSONS LEARNED AND CONCLUSIONS

- A dominant theme in my interviews was the development of hospital-based bereavement programs in response to complaints from bereaved parents themselves. Parents whose child has been cared for in the health system and who has died, want and expect transitional care from health professionals they know and trust as they reintegrate into life following the death of their child.
- From a community-based perspective, service providers acknowledge the 'black hole' that exists for those families who experience geographical, financial or other logistical or emotional barriers to accessing bereavement care in their local community. As a sector we need to consider sustainable and accessible alternatives to current models of support. This is particularly relevant when developing an equitable service response for bereaved families in Australia.
- Of most interest was having the experience of grief normalised by all the colleagues I met. As professionals we are often encouraged to turn to published research literature for guidance. This literature can be driven by science and pathology. However, peer support, peer mentoring and companionship/walking alongside the bereaved appear to be the dominant and accepted models of hospital and community-based care in the paediatric sector.

DISSEMINATION AND IMPLEMENTATION

This report will be disseminated through paediatric bereavement care networks in Australia and internationally and used as a supporting document when advocating at a health policy level for the integration of bereavement care as core business in the paediatric health setting.

BACKGROUND

In November 2012 I stepped into the inaugural role of Bereavement Coordinator in the Paediatric Palliative Care Service, Royal Children's Hospital, Brisbane. This role was the first of its kind for the service and in the hospital. The first step was to seek guidance and benchmark with colleagues in similar positions interstate. This step saw the unfolding of a mission I remain committed to today.

At the time a similar position had been appointed in the Paediatric Palliative Care Service, The Children's Hospital at Westmead. The Kids Cancer Centre, Sydney Children's Hospital had offered, for some time, an outreach bereavement counselling service for families of children who had died from cancer. Neither of these hospitals funded a dedicated hospital wide bereavement coordinator nor offered a coordinated service to all bereaved families. The Royal Children's Hospital, Melbourne offered what continues to be the longest standing bereavement service. However a limitation of this service is that it sits within the remit of the social work department, with an expectation that bereavement care will be provided within the day to day functioning of what is an acute care department. At the time no other tertiary children's hospital in Australia funded a hospital wide bereavement position nor offered a coordinated approach to bereavement care.

The death of a child brings with it an insurmountable life change for the child's immediate family and sees a ripple effect of grief for the broad community of informal and formal support networks surrounding the family. Families whose child has been cared for in a children's hospital often develop long term relationships with staff and come to rely in some part on the guidance and support of the health care team for issues surrounding their adjustment to their child's illness. In the case of a sudden or unexpected death these relationships are brief yet intense and see a family come to quickly rely on the health care team for support throughout a devastating life change.

In 2017 I completed my PhD, The Compass Study, exploring the experience and needs of parents whose child had died from cancer. This study adopted a mixed methodology approach with 119 parents participating in a questionnaire and 41 of these also participating in a semi structured telephone interview. Overwhelmingly, participants described the isolation and abandonment they experienced from the health care team who throughout their child's illness became 'like family' yet following the death of their child failed to offer the guidance and support many families expected. This is a theme that remains consistent in the published literature. Additional barriers to support described by families included: not knowing where to go or who to turn to for support; and, their informal community of support withdrawing for fear of saying or doing the wrong thing. The

experience for families whose child has died from a sudden or unexpected death is often heightened given the immediacy of the life change for the family and their community.

I should caution that families' experiences and perceptions of bereavement care should not necessarily be a reflection on the inadequacy of the child's treating team. Children's Hospitals by their very nature are centres of high acuity and offer an acute health care response. Balancing the demands of an acute care setting while sustaining connections with bereaved families throughout the course of their bereavement is difficult, bearing in mind the trajectory of bereavement is undulating with parents often adopting help seeking measures at multiple time-points into the future. Additional complications arise when staff turnover means the professional with whom the trusted relationship was built has moved on.

However, the reality remains that a proportion of children who arrive and/or are cared for in tertiary children's hospitals in Australia die. Each year approximately 100 families whose children have been cared for at Lady Cilento Children's Hospital (recently re-named Queensland Children's Hospital), Brisbane, leave the hospital with 'empty arms'. Approximately 70% of these families will be offered transitional bereavement care through the Bereavement Support Program, based in the Paediatric Palliative Care Service. A range of information, resources and professional connections are offered to families through this service. A connection point remains available for families for as long as they need. For the remaining 30% care will be provided most often through the family's primary care social worker and the limitations of this have already been noted. This has arisen because the hospital and health care system have taken the stance that bereavement care is the business of the community. It is not right nor is it ethical for some bereaved families to be offered coordinated bereavement care and a broad array of information, services and support following the death of their child while others are not.

Supporting families as they reintegrate into their community following the death of their child is simply the right thing to do.

This Churchill Fellowship experience and associated report are the next step in gathering information through an international benchmarking project to support ongoing advocacy in this critical area of care and unmet need in the Australian health system.

PROGRAMME

Location	Organisation	Program	Meetings
USA/CANADA			
5 April 2018 Portland, Oregon	Doernbecher Children's Hospital	PACT Team/Bereavement Service	Kathy Perko Nurse Practitioner, PACT Lindsay Wooster Social Worker, PACT
5 April 2018 Portland, Oregon	Randall Children's Hospital	PACT Team/Bereavement Service	Lynn Davis Molly McCarthy Child Life Specialists (CLS)
5 April 2018 Portland, Oregon	The Dougy Center	The national centre for grieving children and families	Donna Schuurman Senior Director for Advocacy and Training Alysha Lacey Program Director
9 -10 April 2018 Memphis, Tennessee	St Jude Children's Research Hospital	Quality of Life Team/Bereavement Service	Lisa Clark Director of Bereavement Services Brittany Barnett Patient and Family Centred Care Manager Brent Powell Chaplaincy Joanna Lyman Program Coordinator Paediatric Palliative Care Le Bonheur Children's Hospital
13-14 April 2018 Little Rock, Arkansas	Arkansas Children's Hospital	Centre for Good Mourning and Staff Bereavement Support	Greg Adams Program Coordinator Brent Fairchild Director of Palliative Care Nancy Thomas Social Worker, Palliative Care Team Music Therapy Team Bereavement Care Committee
17-18 April 2018 Toronto, Ontario	Sickkids	Pathways Grief Support Program, Paediatric Advanced Care Team	Norah Shaughnessy Lori Ives-Baine Grief Support Coordinators Dr Adam Rapoport Medical Director PACT Fred Mackay and Ami Chaplaincy

			Corey Interlink Nurse Representative Mary and Emily Social Work Representatives
19 April 2018 Toronto, Ontario	Emily's House	Children's Hospice	Paul Davidson Chaplain
19 April 2018 Toronto, Ontario	Dr Jay's Children's Grief Centre	Community based organisation for bereaved young people	Tara Noble Family and Youth Program Facilitator Becka Soyka Intake and Volunteer Coordinator
20 April 2018 Toronto, Ontario	Lighthouse	Peer Support for grieving children, youth and their families	Deidre Thomas Executive Director Candace Ray Director of Services and Operations
23-24 April 2018 Boston, Massachusetts	Dana Farber Cancer Centre/Boston Children's Hospital	The Bereavement Program, Department of Psychosocial Oncology and Palliative Care	Sue Morris Director Bereavement Services Jennifer Snaman Paediatric-Haematologist Oncologist Marsha Joselow Clinical Social Worker, PACT
UNITED KINGDOM			
27-30 April 2018 London	Great Ormond Street Hospital/Child Death Helpline	Bereavement Services Department	Rachel Cooke Bereavement Service Manager Joint National Manager of Child Death Helpline Jamie Johnstone Training and Practice Coordinator and Bereavement Support Worker Esther Rose Family Liaison Nurse, PICU/NICU Mortuary Representative
9 May 2018 Saunderton	Child Bereavement UK	Family bereavement care after death of a child	Ann Rowland Director of Bereavement Support and Education Stella Pearson Support and Information Coordinator Lorna Franks Lee Fundraising Representative
11 May 2018 London	St Christopher's Hospice	Adult hospice and child bereavement program	Isobel Bremner Candle Child Bereavement Service Lead
14-15 May 2018 Milton, Cambridge	East Anglia Children's Hospice	Children's Hospice	Linda Maynard Consultant Nurse Children's Palliative Care

			<p>Sue Price Spiritual Care Adviser/Occupational Therapist</p> <p>Victoria Montgomery Clinical Psychologist</p> <p>Lorraine Kaka Family Therapist</p> <p>Jayne Chesterton Care manager, Well Being Team</p> <p>Amy Brown Counsellor, Well Being Team</p> <p>Bereavement Care Team</p>
	<p>Addenbrooke Children's Hospital</p> <p>The Rosie Hospital</p>		
22 May 2018 Liverpool	Alder Hey Children's Hospital	The Alder Centre	<p>Shelagh Hatton Senior Counsellor Joint National Manager Child Death Helpline</p> <p>Val Bereavement Care Team representative</p>
IRELAND			
23 May 2018 Dublin	Irish Child Bereavement Network (ICBN)		<p>Maura Keating Coordinator ICBN</p>
SOUTH AFRICA			
28 May-2 June Durban	International Children's Palliative Care Network (ICPCN) Conference		

PORTLAND, OREGON, USA

Keeping in mind my aim to understand how hospitals and communities work together to respond to the needs of families following the death of a child, I began my eight-week Churchill fellowship by meeting with members of the paediatric palliative care teams (PACT) at OHSU Doernbecher and Randall Children's Hospitals (Oregon's two Level 1 Trauma Hospitals) and The Dougy Centre (an internationally renowned child and family grief centre).

DOERNBECHER CHILDREN'S HOSPITAL

OHSU Doernbecher Children's Hospital is one of two major referring hospitals for children in Oregon, USA. It sits on a majestic hill on the OHSU Marquam Hill Campus together with OHSU (Adult Hospital), Casey Eye Institute and the VA Medical Centre. The hospital bereavement service sits within the Paediatric Palliative Care Service (Bridges Palliative Care Program) which itself originally evolved in the paediatric oncology service in response to the needs of families who sought to care for their child at home when care was no longer curative. Kathy Perko, the current nurse practitioner in the service served as Program Director for some years with a small team including social worker and chaplain. The service was originally funded through the Cambia Health Foundation.

Bridges is a consultative service that services the state of Oregon and the southern region of neighbouring Washington State. Approximately 80% of children with a Life Limiting Condition [LLC] are referred to Bridges with the remainder referred to Randall Children's Hospital. The Bridges team work in collaboration with regional hospice* teams who care for referred children and their families in their local community. Regional hospice teams care for people across the lifespan from neonates to the elderly and draw on the specialist paediatric expertise of Bridges for medical and psycho-social guidance and support. The greater proportion of children with a LLC referred to Bridges die at home (~80%).

*Hospice in the USA refers to a program of care for people who are expected to die within six months. Prior to the introduction of the Affordable Care Act (Obama) persons transitioning to palliative care could no longer access care with curative intent (chemotherapy, radiation, some pharmaceuticals). The Affordable Care Act legislated for Concurrent Care, ensuring children with a LLC referred for hospice care via insurance could access dynamic care which includes curative and palliative care running alongside each other as long as required (which meets international best practice paediatric palliative models of care). Hospice is required to provide bereavement care for thirteen months following the death of a child or adult. However, the standard of care is variable depending

on each hospice program. No standardised guidelines exist for the provision of bereavement care in palliative care.

Bridges Program is an interdisciplinary team including physicians, nurse practitioner, nurses, a social worker and chaplain. The service works closely with Doernbecher's Child Life Program and chaplaincy services with the aim to meet the child and family's physical, emotional, social and spiritual needs at all stages of care:

- Pain and symptom management
- Counselling and education
- Comfort items, including blankets, journals, books, phone cards and other items
- Spiritual, religious and cultural services
- Family portraits for terminally ill children
- Family bereavement services
- Annual memorial service
- Assistance with identifying community home or hospice care
- Staff education (targeting staff within Doernbecher OHSU and throughout Oregon)

Bridges PC Program funds a full time social worker who meets all families on referral to the palliative care service. The social work role provides counselling, psycho-social support and education, participates in advanced care planning and end of life conversations and legacy making. This role also takes responsibility for delivering bereavement care for all families whose child had been cared for at OHSU Doernbecher Children's Hospital and has died (expected and unexpected deaths).

