

January 2011



"Paige lived for seven months because of SickKids, and that's a miracle. But the experience of her death could, and should have been, as miraculous. She could have died at six or eight weeks, and she came close to death many times over the next five months. We were blessed with seven months of memories of our daughter, and that's because of this hospital and the world-class staff and patient care. But, as an institution, you can't be world-class at everything, except death and dying."

Malcolm Berry, December 2008

Malcolm & Laura Berry's daughter, Paige Berry, died at SickKids after a lengthy battle with Hemophagocytic Lymphohistiocytosis.

Report of the Bereavement Care Task Force

Executive Summary



January 2011

A review of bereavement care at SickKids was initiated in 2009 with the creation of the Bereavement Task Force. The aim of the review has been to conduct a thorough examination of current bereavement practices at the hospital, to undertake an external survey of best practices in bereavement care, and to make recommendations for enhancements to existing practices where appropriate.

This report details key findings of the Task Force, including existing best practices and areas where enhancements will result in improved patient and family care outcomes. Recommendations put forward in the report are informed by the findings of the review. They seek to address some of the identified gaps and to ensure that the standard of bereavement care is consistent across the hospital and with best practices.

The review undertaken by the Bereavement Care Task Force included a comprehensive examination of existing practices and resources at the hospital, as well as an external survey of best practices and a literature review. Staff from across the hospital and across disciplines were interviewed, including: 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. Staff were interviewed about current bereavement practices, standards, policies, and protocols.

Staff were also asked to identify families who had experienced the death of a child to be interviewed. Ten families from varying programs and clinical areas across the hospital were interviewed. Six of the interviews were conducted in person; four were conducted by telephone. All of the families interviewed had experienced the death of a child within the past three years, and the ages of the children at time of death ranged from three weeks to 16 years. The families came from diverse backgrounds, and one family required interpreter services to complete the interview. Families were asked to share their experience of bereavement care at the hospital. The interviews were guided by pre-established questions and prompts.

This report describes the work and findings of the Bereavement Care Task Force with regard to the current state of bereavement care at SickKids, as well as current thinking and evidence on bereavement care best practices. Both the strengths and gaps, with respect to the bereavement care being provided at the hospital, have been investigated and documented. The report recognizes that families value many of the existing bereavement practices, such as legacy creation, follow-up, active support, and timely and compassionate communication. It also indicates that there are considerable and problematic inconsistencies in the quality of bereavement care being provided to children and families. Additionally, other insights, such as the need for support for staff who are impacted when a child dies, have surfaced as a result of the work.

Based on these findings, the report offers a number of recommendations that seek to build on successes and strengths, while addressing identified gaps and inconsistencies. Where possible, the Task Force has already begun implementing recommendations, such as building closer working relationship with the Coroner's Office. A key recommendation of the Task Force is the creation of a hospital-wide, comprehensive bereavement program. The Task Force members are committed to continue working with stakeholders and partners within and outside of the hospital to develop and promote best practices in bereavement care at SickKids and beyond.

Recommendations

The interviews with staff and families, as well as the literature review, revealed both strengths and gaps in terms of existing bereavement care practices at SickKids. Based on the data gathered, the Task Force has put forward recommendations that address a number of areas, including: enhancements to staff education and resources in the area of bereavement care; the need to challenge existing beliefs and attitudes about death as a care outcome and the potential for a dignified death to support a positive bereavement process; and the development of policies and procedures where needed to ensure consistency of bereavement care across the hospital.

1. Develop a strategy to ensure consistent bereavement care is delivered at all times, in all settings.

- a. Integrate existing policies into one comprehensive guideline, while making explicit those parts of the guideline that are legislated and/or mandated aspects of care (i.e., Coroner's cases).
- b. Implement and evaluate a triage model to identify families at high risk for post-traumatic stress following the death of a child.
- c. Develop a system for staff to refer families who require support following the death of their child (i.e., a bereavement clinic).
- d. Develop, implement and evaluate bereavement care plans for every family whose child has died.
- e. Ensure the utilization of interpreter services for families with limited English proficiency who experience the death of their child.

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.

- a. Centralize all present and future hospital bereavement resources under the leadership of one director to ensure consistent bereavement care throughout the organization.
- b. Ensure this program is responsible for the implementation and evaluation of all recommendations put forth by the Task Force.
- c. This program is to assume accountability for implementing best practice guidelines throughout the hospital.
- d. The Bereavement Task Force is to be reconstituted to become an advisory to the Bereavement Program.
- e. Utilize TRAC-PG (Team for Research in Adolescence and Children in Palliation and Grief) as an overseeing body for research development and implementation in the area of palliative and bereavement care.
- f. Integrate bereavement work with other hospital initiatives, such as the New Immigrant Support Network (NISN) and interprofessional practice initiatives.
- g. Examination of the bereavement experiences of families from diverse cultural and religious backgrounds is to be considered a priority for further research.

3. Develop new resources to promote best practices in bereavement care including bereavement care across cultures, such as:

- a. A parent information package.
- b. Parent-to-parent support program.
- c. A bereavement website that indicates available internal and external (provincial, national and international) support and resources.
- d. A mechanism through which staff may continue to stay apprised of current literature and evidence-influenced practice.

4. Link with available community resources to optimize their use, foster existing relationships, and create opportunities to develop new partnerships.

- a. Work specifically with the Coroner's Office to improve relationships and care.
- b. Work to develop relationships with appropriate external agencies (e.g., hospices, Bereaved Families of Ontario).
- c. Work with external agencies with which SickKids is already engaged to make bereavement care a priority in our continued work and collaboration.

5. Provide education about the principles of grief, death, dying and bereavement to all hospital personnel and, where possible, to community partners.

- a. Utilize a