Bereavement follow up includes the following components:

Universal bereavement follow-up protocol and resources		
Timing	Intervention	Role
Three months	Sympathy card and information pack	Bereavement Service
One year	Anniversary card	Bereavement Service
First birthday after death	Birthday card	Bereavement Service
	Follow up phone call	Bereavement Service
	Referrals for community-based care	Bereavement Service

	Build a bear (incorporating child's heartbeat)	Bereavement Service
Annually	Bereavement Memorial Service	Child Life Department
Resources		
	Library of books for children and families	Bereavement Service
Future developments		
	Bereavement service website	Bereavement Service

RANDALL CHILDREN'S HOSPITAL

Randall Children's Hospital (RCH) is a sensitively built and fairly new hospital opened in Portland in 2012. The paediatric palliative care program is currently undergoing review to ensure future sustainability for staff and families. I met with Lynn Davis and Molly McCarthy, Child Life Specialists (CLS) who are both committed to ensuring a creative and responsive approach to legacy work with families whose child has a life-limiting condition.

The role of CLS seeks to minimize trauma for children and families in the hospital setting through a range of interventions, including:

- Procedural play and support
- Medical play
- Coping plan
- New diagnosis education
- Advocate for child (e.g. numbing meds)
- Advocacy around developmentally appropriate response for siblings in PICU
- Work with families to support sibling to understand death and dying
- In the moment memory making (e.g. Handprints, castings etc.)

CLS are very involved in working with families to support the developmental, social and emotional needs of siblings whose brother or sister is dying. Memory making is a core feature of their role and the CLS team has a vast array of resources they draw on to maximise memory making opportunities for families caring for a child who is dying or has died.

The formal bereavement follow up program is managed by the social work department; however follow up phone calls are made by the hospital staff member who knew the family. The follow up protocol includes:

Universal bereavement follow-up protocol and resources		
Timing	Intervention	Role
At death	Sympathy card	Social Work Department
24/48 hours	Follow up phone call	Social Work Department
Two months	Letter and resource pack	Social Work Department
Six months	Letter and 'checking in'	Social Work Department
First anniversary	Anniversary card	Social Work Department
First birthday	Birthday card	Social Work Department
Annually	Memorial Service	Compassionate Care Committee
Resources		
	Memory making	Child life specialists
Future developments		
	Memorial Garden	

RCH holds an annual memorial service where invitations are forwarded to families of any child (0-18 years) who has died (emergency, neonatal/paediatric intensive care, labour/delivery). The service is held each spring and invitations are forwarded to families whose child has died in the past year. The earliest invitation would be at four months bereaved. Families unable to attend are offered the opportunity for their child's name to be read out and to attend the following year if the first year is too difficult.

One of the most impressive features of RCH is the Compassionate Care Committee. This committee has been running for eighteen years and is comprised of a nurse representative from each floor (medical unit), and representatives from social work, child life specialists, and the palliative care nurse practitioner. The committee oversees the following:

- Manages annual hospital memorial service
- Manages grant which allows purchase of memory making supplies, books, resources, Comfort Cubs, canvas for each family memorial service
- Development of a hospital memorial garden

- Response to staff support and compassion fatigue (recently became its own sub-group)
- End of life task force

THE DOUGY CENTRE

I completed my Portland itinerary with a visit to The Dougy Centre and Donna Schuurman. The mission of The Dougy Center is to provide support in a safe place where children, teens, young adults and their families grieving a death can share their experiences. Donna, renowned for leading the growth of The Dougy Centre, now sits in the role of Senior Director of Advocacy and Training and travels within the US and internationally to share her learnings and teach others of the Dougy Centre peer support model of care. A host of educational and training resources can be found on The Dougy Centre website.

The Dougy Center, founded in 1982 was the first center in the United States to provide peer support groups for grieving children. The center evolved in response to the peer support needs of a 13 year old boy 'Dougy Turno' who died of an inoperable brain tumor at the age of 13. Beverley Chappell of OHSU Doernbecher who cared for Dougy in the two months prior to this death, observed his ability to bond and talk with other teens facing serious medical issues. After Dougy's death, Bev established an informal grief support group in her home for children, teens and their parents coping with the death of a family member. From these humble beginnings evolved The Dougy Centre which now forms part of the National Alliance for Grieving Children (NALAG).

The Dougy Centre is founded on the belief that every child deserves the opportunity to grieve in a supportive environment. However, it also believes that our society fails to understand or support the needs of a child and family in grief. Based on these beliefs the principles of The Dougy Center are:

1. Grief is a natural reaction to loss of a loved one for children as well as adults
2. Within each individual is the natural capacity to heal oneself
3. The duration and intensity of grief are unique for each individual
4. Caring and acceptance assist in the healing process

The Dougy Center serves around 500 children and their 350 adult family members each month and maintains strong connections in the form of promotion and referrals with hospices, hospitals, schools, children's cancer organizations. Referrals are open to any child whose parent or sibling has died. Sixty-eight open-ended peer support groups meet every

other week and are divided by age, type of death (illness, sudden death, murder, suicide) and who died (parent, sibling).

- 3-5yrs
- 6-12yrs
- Teens 15-18yrs*
- Young adults 18-24yrs
- Older young adults 25-35yrs

*Concurrent adult support groups meet at the same time for the caregiver of the child or teen who is attending group. Average attendance is around 15 months although this fluctuates depending on the needs of each family.

The newest service addition to the Dougy Centre is the Pathways Program for those with an advanced illness and their families. Four groups meet concurrently for 1.5 hours followed by a collective meal between all group members:

- Person with illness
- Parent
- Child (3-12 years old)
- Teen (13 and beyond)

Group programs at The Dougy Centre rely on the support of over 200 trained volunteers.

MEMPHIS, TENNESSEE, USA

While Memphis is famous for many things including BBQ ribs and the origins of rock n roll it is also the home of St Jude Children's Research Centre. I was privileged to spend two days at St Jude with my visit facilitated by Lisa Clark, Bereavement Coordinator in the Quality of Life for All (QOLA) team.

ST JUDE CHILDREN'S RESEARCH HOSPITAL

St Jude is a world leader in paediatric oncology and was built from the vision of Danny Thomas, a once destitute man who committed in a prayer to St Jude 'Show me my way in life and I will build you a shrine.' Danny came into good fortune unexpectedly and began building a legacy based on the dream that 'no child should die in the dawn of life.'

St Jude now offers a remarkable suite of care for children diagnosed with cancer and blood related disorders including treatment, local accommodation, a free shuttle to and from accommodation and food vouchers for meals. When families arrive at St Jude all these costs

of attending with their child for treatment are covered thanks to external funding from a host of corporate and organisational partners.

Palliative Care at St Jude is integrated into standard oncology care. The Quality of Life for All (QOLA) team attempts to meet and establish a relationship with all children and their families at diagnosis. The level of contact then adjusts depending on the child's treatment outcomes or diagnosis. Children with a very poor diagnosis are more fully integrated into QOLA care from diagnosis. The principle of care at St Jude is to ensure children's outpatient treatment is maximised. St Jude has approximately 80 inpatient beds with children and their families offered free St Jude accommodation locally while children undergo outpatient treatment, with some children able to return home on treatment (depending on treatment protocol and child's condition).

Lisa Clark stepped into the Bereavement Coordinator role in the QOLA team just over two years ago and was incredibly generous in sharing her learnings in my two-day visit. The Bereavement Program offers a host of innovative program elements based on the philosophy of ensuring a parent informed and driven response to bereavement.

The central tenets of the St Jude Bereavement Program acknowledge a positive experience of grief being meaning centred, continuing bonds and finding purpose in life following the death of a child. The bereavement program is robust and offers traditional follow up services together with a range of innovative programs acknowledging the presence of bereaved parents as fundamental to improved service delivery for the hospital and improved outcomes for the bereaved themselves.

Stay in Touch Program

The most recent addition to the Bereavement Program is the 'Stay In Touch' program whereby bereaved parents, after completion of a training program, make follow up phone calls to newly bereaved parents as a way of reaching out and 'checking in' with families. Lisa describes this as a focused and sustainable way of ensuring all parents whose child was cared for at St Jude and has died feel cared for and supported.

Day of Remembrance

Each year St Jude holds an annual Day of Remembrance weekend commencing on Friday night and closing on Saturday afternoon. The mission statement for the Day of Remembrance is:

- St Jude is bound to recognize children who have died
- St Jude must recognize bereaved parents

- St Jude needs to communicate to parents and siblings that their children meant something in their lives

The schedule of the weekend is comprised of:

Friday	<ul style="list-style-type: none"> • Family check in and memory board decoration • Welcome reception and an opportunity for families to reconnect with staff and decorate a display board honouring their child’s legacy • Family reception incorporating a dinner hosted by St Jude Executive Officer and bereaved parent panellists. Sibling activities are arranged to support children and teens
Saturday	<ul style="list-style-type: none"> • Breakfast buffet • Parent panel with panellists representing St Jude families exploring a variety of topics in relation to grief and bereavement. • Lunch buffet • Celebration of Remembrance to honour deceased children

Volunteer opportunities for bereaved parents

Bereaved parents are encouraged to become involved in a range of forums at St Jude to ensure the parent voice informs service delivery. All bereaved parent volunteers must complete the Patient Family Centred Care Training.

Parent Mentor Program

The Parent Mentor Program was established in 2011 and matches parents of past patients with families new to St Jude. The program also matches newly bereaved parents with mentors whose child has died. Mentors provide support, encouragement and insight to help families navigate their journey through treatment. They draw on their own experiences to provide a special connection for those trying to become accustomed to a new way of life in the hospital or at home.

Mentors guide families at various stages of their child’s care trajectory including:

- At a child’s diagnosis, families new to St Jude or families transitioning between clinics from the point of diagnosis. Mentors are matched with mentees for at least twelve weeks.

- Transition to Quality of Life (QOL). Mentors whose child has died at least two years previously are matched with mentees for at least fifteen months. Mentors guide parents of patients facing end of life or parents of children who have died.
- Mentors in the H Clinic are parents of a patient with a haematological disease. They will be matched with parents of children with similar diagnoses. H Clinic mentors are matched with mentees for at least 15 months.

Bereaved parents can opt into the mentor program for fifteen months from one month bereaved with the goal of the relationship being to walk alongside each other without creating a sense of dependency. Care can be extended for two extra blocks of six months if required.

The process to become a parent mentor is extensive and includes the successful completion of an application, a phone interview and a day-long in-person training session at St Jude. Potential mentors must be willing to commit a sufficient amount of time to successfully complete the onboarding and training. Mentors can expect to put in approximately one to five hours a month communicating with their mentees, managing encounters and monitoring their St Jude emails. Mentors are not expected to be on campus any other time except for training. There is an annual meeting that all mentors are encouraged to attend, but it is not mandatory.

Quality of Life Seminar

Parent educators for the Quality of Life Seminar are bereaved parents who have a desire to improve end-of-life and bereavement care for patients and families by sharing their personal experiences with staff. The role of parent educators for the Quality of Life Seminar includes facilitating small group discussions between participants during breakout sessions. Parent educators will go over case studies with participants, facilitate discussion and help educate participants on how to better serve patients. Parent educators also serve on the parent panel, share their stories and answer questions from participants.

Quality of Life Parent Adviser Opportunities

Parent Advisers who serve on the Council play an essential role in providing insight into strategies for improving care for patients at the end-of-life and for bereaved families, as well as for all St Jude families. Bereaved parents who serve on the Council are at least two years removed from the death of their child and have been trained as Parent Advisers.

While in Memphis I also had the opportunity to meet with Joanna Lyman, Program Coordinator of the Palliative Care Program at Le Bonheur Children’s Hospital. Le Bonheur was founded in 1952 and is located in the heart of the Memphis Medical District Collaborative and sits as part of the Methodist Healthcare Family. Le Bonheur forms part of the newly formed community based palliative care between St Jude QOLA team, Methodist Family Care. The team which now meets fortnightly, was formed as a way of integrating care between the two leading children’s hospitals in Memphis and community palliative care team. Many children diagnosed with cancer receive care across campus.

Bereavement Care has evolved organically at Le Bonheur in response to the expressed needs of families. The service is managed by a Bereavement Coordinator who holds the dual role of NICU chaplain. Legacy services are provided prior to the death of a child or at the child’s death through child life specialists and palliative care. The palliative care program has integrated two parent mentor roles which are a resource for newly referred families in terms of ‘demystifying’ the role of palliative care in paediatrics.

The Bereavement follow up protocol includes:

Universal bereavement follow-up protocol and resources		
Timing	Intervention	Role
Proactive	Follow up phone calls	Bereavement Coordinator
First and second anniversary	Anniversary card	Bereavement Coordinator
First birthday after death	Birthday acknowledgement card	Bereavement Coordinator
First Mothers and Father’s Day	Acknowledgement cards	Bereavement Coordinator

A suggestion box sits in each medical unit where a child has died inviting staff to write a message for the family. These messages are then forwarded onto the family through the standard mail-out as a way of affirming for families that their child is honoured and remembered by hospital staff. The hospital bereavement coordinator also facilitates a monthly support group. Each year a Celebration of Remembrance is held with invitations forwarded to bereaved families whose child died within the previous two years. The service is held at the same time each year to allow families planning for the year ahead.

Referrals for support in the community are initiated on request and when risk in bereavement has been identified. The main local referring centre is the Centre for Good Grief in Memphis; however long waiting lists prohibit access to timely care. The Forrest Spence Foundation (who traditionally provided non-medical needs for families) can fund up to six sessions of grief counselling for families that do not have insurance.

LITTLE ROCK, ARKANSAS, USA

My visit to Little Rock was prompted by hearing Greg Adams, Coordinator of the Centre for Good Mourning, Arkansas Children's Hospital (ACH), speak at the annual Australia New Zealand Children's Haematology Oncology Group (ANZCHOG) conference in Queensland in what we believe was 2004. Greg presented a very well received plenary on professional boundaries and it was his genuine compassion and wisdom that made a significant impact on me at the time when I had only recently entered paediatric oncology. A few of us who experienced learning from Greg continue to draw on his work. Fast-forward fourteen years and the first person I thought of when awarded my Churchill Fellowship was Greg. He is someone who has worked in the field of bereavement care within a children's hospital for many years and become highly respected in the world of thanatology. I will be forever grateful for the energy Greg put into arranging a variety of meetings with colleagues in the hospital who had become involved in the care of children and families through end of life care and of bereaved families.

ARKANSAS CHILDREN'S HOSPITAL

Throughout my two-day visit at ACH I met with a range of staff involved in the care of children with a life limiting condition and bereaved families.

Palliative Care Team

The Arkansas Children's Hospital (ACH) palliative care team is comprised of a Director (pastoral care), medical, nurse practitioner, social worker, child life therapist, chaplain and speciality nurse. Greg Adams, past director of the program now takes responsibility for team staff care. A music therapist consults to the team from the rehabilitation unit.

Approximately 75% of children referred to the program have a neurodegenerative condition. To date around 80% of children die in hospital; however this figure is slowly shifting to home-based deaths.

A core component of care is the creation of legacy items for children nearing end of life. A combination of social work and child life specialists support families in creating a range of legacy items including:

- Handprints and moults
- 'Mammies poppy plates' (hand/footprint design)
- Family photos
- Locks of hair
- Work with the child to understand their illness
- Work with the siblings of a child referred to the team

The social worker in the paediatric palliative care team has developed a uniform bereavement follow up protocol which includes: sympathy/thinking of you cards at one, six and twelve months into bereavement. At one-month psycho-educational literature is included. Memorial services are held three times each year and invitations are forwarded to families whose child has died at the hospital or was strongly connected to ACH. Families from four months bereaved are invited to attend.

Music Therapy Team

I was fortunate to meet with the Music Therapy team who have, in collaboration with Brian Schreck, commenced The Heartbeat Music Therapy Project, recording heartbeats of children with a neurodegenerative condition (and life limited). A clever recording device has been developed in the guise of a stethoscope which records the infant or child's heartbeat. The family then chooses a piece of music which may be instrumental or a song and their child's heartbeat is inserted into the song (I'm sure there is far more technical language around this and excuse this lay language!). The family are then presented with this musical piece to keep as a memento of their child. Running alongside this program is a qualitative study exploring the impact this project and listening to the music has had on parents (bereaved and non-bereaved). Initial results indicate that this legacy project brings enormous gratification to parents who feel closer than ever to their child through their heartbeat. We also mused around the introduction of such a project in ante-natal care where an infant is not expected to live after birth, and the relationship between siblings and their deceased brother or sister who they may never have met or may not remember.

Centre for Good Mourning

Greg Adams established the Centre for Good Mourning, a grief and support outreach service based in Arkansas Children's Hospital and has been writing the quarterly Mourning News since its inception in 2004. Greg shared his philosophy around bereavement care:

- Trying to make safe spaces for all the different realities that we deal with in bereavement
- Helping have difficult conversations about important things and emotional topics

The Good Mourning Program runs two outreach group programs each fall and spring for children and young (5-18 years) people who have suffered the death of a loved one. The aim of the group is:

- To ensure families don't feel alone in their grief and to know others are experiencing similar losses;
- To allow family members to share their story in ways that enable them to develop a story that they can live with more easily.

The eight-week program follows a weekly curriculum with associated discussion topics and activities and structured peer support. The group program is followed by a three-month reunion. Parents are encouraged to participate in the adult group which runs alongside the child and young person's program. The program is comprised of approximately thirteen facilitators (comprised of Greg, social workers, child life specialists and pastoral care) and is funded through the hospital auxiliary with the support of paid staff.

While the Good Mourning Program is a long-term venture of ACH, individual family bereavement care within the hospital is less coordinated and delivered through independent medical units (e.g. Paediatric oncology, NICU, PICU).

Bereavement Committee

The Bereavement Committee is comprised of a diverse range of staff members including Child Life, Speech Therapy, Social Work, Spiritual Care, Nurses and a staff member who is also a bereaved parent. The committee was developed in response to the variety of bereavement care responses taking place across medical units within the hospital to avoid replication of services. One of the most interesting developments has been the annual Bereavement Week, which has now extended to Bereavement month. Each year a month is set aside to acknowledge bereavement for families whose children have been cared for at ACH and for staff members who have experienced their own loss. Events throughout the month include Psycho-Social Rounds (for example this year focused on the experience of bereaved siblings who were invited to share their experience), a staff bereavement panel (whereby staff shared their experience of bereavement), creation of a large reflection wall of glass/whiteboard where anyone within the hospital was encouraged to write their thoughts and reflections, Bucket List Cards (encouraging staff to consider their own bucket list), and Schwartz Rounds which focused specifically on bereavement.

TORONTO, ONTARIO, CANADA

Toronto is the home of Sickkids an internationally renowned tertiary children's hospital. I was very fortunate to make contact with Norah Shaughnessy and Lori-Ives Baine, joint coordinators of the Pathways Bereavement Program at Sickkids who supported me in developing a robust itinerary of visits to hospital and community-based organisations that care for bereaved families in the Toronto region.

I was warmly welcomed by the Paediatric Advanced Care Team (PACT) and Pathways Bereavement Program. Norah Shaughnessy, Co-Coordinator of the Pathways Program had also arranged meetings with unit based Social Work representatives, members of the spiritual care team, interlink nurse and Lori Ives-Baine (Co-Coordinator Pathways Bereavement Program) who is well known in the palliative care/bereavement care education space. I am also very grateful to Dr Adam Rapoport, Medical Director of PACT who agreed to meet with me to share the background to the development of the hospital-wide bereavement response at Sickkids.

The origins of bereavement care at Sickkids, like many hospitals I visited, evolved organically. Medical Units with high acuity deaths (NICU, Oncology and Palliative Care) had responded to child deaths in the course of their work and often due to the attention of skilled and attentive staff understanding the need that was presenting. However, there was a growing realisation that unless you were a family that experienced a death in one of these areas you may not receive any bereavement care. Sickkids experience approximately 250 child deaths per year.

Some of the historical barriers for standardised bereavement were an organisational culture which hadn't accepted death as part of their mandate and consequently not something that should be core business. Death was seen as a failure in a paediatric hospital and not something to focus on or invest more resources into. At the time the organisation was focused on 'making miracles happen', a theme that in some organisations continues to pervade.

In 2009 in response to a brewing conversation on post death care, a Bereavement Care Taskforce was established to undertake a comprehensive examination of existing practices and resources at the hospital, an external survey of best practices and a literature review. Staff from a diverse range of programs and clinical areas were interviewed about current bereavement practices, standards, policies and protocols -doctors, nurses, social workers, psychologists, bereavement coordinators, members of the palliative and bereavement care team, chaplains, members of the protection and transport services, child life specialists, members of the division of pathology and representatives from the Coroner's Office.

The review identified strengths and gaps in existing bereavement care practices at Sickkids. Based on the findings the Task Force put forward the following key recommendations:

1. Develop a strategy to ensure consistent bereavement care is delivered at all times, in all settings.
2. Create a hospital-wide bereavement program that integrates education, policy, research, clinical care, and evaluation. Consideration should be given to include this resource within the current Palliative Care and Bereavement Service.
3. Develop new resources to promote best practices in bereavement care including bereavement care across cultures.
4. Link with available community resources to optimize their use, foster existing relationships, and create opportunities to develop new partnerships.
5. Provide education about the principles of grief, death, dying and bereavement to all hospital personnel and, where possible, to community partners.
6. Implement a standardized follow-up process after the death of a child.
7. Adopt and implement a quality of care measurement system, for example, a tool similar to the Picker for pain (an indicator to monitor quality of care).
8. As is appropriate, continue to engage our bereaved families:
9. Implement facility upgrades to the hospital's morgue and quiet room.

In summary, a confluence of historical events meant that Adam Rapoport was in the right place at the right time to advocate strongly for a funded hospital-wide bereavement program. He strongly supported and introduced a model whereby all families whose child had been cared for at Sickkids and whose child had died, were offered care, guidance and support through an evidence-based program based within the PACT team. It is heartening to hear this and Adam shared a very eloquent conversation which will prove a good advocacy tool with children's hospitals struggling to engage stakeholders in this important mission.

Pre-bereavement support and transitional bereavement care

Oncology interlink nurses (funded through the Pediatric Oncology Group of Ontario) are introduced to families at each new diagnosis of childhood cancer. These positions establish a linking role between community nursing, hospital-based nursing teams and with the PACT team for when a child transitions to palliative care. Five positions currently sit within the oncology unit. These roles are dispersed throughout children's hospitals in Ontario.

At diagnosis an interlink nurse is introduced to the child and family. On application POGO offers families financial assistance to cover costs such as accommodation and child care. Interlink nurses work with the family and community to sustain connections with important aspects of the child and families life such as: school integration, home instruction and education with teachers; and support for siblings at home and/or in the classroom. Home visits form part of the interlink role. Interlink nurses often continue a connection with the family after a child's death through a home visit, sympathy cards, and sometimes funeral attendance.

Childhood Cancer Canada is an additional resource that provides support for families with a child diagnosed with cancer. The bereavement fund can provide \$1500US funeral support through the Benevolent Fund for bereaved families.

Paediatric Advanced Care Team (PACT)

The Paediatric Advanced Care Team (PACT) is a consultative service based at Sickkids lead by Medical Director, Adam Rapoport, also Medical Director of Emily's House, Toronto's first paediatric children's hospice. The team incorporates four palliative care physicians, three nurses, two grief support coordinators and one administrative assistant. PACT also draws on the special knowledge of other professionals and volunteers like chaplains, social workers, nurses, bioethicists, physicians, pain experts, volunteers and parents. PACT maintains strong links with community partners including: Holland Bloorview Kids Rehabilitation Hospital, Community Care Access Centres, Interlink Nurses, Tammy Latner Centre for Palliative Care, and Emily's House.

Services available to families and health care teams include:

- Inpatient, community and family consultation
- Collaborative community care
- Intensive symptom management
- Psychosocial and spiritual support
- Music therapy
- Bereavement counselling
- Financial support

The Paediatric Advanced Care Team leads a robust program of professional development of health care providers and volunteers who care for dying children and their families and high quality research to inform an evidence based program of care.

Legacy Building in Palliative and Bereavement Care

The power of anticipatory grief support making memories has been embraced by the PACT team. Grief Support Carts are housed on medical units, and staff throughout the hospital have received training on how to use memory making items within the carts. Memory making items include:

- Photography (Grief Support Cart Camera and SD card)
- Hand/foot prints
- 3D moulds made with family and child
- Sound disks to capture a heartbeat or the sound of a child's or parents' voice
- Painted hands/feet on art boards

- Fabric hugs (a strip of fabric the length of your arms and chest decorated with loving memories)
- Memory Boxes

Specific written resources to support families are also available on the Grief Support Cart for parents, grandparents, siblings, special circumstances (single parents, death of a twin, same sex couples)

After death legacy creation options for grieving families are provided on the Pathways website. Suggestions include: donations to a charity of choice, creating a memento space, creating a pillow/quilt made from the clothes and blankets of the child.

Pathways Grief Support Program

The Pathways Grief Support Program developed in response to the recommendations of the report of the Bereavement Care Taskforce. A successful pitch was made to the hospital executive to secure funding for a hospital wide grief support program through the hospital foundation. Seed funding was originally provided through philanthropic funding the goal being to review the established program and create a business case for the hospital to take over funding and administration of the service. Additional funding was appropriated from medical units who experienced high acuity including PICU, NICU, cardiology, palliative care, oncology on the premise that bereavement care at Sickkids was 'everyone's business'.

Pathways Grief Support Program is housed within the Paediatric Advanced Care Team (PACT) at Sickkids. All bereaved families who have experienced the death of a child who was cared for at Sickkids are offered the opportunity to receive services and support from Pathways. Two Grief Support Coordinators (1.8FTE) are available for families Monday-Friday, 8:30-4:30.

The program has a well-developed public website which provides information on: the Pathways Program, preparing for your child's funeral, books and internet resources, camps, library and community based grief support centres and resources.

Historically, promoting the value of the Pathways Program to all medical units within Sickkids has been difficult. Some medical units (for example ICU) took some time to see the value of a hospital wide bereavement response. The Pathways team have worked sensitively around these barriers, one example being attending ICU morbidity and mortality meetings whereby a member of the bereavement team provides updates on their contact with bereaved families. There is a sense that sharing the experience of bereaved families provides some satisfaction for staff given their role in caring for the child.

A standard protocol is now in place to ensure the Pathways team are notified of all child deaths. A deceased patient report list is emailed to Pathways each morning (includes MRN number, child's name and location of death). A member of the Pathways team then refers to the child's medical record for background information and contacts the key HCP who cared for the child prior to contacting the family. The Pathways coordinators describe this process as 'cold calling' and suggest in an ideal world these phone calls would be much easier had they met the child and family prior to death. The PACT team tries to ensure families have the opportunity to meet a member of the Pathways' program prior to their child's death however as the bereavement service has grown over the years the capacity to meet this goal has become increasingly difficult. As is a consistent theme in most hospitals I visited, record keeping following the death of a child continues to be complex with staff unable to upload notes without contacting medical records with a special request for notes to be added. The team found this onerous given the regular recording of notes and have since established a static database in an excel spreadsheet for use only within the Pathways program. Interactions with families are logged to ensure consistency of communication between team members.

The Bereavement Coordinators describe their role as navigators for the bereaved family both within the hospital context and as the family transitions into their community. In the first year of bereavement families receive a package of mailings. Administrative and volunteer support is accessed to pre-package this high workload service. Packages are targeted to the deceased child's age at death (infant, 1-6years, older than 6 years). Feedback from families confirms their preference for post rather than email as this allows some control over when to open the package and read through the various information resources.

Bereaved families can access Pathways support via phone and a dedicated service email address. At first phone contact with the newly bereaved family a member of the Pathways team tries to collect the family's email address and this is then recorded on the database and used for email updates/promotion of Pathways events throughout the year. Families remain on mail/email distribution lists unless they request to be removed, acknowledging the uncertain life course of grieving and multiple touchpoints that may be sought throughout this time.

Pathways offers a range of services for families and staff throughout the year as noted below.

Family support

Coffee Klatches

A peer support forum where bereaved parents/carers are invited to 'drop in' for an informal gathering is held between 6.30pm-8.30pm every second month. This event takes place in the research tower adjacent to Sickkids. The evening is always facilitated informally by two team members from the Pathways Program. Attendance ranges from 4-12 parents (average of 8) with a mixed background of losses.

Parent education forums

An educational forum which is offered twice per year for families is held at the research centre meeting room (as above) on a weekend. The format of the program allows for a ten minute 'arrival and mingle', a teaching component followed by a group discussion. Childcare support is provided by volunteers.

Summer picnic and butterfly release

This is an annual event held in a local park. Pizza is donated by a local provider and families are invited to bring salad and dessert. Activities are coordinated by volunteers and the PACT team massage therapist provides services for families on the day.

Hospital wide memorial service

This is a formal service whereby all families whose child was cared for and died at Sickkids are invited. There are no timeframes for attendance and the service now attracts close to 300 people (representing approximately 70 child deaths). The event was traditionally held in the research tower; however it has recently been moved to another venue to cater for increasing numbers of attendees. An activities space is created in the lobby for children. Staff is invited to attend the service although numbers of staff represented are low. Given the size of the event the Pathways Coordinators have learned to delegate practical and logistical tasks on the day to enable them to focus on the families with whom they have built relationships in their role as Bereavement Coordinators.

Unit Based Memorial Services

Several inpatient units within the hospital host memorial services each year. This is a time for families to reconnect with staff who cared for the child, and to honour that child's memory. Units who have held these services in the past are: Haematology/Oncology, Cardiology, Paediatric Medicine and the Neonatal Intensive Care Unit.

Staff education and support: End of life membership team

Initiated in the first year of the program where representatives from each medical unit hospital wide are invited to discuss best practices and share updates in relation to end of life and bereavement care at Sickkids. The team meets every two months and is chaired by Lori Ives-Baine, Bereavement Coordinator, Pathways Program.

Staff peer support

Pathways offers a range of staff supports which have evolved in response to need over time including: a hospital wide peer support program (critical incident debriefing); team debriefs after a child has died (informal debriefs); ‘Voicing Spaces’ a casual drop in session.

Universal bereavement follow-up protocol and resources		
Timing	Intervention	Role
As required	Supported morgue visits	Pathways Program
As required	Phone and email support	Pathways Program
As required	Referral to community-based support	Pathways Program
Mailings**	Mailing information package	Pathways Program
1 month	Mailing information package	Pathways Program
4 months	Mailing information package	Pathways Program
7 months	Mailing information package	Pathways Program
11 months	Mailing information package	Pathways Program
Mother’s Day	Mailing information package	Pathways Program
Father’s Day	Mailing information package	Pathways Program
First birthday	Mailing information package	Pathways Program
**Flyers for upcoming events are included in mailings		
Events		
Every two months	Coffee Klatches	Pathways Program
Twice yearly	Educational forums	Pathways Program
Annually	Summer Picnic	Pathways Program
Annually	Memorial Service (Hospital Wide)	

	Unit based memorial services	Medical Unit (onc/haem, ICU, cardiology, paediatrics)
Resources		
	Grief Support Carts	On each medical unit
	Library of book resources	
Staff support and education		
	Nursing orientation program for nurses new to the hospital	
	End of life care class with haem/onc, ICU	
	Critical incident debriefing	Pathways and hospital wide peer support program

As with any hospital-based program, there exist challenges of reaching a geographically dispersed population of bereaved families. This continues to be a theme on my travels.

DR JAY CHILDREN'S GRIEF CENTRE

Dr Jay's is currently based in central Toronto and offers therapeutic counselling support to children and young people who have had a sibling or parent die, a family group program, and coordinates Camp Erin annually, a weekend camp for bereaved children and young people. I was thrilled to be invited to join a Family evening based in Toronto Children's Hospital where parents/guardians and children constructed and painted bird houses while sitting alongside each other in a space of compassion and comfortableness.

LIGHTHOUSE

Lighthouse is an organisation based in Oakville around 30 minutes outside Toronto. This program is based in a beautiful and purposely converted Church with staff trained in the Dougy Centre model of peer support for children and young people, with concurrent sessions offered for parents. Deidre Thomas (Executive Director of Lighthouse) shared their activity in building capacity in communities beyond their centre, again acknowledging the geographical divide that prohibits many children, young people and families attending the program in person. Education is delivered remotely via a tele-health type model to a broad range of services and professionals across Canada.

EMILY'S HOUSE

My final stop in Toronto was a brief visit to Emily's House Children's Hospice. The PACT team work closely with Emily's House with Adam Rapoport also Medical Director of the hospice. The hospice forms part of the Philip Aziz Centre which provides palliative care in home and through hospice care. Around 80% of referrals are from the PACT team and around 300 volunteers enable the hospice to provide the level of care required for families of children diagnosed with a life limiting condition either in the hospice or in their home. Hospice funding is 50% Ministry of Health and the remainder through fundraising. A 'virtual tour' has been developed and sits on the hospice website to enable families a first glance at the house prior to committing to a visit. The team at Emily's House feel this helps break down the misconceptions of hospice for some.

BOSTON, MASSACHUSETTS

My final stop in the USA was Boston, Massachusetts. Some years ago, I visited the Dana Farber Cancer Institute to meet Joanne Wolfe and the PACT team. This was in my early days working in paediatric palliative care and PhD studies. I was thrilled to meet Dr Sue Morris (fellow Australian!) who held the position of Director, Bereavement Care at Dana Farber and across multiple hospital campuses. Sue continues to hold this position and I spent a full day with Sue and her colleagues on this most recent visit.

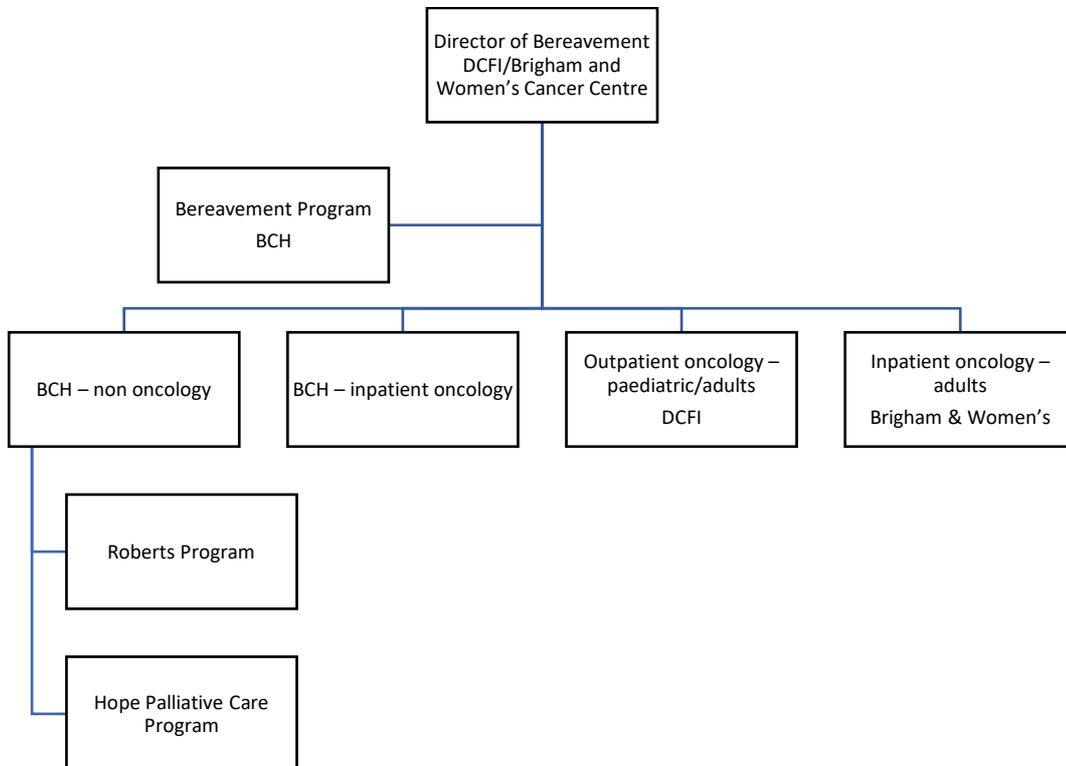
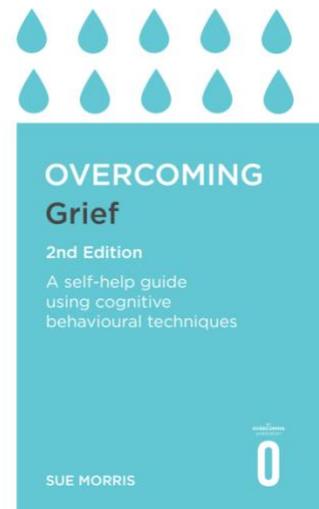
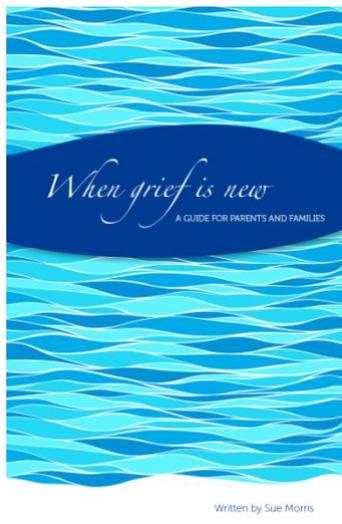
DANA FARBER CANCER CENTRE, BOSTON CHILDREN'S HOSPITAL AND BRIGHAM AND WOMEN'S HOSPITAL

The following historical summary of the development of the Boston Children's Hospital Bereavement Program is drawn from the following citation:

Morris, S. E., Dole, O. R., Joselow, M., Duncan, J., Renaud, K., & Branowicki, P. (2017). The Development of a Hospital-Wide Bereavement Program: Ensuring Bereavement Care for All Families of Pediatric Patients. *Journal of Pediatric Health Care*, 31(1), 88-95.

Dr Sue Morris is the Director of Bereavement Services for Dana-Farber and Brigham and Women's Cancer Centre, Boston, Massachusetts. The service sits in the Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute (DCFI). This dense medical campus also incorporates Boston Children's Hospital (BCH), a 404-bed comprehensive centre for paediatric health care and one of the largest paediatric medical

centers in the United States. Health care services are provided for children from birth through 21 years of age. Sue commenced in the role of Bereavement Coordinator at DCFI in 2010. This program is well established and offers a suite of service elements to families whose loved ones were cared for through DCFI and received oncology care through Brigham Women’s Hospital. Sue has written a number of books on grief following the death of a child and coping with grief, which are distributed through the Bereavement Service:



Boston Children's Hospital Bereavement Program

In September 2013 BCH officially launched a hospital-wide bereavement program for both oncology and non-oncology services. Prior to this bereavement follow up was provided by a discrete number of medical units (palliative care, oncology intensive care units) due to the lack of a hospital bereavement coordinator role and funding for bereavement resources.

Acknowledging the need for a hospital wide approach to bereavement care, in 2011 the vice president of Medicine Patient Services established an interdisciplinary bereavement task force led by the Director of Bereavement Services, DCFI and comprised a range of stakeholders including nursing, social work, child life, chaplaincy and the Hale Family Center for Families. Feedback from bereaved families was integral to informing this new service.

The overarching goal of the new program was to standardize bereavement care hospital-wide by guaranteeing a minimum standard of care was offered to all bereaved families in the first two years following the death of their child. The goal of the new service was to provide an additional layer of support to those teams already providing unit based bereavement follow up.

The BCH bereavement program was modelled on the existing program developed at DFCI and led by Dr Sue Morris. Education, guidance and support remain the key constructs which underpin service development and delivery. The aims of the BCH program are:

- Decrease the deep sense of isolation that bereaved parents often report by providing opportunities for support
- Provide information about what bereaved parents and families might expect during the course of their bereavement
- Outlines strategies to help parents and families deal with their grief and maintain a connection with their child
- Provide information about community resources and referral information

Development of the BCH bereavement program spanned two phases to ensure development of a cost-effective program that would be sustainable over time.

Five essential components were identified matched by a service response:

1. Acknowledgement of the death of the patient by the hospital and clinician
 - A formal hospital condolence letter
 - Distribution of condolence guidelines and sympathy cards for staff use
 - Memorial events
2. Information and education about the experience of parental grief

- A psycho-educational bereavement guide, *When Grief is New: A guide for Parents and Families*
 - Dedicated bereavement pages on the BCH web site
 - Seminars for families about coping with grief
3. Support Services
- A support group for bereaved parents: The Hope Group
 - An annual day-long ‘keeping connections’ workshop for bereaved families, including siblings
 - Seminars for bereaved parents/caregivers based on cognitive behavioural principles (Morris, 2008)
 - Telephone support
 - Referral and resource information
4. Staff support and education
- Quarterly seminars about working with the bereaved, the nature of grief, offering condolences and self-care for clinicians, facilitated by members of the Bereavement Task Force
 - Debriefing with teams after a difficult death on a needs basis facilitated by the members of the Bereavement Task Force
5. Program evaluation and research (Phase Two)
- Provision of a survey to bereaved parents about the bereavement program
 - Identification of additional support services that might be helpful to bereaved families
 - Increased efforts to support staff based on feedback from the quarterly seminars offered.

Following the death of a child each newly bereaved family is mailed a bereavement packet which includes a formal condolence letter from BCH (signed by the president of BCH/DFCI), a psychoeducational bereavement guide ‘*When Grief is New*’ based on cognitive behavior therapy principles, a flyer outlining upcoming seminars at BCH and a resource list of community and online bereavement programs.

The authors acknowledged a number of challenges in developing the program:

- Identifying deceased patients – four sources of information are collated each month to generate the bereavement mailing list
- Geography and access to BCH – families travel from vast distances to access medical treatment for their child and returning to Boston for bereavement care is not always practical nor helpful in supporting parents’ reintegration in their local community
- Emotional difficulty returning to the hospital – many parents find it too painful to return to the hospital where their child was cared for.

- Addressing expected and unexpected deaths – allowing for the needs associated with each experience
- Low attendance – approximately 5% of bereaved parents have attended psycho-educational seminars. Memorial Services are better attended.
- Determining the timing, frequency and format of the program – understanding the best times to connect with parents at differing time-points in the bereavement trajectory

TABLE. Template for the development of a pediatric bereavement program—education, guidance, and support model

Essential components	Factors to consider
1. Acknowledgement of death of patient Institutional condolence letter Condolences and outreach by individual teams and clinicians	1. Identify champion for the program
2. Information and education about grief for parents and families Psycho-educational materials for parents, siblings, and grandparents Content on hospital Web site Seminars for families about coping with grief and maintaining a connection with their child	2. Determine departmental oversight Funding source and budget Resources Bereavement policy
3. Support services Groups Individual counseling Seminars Telephone support Referral and community resources information	3. Identifying deceased patients Inpatient, outpatient Sudden, expected death Number per year
4. Staff support and education Ongoing education opportunities about the nature of grief, offering condolences, and self-care for staff	4. Identifying bereaved Who? Contact information Database for mailings, invitations Documentation of visits
5. Program evaluation and research Survey to bereaved parents to guide quality improvement efforts	5. Types of services offered Groups, individual counseling, sibling groups, online support Memorial events—hospital-wide, team-based
	6. Staffing Task force/steering committee Administrative support Bereavement coordinator, ideally trained in mental health
	7. Scope of the program Mailings—frequency Telephone support Education materials, e.g., bereavement guide Web site content Clinical contact—group support, risk assessment, individual counseling
	8. Clinical backup Emergencies, vacations, supervision
	9. Staff support Continuing education Support—debriefing, bereavement rounds
	10. Evaluation, feedback, and quality improvement

Pediatric Advanced Care Team (PACT)

Development of the Boston Children’s Hospital (BCH) Bereavement Program acknowledged the service-based bereavement support that was in place in core medical units within BCH. Marsha Joselow, Clinical Social Worker in the PACT team described the critical connections that develop between the child undergoing cancer treatment and their families which many

families seek to sustain as they transition into bereavement following the death of their child. Families are cared for through a variety of ways:

- Sympathy cards
- Information packet
- Library of books
- 1, 6 and 12 month anniversary card
- Parent bereavement group
- Bereavement visits

How best to target care to individuals and families in greatest need or highest risk in bereavement appears to be an ongoing challenge for all centres I've visited. While generally colleagues I have met follow a model of universal response, equally they struggle in targeting care appropriately. I met Jennifer Snaman, Paediatric Palliative Care Consultant in the PACT team at Dana Farber who shared her work in this area. Jen undertook a fellowship at St Jude Children's Research Hospital in Memphis and has become very committed to the area of bereavement care and is currently working on developing a measure that fits within the context of parental bereavement. To date, no specific measure has been developed for this population. Jen and I agreed to keep connected in this space and I look forward to an ongoing conversation in the future.

Roberts Program

I was very fortunate to also meet Rick Goldstein and his colleagues from the Roberts Program. Robert's Program is a clinical service offered to families in Massachusetts who have lost a child under the age of three years suddenly and unexpectedly. The aim of the program is to help understand the cause of the child's death while supporting families through a very difficult time. Based at Boston Children's Hospital, the multidisciplinary team uses the most current medical knowledge about sudden and unexpected death and works to find answers. Members of the Roberts Program contribute to the care of Sudden Unexpected Death in Pediatrics (SUDP) - which encompasses Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Death in Childhood (SUDC).

The Program involves clinicians and scientists from the fields of:

- General paediatrics
- Neurology
- Genetics
- Cardiology
- Metabolism
- Endocrinology
- Neuropathology
- Paediatric and forensic pathology

- Bereavement support

The Roberts Program works collaboratively with the Massachusetts Office of the Chief Medical Examiner (OCME) the Massachusetts Center for Unexpected Infant and Child Death (SIDS) and local Paediatricians.

The bereavement model of care is interwoven into the Roberts Program. Sue Morris, Director of Bereavement Services DCFI, holds the role of bereavement coordinator and joins the Director at intake of newly referred families. Sue then maintains a connection with families through the assessment and diagnostic process. Sue describes meeting families at intake as critical to developing an immediate and genuine relationship and one that then enhances ongoing bereavement care.

LONDON, UNITED KINGDOM

My first stop in the United Kingdom was Great Ormond Street Hospital for Children (GOSH) in London. GOSH is the tertiary hospital hub for a large range of specialist paediatric services in the UK and most patients are referred from other children's hospitals throughout the UK and overseas. At the recommendation of colleagues, I also took the time to join a 'Friday tour' of St Christopher's Hospice, home of the modern hospice movement.

GREAT ORMOND STREET HOSPITAL

Great Ormond Street Hospital was formed in 1852 and now offers the United Kingdom's widest range of specialist health services for children on one site. Most children are referred from other UK hospitals and overseas. GOSH is the largest paediatric centre in the UK for:

- Paediatric intensive care
- Cardiac surgery
- Neurosurgery
- Paediatric cancer services including bone marrow transplants
- Nephrology and renal transplants
- Children treated from overseas

Given the specialist services provided and high morbidity, GOSH experiences approximately 100 deaths per year with 70% of these children dying on the intensive care unit. Children referred to the haematology/oncology service represent the next highest proportion of deaths at GOSH.

Rachel Cooke is Bereavement Service Manager for GOSH and her position sits under Patient Experience. Rachel very generously dedicated two days to supporting my visit and enabled connections and meetings with a range of GOSH colleagues who are involved in the care of a dying child, deceased child and bereaved families. GOSH is presented with a similar geographical challenge as children's hospitals in Australia whereby children travel from outside London, broadly across the UK and for some, internationally to receive care.

Pre-death and anticipatory grief care

The Louis Dundas Centre for Palliative Care

Children diagnosed or recognised as having a life threatening or life shortening illness can be referred to The Louis Dundas Centre for Palliative Care at GOSH. The Centre offers a multi-disciplinary approach to palliative care with clinical, psychosocial and research teams working collaboratively. The child and family members can be referred to the psycho-social team (family support officer, social worker and psychologist) for support and guidance in anticipatory grief. GOSH employs thirty psychologists hospital-wide who can provide anticipatory grief support for family members.

Family Liaison Nurses – Paediatric and Cardiac Intensive Care Unit

I was interested to meet with Esther Rose, Clinical Nurse Specialist in the Family Liaison Team. Esther and her colleagues meet families on arrival at GOSH and have a responsibility to assess the psychological needs of families from admission, during their stay and through to discharge from intensive care. Importantly, these roles ensure transitional bereavement care for families following the death of a child.

Acknowledging the additional support required by families who travel vast distances, a family liaison model of care was established in 2004. The Family Liaison role is filled by clinical nurses with an ICU background and originally funded through charitable funds. The success of the program meant funding became integrated into the operational budget which now funds five staff:

1. 2 FTE and .5FTE one year rotation paediatric intensive care unit
2. 1 FTE and .5 one year rotation cardiac intensive care unit

The PICU and Cardiac Family Liaison work collaboratively to meet the needs of all families on PICU and CICU. The Family Liaison Nurses (FLN) meet families on arrival in ICU and remain the first point of contact for psycho-social issues presenting for the family. Relationships are often built quickly given admissions are often a result of a

trauma/emergency. The FLN undertake a daily check in with allocated families with their role encompassing:

- Day to day support with practical issues
- Review of child's condition and progress
- Working with the bedside nurse if required
- Sibling support
- Managing the needs of extended family members
- End of life conversations
- Being a presence with care is withdrawn

The FLN works closely with the broader psycho-social team including psychologists, social workers, chaplains, play therapists and consultants. The GOSH MOC means social workers are not based on the ICU. Referrals are made to social work for child protection and social services issues, and domestic violence issues between family members. Psychologists are referred to in the event parents require a therapeutic response, challenges in adjustment to the new life scenario, or present with mental health issues. Psychologists may also become involved if family members are seeking support and guidance from a non-ICU team member.

FLN's support families at the time of the child's death ensuring death procedures are followed (paperwork, transfer of child to hospice/home as requested by the family, registering the child's death, coronial processes). Funds are available (ward, bereavement service or organ donation funds) to cover the cost of transferring a deceased child to a hospice for post death care if requested by the family.

Transitional bereavement care is provided by the FLN by phone at two weeks post death (usually after the funeral). They also explore any immediate issues or questions the family may have and offer an opportunity to reconnect with the ICU team who cared for the child at GOSH. Approximately 40% of families take up the offer for a death review meeting which includes the consultant and family liaison nurse. Post-mortem results are shared, family members have an opportunity to ask questions, and for some families concerns about future children may be discussed. GOSH have an open-door policy encouraging families to reconnect at any time after their child's death to ask questions, seek clarification or to access bereavement care. All bereaved families go on to receive a letter of introduction from the GOSH Bereavement Care Team. The FLN often liaise with the family's General Practitioner (GP) for bereavement follow up in their local community. The role of the FLN often comes to a natural conclusion- the longer the relationship with the family often the longer the conclusion trajectory.

The FLN team suggest the greatest achievement has been embedding continuity of care for families throughout their child's care trajectory, through the death of a child and into a family's bereavement.

Mortuary

An often-neglected (or not spoken of) component of death care in the hospital system is the mortuary. I was privileged to be taken on a tour of the GOSH mortuary and to meet with mortuary staff. The philosophy of the mortuary team is 'we are looking after your child while they are in our care'. The team is comprised of administrative support and two anatomical pathologists. The mortuary is acknowledged as the next point in bereavement care at GOSH and families are invited into this space at any time following the death of their child. Mortuary staff spoke to a range of important topics in relation to post death care of a child including removal of brain tumours for research purposes (an increasing phenomena) and understanding the cultural impact of loss and need for a child's body parts to be reunited.

Bereavement Service Model of Care

The timing of my visit to the UK meant my interviews and conversations with bereavement care stakeholders were taking place at a time where 'death is on the agenda'. A series of past and more recent events means the National Health Service has developed a structural response to death, dying and bereavement care.

The Bereavement Services Department (GOSH) originally sat in the department of social work and psychology. Following a restructure the program was transferred to the Nursing Patient Experience Division. Unlike some sites I visited there is a demarcation between palliative care and bereavement services.

The current model comprises three elements:

- Bereavement Support
- End of Life Care Group
- Child Death Helpline (CDH)

The Bereavement Services Department aims to be a point of contact for staff (anyone working in the Trust requiring support in caring for a dying child and after the death of a child) (website) and parents. The trust funds 2FTE staff (Bereavement Service Coordinator and Bereavement Support Worker) and administrative support. The Bereavement Service and Child Death Helpline are located in York House, adjacent to GOSH and incorporates separate office space for Bereavement Service Staff, the Child Death Helpline and a separate

meeting space and counselling room 'The Butterfly Room'. The Bereavement Service incorporates a universal model of bereavement care as noted below.

Universal bereavement follow-up protocol and resources		
Timing	Intervention	Role
Mailings	<p>Condolence Letter (co-signed by the service coordinator and Dr Peter Steer, Chief Executive of GOSH)</p> <p>The letter is forwarded to families of all children who die at GOSH and children who died at home but were known to GOSH in the last six months. This includes all palliative care deaths.</p>	Bereavement Service
First anniversary	Anniversary Card	Bereavement Service
Second anniversary	Anniversary Card	Bereavement Service
Services		
	Individual and/or couple counselling for any child, youth or adult member of the bereaved family	Bereavement Service
	Memory work and memory books	
Events		
Annually	Hospital wide memorial event (Invitations forwarded to families bereaved in the last year and over three months bereaved however there is flexibility on these timeframes)	Chaplaincy
Resources		
	Bereavement Services website	
	When a child died	Bereavement Service
	SUD: Sudden, unexpected or unexplained death of a child	Bereavement Service

Staff support and education		
	Hospital wide Community sector Staff self-care	

The Bereavement Service model of care is based on the premise of ‘holding’ a family in early bereavement (a non-therapeutic response). The service is open ended and does not mandate timelines or closure on access to care. Some families self-refer at varying points of their ongoing life and bereavement trajectory. It is important to note that as a result of this extension of care the service is not inundated with referrals and does not have a waiting list.

As with all centers I visited staff education is a core feature of the Bereavement Service. Education is routinely delivered to staff hospital wide and in the higher education and community sector on the themes of ‘when a child dies’ and supporting bereaved parents. Staff self-care is also incorporated in the education program.

In collaboration with a national network of colleagues Rachel Cooke, Bereavement Services Manager for GOSH is currently working on two priorities for paediatric hospitals in the UK:

- Development of a risk assessment tool for bereaved parents, and
- Development of standards for bereavement care for parents following the death of a child

Child Death Helpline

The Child Death Helpline (CDH) is a free-phone service for anyone affected by the death of a child of any age, in any circumstance, however long ago. The first helpline was established in 1989 at the Alder Centre, Alder Hey Children’s NHS Foundation Trust, Liverpool with a similar service established by bereaved parents at GOSH in 1992. In 1995 both services integrated to form the national Freephone Child Death Helpline with each Trust funding the phone bill. The CDH is staffed by bereaved parent volunteers who offer a confidential, safe and supportive environment allowing the caller to speak with a peer about their child’s life and death. The helpline is open 365 days a year and offers a range of sessions:

- Every evening 7-10pm
- Monday, Thursday and Friday 10am-1pm
- Tuesday and Wednesday 10am-4pm

CDH based at GOSH sits within the Bereavement Service in York House adjacent to GOSH and is managed by James (Jamie) Johnston, Bereavement Support Worker and training

practice coordinator for the child death helpline. The GOSH based helpline is supported by 26 bereaved parent volunteers with 20 based in Liverpool.

All volunteers undergo a police check and a 30-hour course in listening skills in the context of a helpline. Trainees are supported to complete a workbook where they learn grief theory and the foundation of listening skills. The practical component of training involves a series of role play scenarios. Each new parent volunteer is allocated a peer volunteer mentor. The course is accredited through the Open College Network. Volunteers are required to participate in an annual review and re-evaluation course two yearly.

On successful completion of the training volunteers are encouraged to undertake at least two three-hour duties per month and rosters ensure two volunteers work alongside each other each shift. Regular supervision and debriefing opportunities are provided for the volunteer team. Guidelines have been developed for each CDH location allowing volunteers to signpost callers to support in their local community. The helpline is promoted widely to stakeholders connected to Child Death throughout the UK (funeral homes, coroners, hospices, children's hospitals).

Call data is collected via British Telecom (answered calls) and the volunteers complete call sheets for each caller (demographic data). Data is collated twice yearly. The Helpline takes around 1000 calls per year.

National Bereavement Networks

Given Rachel Cooke's national position she was able to share with me the levels of strong networks that exist in relation to bereavement care in the UK that in part arose out of the End of Life Care agenda. The National Bereavement Alliance ensures a coordinated policy level agenda within statutory organisations and the third sector. The Bereavement Services Association was developed in an attempt to provide a network for all those providing bereavement support services primarily within the National Health Service (NHS). The Bereaved Parents' Support Organisations Network (BPSON) are a network of professional organisations that work together to encourage mutual learning and improve the support available to bereaved parents in the UK and includes peer driven bereavement care organisations such as A Child of Mine, Child Bereavement UK, SANDS and many more. The Childhood Bereavement Network has developed a hub for those supporting bereaved children. Rachel also shared the Children's Hospitals Bereavement Network whereby bereavement colleagues based in children's hospitals in the UK share resources and work collaboratively on policy, standards and research interests. This last network group is similar to that we are trying to evolve in Australia. While I am not visiting Scotland due to time constraints, Rachel did share the Support Around Death website that has been developed by

NHS Scotland and acts as a hub of guidance, information and support around any type of death in Scotland.

ST CHRISTOPHER'S HOSPICE

St Christopher's was born out of the vision of Dame Cicely Saunders. Dame Cicely made three professional transitions in her life from that of nurse, to social worker, to physician. However, I suspect all three of these professional roles informed each other. Driven by her faith and experience of watching the pain and suffering of the dying, she responded to her vision of providing total care (practical, emotional, social and spiritual care) for the dying by offering palliative and bereavement care through St Christopher's Hospice.

On the day of my tour to St Christopher's our group was blessed to meet Dr Mary Baines, herself a doctor who undertook medical training alongside Dame Cicely and at her encouragement became a hospice physician. Dr Mary, who she is fondly known as, shared her most intimate memories of Dame Cicely and continues to volunteer at St Christopher's regularly.

What struck me most about this hospice was the light, colour and laughter that greets you on arrival. The main entrance leads directly into the Anniversary Room, a lounge/dining room whereby those receiving care, their families and friends, and anyone in the community is invited to share a meal, a cuppa and participate in activities. The hallways are adorned with the art of professional artists, those accessing care, school children and others. Care is intentionally person centred and those referred for hospice care are encouraged to complete a 'one-page profile' sharing who they are beyond that of person with a life-limiting condition.

St Christopher's extends care into the community through hospice care at home, and also offers a complementary therapies program, creative art therapies, spiritual care and a young adults group. Bereavement care is intertwined with the hospice program acknowledging the symbiosis between life, death, loss and bereavement. I was very grateful to spend time with Isobel Bremner who leads the Candle Child Bereavement Service. Again, I was so affirmed to hear Isobel share her thoughts around the very best care for bereaved children being that care they receive from their parents and trusted others in their community. Most organisations I have visited to date share this philosophy of care acknowledging grief and bereavement as a natural, albeit difficult life experience, that simply requires the tender care of loved ones, compassion from their community, connections with those living a similar life experience, and ongoing acknowledgement of their person who has died.

The grounds of St Christopher's are extensive and the ashes of Dame Cicely herself and her husband are interred in the grassy parkland at the rear of the complex. Nearby sits a centre for creative arts and not long before our tour group arrived, local school children had been participating in felt art activities with those receiving care at St Christopher's. You could still feel the light in the building as a result of this activity.

While we toured through a ward we saw a glimpse into the lives of those receiving care. While I suspect there are many moments of fear, sadness, emotional loneliness and sometimes hard to control pain, St Christopher's is a place that does its very best to remain true to the original mission of Dame Cicely, to relieve the suffering of the dying and ensure total care for the dying and their family.

SAUNDERTON, UNITED KINGDOM

This week I escaped the busyness of London and visited Child Bereavement UK, (CBUK) a national charity whose head office is based in Saunderton, Buckinghamshire, in a beautiful old building now named the Clare Charity Centre.

CHILD BEREAVEMENT UK

Next year CBUK mark their 25th anniversary and over time have evolved their services in response to the changing needs of the bereaved population they serve. Their remit is care of those whose life has been touched by the death of a child. Examples of care include anticipatory grief support for children of parents with a life limiting condition, parents of multiple failed IVF attempts, parents of children of any age who have died, and children and young people (up to 25 years) who have experienced the death of someone close to them.

The mission of CBUK is to provide support, psycho-education, information and signposting to local services. CBUK is very clear that they do not provide counselling support, acknowledging grief as a natural life experience and not one that necessarily requires a therapeutic response. Support can be accessed via a national Helpline (Freecall phone service and email support 9am-5pm Monday-Friday), booked Phone Support, face to face individual, couple or family support in one of the eight regional offices scattered throughout the UK. The variety of connection points means anyone throughout the UK, no matter where they live, can access support of some kind.

CBUK has an excellent website and hub of information which contains information on accessing guidance and support, information and resources (some published by CBUK and others recommended by the organisation) and a training calendar. Each year CBUK undertakes a service mapping exercise to identify bereavement services throughout the UK, allowing service users and professionals access to up to date information in their locality directly from their website.

Training for professionals is a core feature of the remit of CBUK with approximately 1000 professionals accessing training in bereavement care each year. An annual training and conference calendar is presented on the CBUK website and a range of professionals attend including health care professionals, teachers, counsellors and many more. Targeted training is provided to a range of groups including The Royal College of General Practitioners. Bespoke training is also provided when required. Training is provided in a variety of locations throughout the UK. Online training has also been developed for the Royal College of Midwives and educators in schools. While CBUK employs training professionals directly they also recruit consultants with specialist bereavement skills and in a variety of locations throughout the UK.

CAMBRIDGE, UNITED KINGDOM

I based myself in Cambridge for my visit to East Anglia Children's Hospice (EACH). EACH is a network of three sites in East Anglia: Milton (Cambridge), Quidenham (Norwich) and The Treehouse (Ipswich). Over the course of my two day visit I spent time meeting members of the Well Being team at the Milton and Quidenham Hospice sites, the Bereavement Coordinator's in PICU at Addenbrookes Hospital and NICU at Rosie's Hospital, and a counsellor from a community-based child health team. The breadth of roles, sites and conversations meant I was able to understand at a deeper level how children, young people and families navigate their way through the government and non-government health systems throughout the palliative care trajectory and in bereavement.

EAST ANGLIA CHILDREN'S HOSPICE

East Anglia Children's Hospices support families and care for children with life-threatening conditions across Cambridgeshire, Essex, Norfolk and Suffolk in the UK. Care can be accessed at one of the three EACH hospices (Ipswich, Milton and Quidenham) or in the family's home.

EACH has a strong history in the hospice sector and over time continues to review service provision as a way of ensuring a contemporary response to the care of children and families who access EACH services. One of the most significant changes in the last four years has been the review of the Family Support Team now termed Family Well-Being team. With this change came a drive to ensure family well-being was integrated at every level of the organisation rather than being the sole responsibility of the 'well-being' team and psycho-social staff. The team is now comprised of counsellors, a family therapist, art therapists and music therapists.

With the service redesign four core principles emerged:

- Needs lead
- Outcomes focused
- Resilience focused
- Preventing escalation
- Empowering families

However, over the course of the last year a growing question for the service became 'how do we know what we're doing is keeping true to these principles and really meeting the needs of families?' EACH like many health care organisations offers service within a person centred model of care; however what this looked like in practice became a focus. Once a culture of 'saying yes' the well-being team was challenged to start having conversations in different ways acknowledging that offering care and support as a first option may be in fact be disempowering for families. Could it be more empowering to be asking questions such as 'what is the change you are looking for?' and 'what might make a difference toward that change?' In the past the default response had been directing family members toward counselling and a therapeutic response.

The Family Well Being team developed a six-step process when working with families to slow down the conversation and explore alternative options (as opposed to a traditional therapeutic response). This alternative way of doing things was based on the UK model of 'co-constructing with service users' a model of working with service users for shared decision making. Adjusting to a change in working can be challenging for staff particularly for those staff traditionally drawn to a therapeutic response. Further, as with many hospices, nurses make up the greater proportion of staff with many expressing an uncomfortableness sitting in a deeply emotional space with a family and feeling the need to respond through a task oriented lens (e.g. Refer to counselling).

The well-being team spent a year working together to develop and test a targeted family intervention and assessment process. Sixteen themes and educational components of the process were drawn from the MindEd Learning Portal.

On referral to the well-being team, assessment became a six-step process:

1. Exploring the referral – who has been referred and why/why now?
2. Meeting with the relevant people – widening out the conversation to the broader family network (e.g. Schools, teachers)
3. Pulling the ‘formulation’ together – one page based on the Four P’s (predisposing factors, what is it precipitating, what’s perpetuating or maintaining, protective factors). The goal of this process is to normalise the experience and empower families to consider possible alternatives.
4. What do we do now – widening out to possible solutions
5. Who is best placed to become involved – looking beyond EACH into the family’s existing support networks and other community-based options.
6. A written copy of this dynamic conversation provided to the family.

Over the course of the year, team members noted that nine of the fourteen families who worked through this new process arrived at step 4 and created their own solutions drawing on their informal and formal support networks. In the past, these nine families would have been directed to a therapeutic response in the first instance.

This new model of care is also based on the principle that the three main predictors of well-being are sleep, nutrition and exercise. Identifying these needs as the foundation of the referral and developing a targeted response often meant the referral for counselling became irrelevant.

Another important issue raised by EACH staff was the perceived absence of normalising the experience of trauma for families accessing care from an EACH service. This is an emerging theme in the paediatric palliative care and bereavement literature in relation to witnessing suffering through a child’s chronic/life limiting or trauma experience. Members of the well-being team are integrating conversations around the experience and impact of trauma for family members, normalising and providing psycho-education.

In my conversations with members of the EACH Well Being team I could hear their desire to embed family well-being services within a stronger evidence base. In March 2018 Professor Jane Coad of Coventry University was commissioned to undertake a literature review on the experience of parents of children with a life limiting condition. This included their

experience of suffering anxiety, depression and trauma to understand how literature can be transferred from cross-disciplines to support a stronger evidence base for best practice at EACH. The Well-Being team anticipate using the findings from this review to strengthen their model of care.

ADENBROOKES CHILDREN'S HOSPITAL AND THE ROSIE HOSPITAL

I was very grateful to meet with the PICU Bereavement Coordinator (Addenbrookes) and NICU Bereavement Coordinator (The Rosie Hospital) who immediately affirmed similarities in opportunities and challenges of care of bereaved families whose infant or child had been cared for in the medical setting. For the second time on my travels I heard a hospital-based bereavement coordinator role being established in response to the complaint from a parent who expected, but didn't receive, transitional bereavement care following the death of her baby.

Adenbrookes PICU service now offers standardised follow up bereavement care. The service offerings mirror that of many other hospitals I visited.

Universal bereavement follow-up protocol and resources		
Timing	Intervention	Role
Phone calls		
Pre-funeral	Phone call	Bereavement Coordinator
4-6 weeks	Phone call and letter	Bereavement Coordinator
Mailings		
	Flowers and condolence card	Bereavement Coordinator
Services		
	Face to face and telephone counselling support	Bereavement Service
	Invitation for a return visit to the hospital/treating team and/or sharing of coroner's findings	Bereavement Service
Events		
Annually	Memorial Service	Bereavement Service
Resources		

	Framed hand and footprint moulds (infants less than 18mths)	
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A novel service feature at Adenbrookes has been the integration of bereavement link nurses on each hospital ward. These staff members maintain links between the ward and bereavement service and manage the bereavement/when a child dies folder on each ward.

The Rosie Hospital offers dedicated bereavement care to families via a clinical psychologist based in the neonatal intensive care unit. End of life and bereavement care pathways were reviewed following a complaint from a bereaved parent regarding a perceived lack of support following the death of an infant. A universal model of care now offers a similar bereavement follow up protocol as that at ACH. Additional features are pre-brief and debrief opportunities for staff involved in care of a dying or deceased infant. Each month Rosie's offers a candle light drop in service held in the hospital chapel. This is a 20 minute service run by the chaplaincy service and available for any staff member to attend.

LIVERPOOL, UNITED KINGDOM

I completed my visits in the UK in Liverpool, home of Alder Hey Children's Hospital and importantly, the Alder Centre. I am most grateful to Shelagh Hatton, Manager of The Alder Centre and Co-Manager of the Child Death Helpline for taking the time to meet me and share the enormous commitment Alder Hey has provided toward the care of bereaved families.

ALDER HEY CHILDREN'S HOSPITAL

The Bereavement Care Centre at Alder Hey Children's Hospital provides a unique and responsive continuum of care for bereaved family members and staff from the point of a child's death, the immediate aftermath of the death and onward throughout the transition into bereavement. An immediate response to child death is provided via the Bereavement Care Team (see below). The Alder centre (see below) offers care and education for family members (parents, siblings) whose child/sibling (0-25years) has died, anywhere (the only prohibiting factor is distance the family wishes to travel) for as long into the future as required by the family.

The Alder Centre was formed around thirty-two years ago by a group of parents whose children had died at Alder Hey and reported their concerns regarding the quality of post-

death and bereavement care. Bereaved parents and staff came together to advocate for improving the hospital's response to the care of bereaved families. The centre was founded originally with a helpline (see Child Death Helpline) which grew to become a hub and counselling centre for bereavement care. The Alder Centre is a novel model of transitional bereavement care in that it provides in-reach to the hospital (via the Bereavement Care Team) and outreach to the community. Approximately 40% of referrals to the Alder Centre come from families whose child was cared for at Alder Hey with the remaining 60% of referrals coming from the community beyond Alder Hey.

Bereavement Care became a corporate responsibility at Alder Hey following the release of the Redfern Report (The Royal Liverpool Children's Inquiry Report, 30 January 2001). While this report goes beyond the remit of this research, the report introduced the concept and functions of a bereavement counsellor in the NHS paediatric hospital system. The NHS funds salaries for sixteen employees in the Bereavement Care Centre which include:

- 1 FTE – Coordinator of the Alder Centre
- 1 FTE – Bereavement Care Team Leader (includes two days counselling appointment at the Alder Centre)
- 7 counsellors – part time positions
- 7 bereavement care support workers – part time positions
- 1 administration coordinator – part time position
- 1 volunteer coordinator – part time position

The centre also relies on the support of bereaved parent volunteers who man reception and meet and greet family members on arrival.

Expenses for resources for the centre and running costs for the Child Death Helpline are supported through charitable funds managed by the Alder Hey Charity. These funds are 'ring fenced' and can only be used for support of bereaved families. A high proportion of charitable funds are raised by bereaved parents seeking to leave a legacy for their deceased child and/or support other bereaved families into the future.

Bereavement Care Team

The Bereavement Care Team is based in the Alder Centre and provides a first response on-call in reach service to Alder Hey Children's Hospital for child death 24hours a day, seven days per week. This level of access to a member of the bereavement service provides reassurance to staff hospital wide. Seven staff members are employed into the service in a part time capacity, acknowledging the emotional burden of undertaking this work in a full-time capacity. Team members rotate through a once per week evening/overnight on call system. Each team member also takes responsibility for a broader range of service related aspects such as education and training, keeping resources up to date.

The 'pick up point' for families differs according to the nature of the death. When a child dies at Alder Hey a member of the team will be called. The Bereavement Care Team also supports families whose child is transferred to Alder Hey for post-mortem. Families are required to consent to the service and while a family rarely declines, each engages with the service at their own level. Most often a member of the team meets the family on the ward the child was cared for. It is the responsibility of this team to transfer the child to one of two dedicated bereavement suites situated with direct access to an outdoors bereavement garden and dedicated parking. Transfer occurs with respect to the pace the family is ready to work through at this time. All deceased children at Alder Hey leave the hospital via the Bereavement Care Suites.

The Bereavement Care Suites were purpose built in the new hospital development. Each suite is identical and offers a bedroom for the infant/child to be rested and separate lounge room for family members. Kitchen and bathroom facilities are incorporated within each suite. Importantly, each suite has an external entry (inward to a hospital corridor) for a direct link to the mortuary. This entry is curtained for the comfort of family members.

A careful procedure is worked through at the pace of the family with siblings actively encouraged to be part of this process. An information pack is provided to the family which offers contact details for the bereavement care team member. Families are encouraged to contact the team member at any time of the day/evening when the child is in the care of Alder Hey. This usually extends to four to five days. The aim of this service is to ensure the families leave knowing their child is safe, well cared for and the family have direct access to dedicated support and information.

Other responsibilities of the bereavement care team involve memory making (photography, hand/footprints) supporting the family through registration of the child's death, visiting their child daily while in the care of Alder Hey, assist family communication with funeral directors. Cultural requirements are facilitated by the team particularly in the case of expediting discharge of a deceased child for a Moslem funeral. The spiritual care department and team are available to conduct baptisms, blessings and mini funerals.

Once the child leaves the care of Alder Hey the bereavement care team member usually contacts the family after the child's funeral. In principle team members do not attend funerals given the sole remit of their role is supporting families through child death. Emotional and practical support is offered to families for up to eight weeks. Both the Bereavement Care Team and Alder Centre work on the principle that at least six months

should pass without inviting a bereaved parent into a therapeutic relationship, thus allowing grief to take its natural course.

Bereavement Care Team members are also involved in education on child death, loss, grief and bereavement within Alder Hey and the community (e.g. Schools).

The Alder Centre 'offers care and education for anyone affected by the death of a child'

The Alder Centre sits adjacent to Alder Hey in the 'old hospital'. This is a large centre with five counselling rooms, a large welcome/reception area, administrative and office space.

The current model of service delivery includes:

- **Counselling:** to anyone affected by the death of a child no matter where the death occurred. Counselling can be provided on a one-to-one basis, as a couple or within a group context.
- **Specialist support for bereaved siblings:** within the family unit, with other children or on a one-to-one basis
- This same range of supports is offered to those parents affected by the death of an adult child
- **Resources for parents, schools and other professionals**
- **Befriending:** recognising that not all those bereaved will want, or benefit from, professional interventions, trained bereaved parent volunteers are available for a befriending arrangement. Meetings are organised by the volunteer coordinator and take place at the Alder Centre.
- **Therapeutic breaks:** annual weekend breaks where families, individual parents, adults and children meet with others who are bereaved. The therapeutic family breaks are supported by trained Alder Centre Volunteer Befriends and paid for from the Alder Centre's fund-raising activities.
- **Telephone Helpline:** run in conjunction with GOSH the Child Death Helpline is a freephone service for all those affected by the death of a child of any age.
- **Light up a Life Service:** annual service that takes place in the Christmas period in memory of a deceased loved one.
- **Cathedral Candle Service:** a non-denominational service of remembrance for children
- **Book of Remembrance:** families may request to have an inscription included to honour and remember their child. The book is available at any time throughout the year for families to access.

Training and Education

The Alder Centre offers a range of training and education opportunities for staff of Alder Hey and extends these offerings to the broader community.

Two thirty hour courses accredited by Open Awards

- Understanding and using basic counselling and effective communication skills
- Understanding and working with child loss and bereavement in counselling and helping relationships

Support for Alder Hey staff

- In house counselling around work and non-work-related issues (no charge)

Clinical Supervision

- For professionals from a broad range of disciplines within and outside the Trust.

Volunteers

Volunteers are welcomed via a number of programs including:

- Child Death Helpline: volunteers must be bereaved parents whose child died at least three years ago
- Befrienders: people who have experienced the death of a child who have undertaken training and supervision
- Welcomers and Reception Support: may or may not have experienced the death of a child
- Fundraising: funds raised by any volunteer (bereaved or non-bereaved)

Evaluation

Shelagh Hatton described evaluation as an important yet challenging aspect of the service. Group programs incorporate service user evaluation. However, Shelagh described evaluation of the bereavement service as difficult 'how can you say it's your input that's made a difference given the dynamic psychosocial background of the client/family?' Shelagh's vision is developing a model of longitudinal research to measure changes in people as they move through their bereavement experience, particularly in relation to the experience of child death.

Redevelopment

The most exciting aspect of the Alder Centre is the new building which is pending and will be the first bespoke bereavement care centre to be built in the NHS. Design of the centre was informed by a conversational process with centre staff, users and bereaved parents. The final design incorporates a series of seven counselling rooms with a large communal space

in the centre ‘the heart’ with a lounge and kitchen. A flexible training room, office and dedicated room for the Child Death Helpline completes the design.

Shelagh describes practice wisdom informing her response to the new design. While the current Alder Centre is based on a model of counselling support, Shelagh suggests that what they have found is that more commonly bereaved families are wanting support from other bereaved families. Given this, the design focused on developing a building in the form of a ‘residential home’ with the heart space being a place people can gather, drop in and engage in the support of others living a similar life experience. The surrounding gardens allow access for solitude and solace in the natural environment. Each counselling room faces the gardens. This is an exciting time for the Alder Centre and the NHS and I look forward to hearing the impact of this model on families and staff alike.

The commitment to bereavement care is driven by Alder Hey and funded through the NHS and The Alder Hey Children’s Charity. I was so impressed that a children’s hospital has acknowledged child death as a devastating yet possible outcome and responded in such a visible and financially viable way. This really is best practice transitional bereavement care and Alder Hey and The Alder Centre truly leads the way in what can be possible if a health system acknowledges bereavement care as core to service delivery.

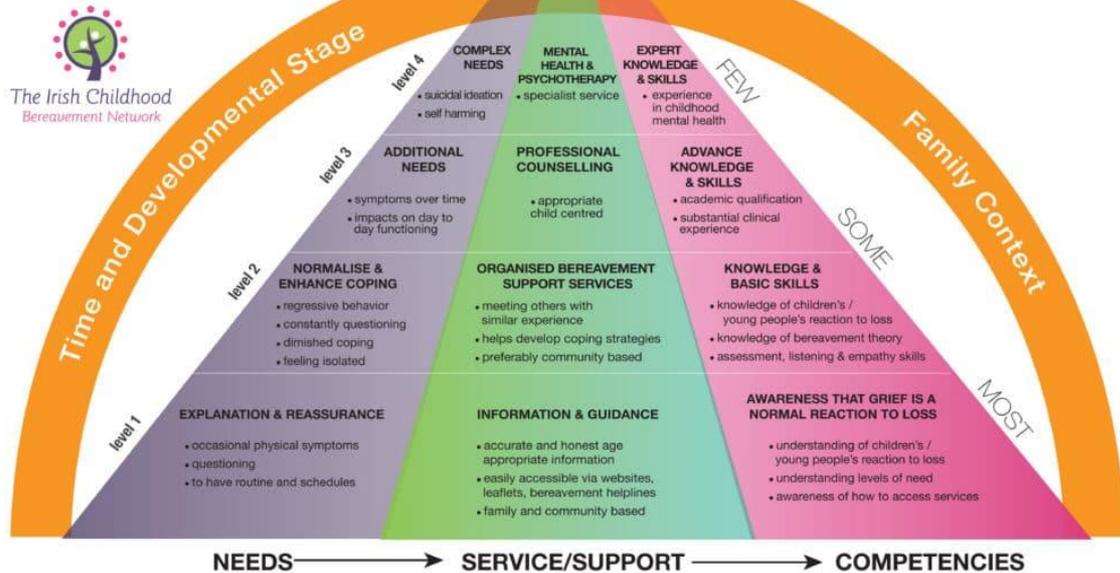
DUBLIN, IRELAND

I completed my formal study tour in Dublin meeting Maura Keating who leads the Irish Child Bereavement Network (ICBN).

IRISH CHILD BEREAVEMENT NETWORK

The ICBN sits under the auspice of The Irish Hospice Foundation in a beautiful old building in Nassau Street, Dublin. I was drawn to meet with Maura after discovering the work the ICBN had developed on the Irish Child Bereavement Care Pyramid. The pyramid was created as a guide for professionals and concerned adults in identifying and responding to the needs of children and young people who have experienced a loss. Maura shared the background to development of the pyramid and confirmed the ICBN is happy for this tool to be used in other countries on the assumption the tool is referenced to ICBN.

The Irish Childhood Bereavement Care Pyramid



www.childhoodbereavement.ie/pyramid

Review Date/ October 2015 

Sourced from: www.childhoodbereavement.ie/professionals/

Since the launch of the pyramid, Maura has been working with a diverse consultative group on development of the *Standards for Supporting Bereaved Children and Young People*. This document will guide the work of adults, professionals, volunteer organisations and policy makers who are concerned about bereaved children. The standards will have a number of functions:

1. To promote public and professional understanding of the impact of bereavement on children and the role of adults in bereaved children's lives;
2. To ensure that family and community are seen as having a key role in the support of bereaved children;
3. To act as an improvement framework for those working with bereaved children and their families;
4. To promote the concept that any services provided to bereaved children adhere to the highest standards when evaluated against the standards that have been set out;
5. To set out the role for policy makers locally and nationally to ensure that appropriate support is provided to children who are bereaved;
6. To act as a preventative mental health approach for bereaved children to reduce the likelihood of future mental health problems;
7. To underpin education and training at public, volunteer and professional levels.

A few themes arose from my conversation with Maura. First, I heard once again the drive to acknowledge child bereavement as a universal experience in the first instance. Given this, the ICBN plays a key role in delivering education around loss, grief and bereavement for children to those most connected to children including for example child care centres, schools, paediatricians. Maura spoke of community capacity building and the vision of ICBN to build confidence and capacity in all sectors around how best to care for a child following a death of someone close to them.

Finally, Maura left me with some sage advice based on her experience of working toward social change. Hasten slowly. While excited to return to Australia with so many novel ideas around how we can enhance the way we care for families following the death of a child, the foundation to change must be strong, evidence based, and championed by the right people at the right time.

CONCLUSION

The main aim of my Churchill Fellowship was to identify best practice transitional hospital bereavement care following the death of a child. To do this I created a schedule of visits that incorporated visits to bereavement care programs in children's hospitals and in the community. I was keen to understand:

1. How hospitals respond to the transitional care of families following the death of a child, and
2. How families identify and navigate their way into services in the community sector.

An overarching theme on my travels was lack of human resources as the greatest barrier to coordinated bereavement care. Children's hospitals are traditionally established on a curative medical model. Acknowledging child death in an environment which seeks to promote healing and improved health is difficult. For many children's hospitals, getting death and dying on the agenda is the first barrier to offering formal and coordinated bereavement care.

The logistics of funding bereavement care service provision is a challenge world-wide. Contemporary health funding models are often based on Activity Based Funding whereby the patient service is costed against the diagnosis-related group (DRG). Activity cannot be attributed to a deceased patient and consequently staff in funded bereavement care positions is most often funded through the operational budget or charitable funds.

Those hospitals who demonstrate best practice bereavement care programs often share a history of being established as a result of complaints from parents who had an expectation that they would receive transitional bereavement care following the death of their child.

While bereavement care may initially extend from a hospital-based service, the ultimate goal is to ensure families have access to formal and informal networks in their local community. I was privileged to visit a number of incredibly robust community-based bereavement services that offer a variety of professional and peer-based services. However, a consistent theme on my travels was how to ensure access to care for all families who suffer the death of a child. One colleague used the term 'black hole' of support whereby families only have access to care dependent on where they live.

Ensuring all bereaved families have access to care following the death of a child in Australia requires collaboration between the hospital and community-based sectors and innovative service design. I look forward to drawing on the findings and recommendations of this report and working in collaboration with service providers and bereaved families to develop a system whereby all bereaved families access the guidance, care and support they need at the right place, at the right time.

RECOMMENDATIONS

1. Develop Australian standards and guidelines

To date paediatric hospital bereavement care in Australia is not driven by a comprehensive and evidence-based set of standards or guidelines. This is a critical next step in ensuring standardised and informed care is available for all bereaved families.

2. Develop a preventative model of care

Contemporary bereavement care practices acknowledge the positive impact anticipatory grief support can have for an individual and/or family's bereavement experience. This report incorporated a wealth of information on the provision of paediatric palliative care, legacy making and memory making as critical components in high acuity paediatric hospital units.

3. Establish dedicated bereavement coordinator roles in paediatric hospitals

One of the risks identified in this report is the delivery of ad hoc bereavement care within paediatric hospitals. Dedicated bereavement coordinators allow for the delivery of a universal protocol for all families whose child has died within each hospital setting. Establishing such roles is dependent on a redistribution of health funds following the death of a child.

4. Deliver an innovative and accessible menu of care

Coordination of care must address the various ways the bereaved experience grief and seek support. Importantly, while care may be coordinated centrally from a tertiary hospital, program elements must take into consideration the geographical and logistical barriers parents and other family members experience in accessing support in their local community.

5. Integrate capacity building in program design

While this report recommends funding for dedicated bereavement care specialists, equally it is critical that hospital staff and formal and informal care providers in the community have access to education on contemporary theoretical models of loss, grief and bereavement. Further, exposure to the lived experience of bereaved family members (parents, siblings, grandparents etc) will enhance the knowledge and confidence of all care providers.

6. Involve bereaved parents in service design and delivery

Contemporary theoretical models of grief and bereavement acknowledge the power of meaning making in bereavement. For bereaved parents, this often takes the form of advocacy, education, participation in research, service design and delivery. Opportunities must be available for bereaved parents to participate in each of these aspects of a bereavement care program.

7. Support and care for staff

Staff companioning the dying and bereaved need to be acknowledged and supported. A program of staff care should involve education (as noted in Recommendation 5), supervision and reflective conversations, and opportunities for memorialising deceased patients and their families.

8. Enhance existing national and international networks

To ensure future sustainability of the sector, specialist networks in the context of paediatric bereavement care should be established in Australia and extended to the international context.

DISSEMINATION AND NEXT STEPS

This report consolidates international benchmarking of bereavement care services from a hospital, hospice and community-based perspective. The report will be disseminated broadly with service providers, funders, policy makers and relevant peak bodies in Australia. I also anticipate this report making a contribution from an international perspective through dissemination with colleagues I visited in the USA, Canada, UK, Ireland and South Africa. Specifically, findings and recommendations in this report have been or will be disseminated via the following forums:

- **International Children's Palliative Care Network Conference, Durban, South Africa 2018.** I attended the ICPCN conference in Durban at the close of my Churchill Fellowship tour. I was fortunate to have an opportunity to share a summary of learnings and recommendations through a previously accepted oral presentation.
- **Children's Health Queensland.** I am grateful for the invitation to share the experience and recommendations of this Churchill Fellowship in a range of education forums through Children's Health Queensland Hospital and Health Service.
- **Annual Paediatric Palliative Care Symposium Westmead.** I am an invited speaker at the 15th annual Paediatric Palliative Care Symposium Westmead. This is an annual forum of delegates from the paediatric palliative care and bereavement care sectors in Australia.
- **Working group for development of the Australian Association of Social Workers (AASW) standards for palliative care social workers.** I have recently been elected as a member of this working group and will draw on the findings and recommendations of this report to inform development of standards that incorporate a paediatric lens.
- **Development, delivery and evaluation of peer mentor program.** I am actively pursuing funding opportunities to develop and evaluate a national peer mentor program for parents of children with a LLC and bereaved parents. I would like to acknowledge St Jude Children's Research Hospital, Memphis, for making this training manual available for adaptation into the Australian context.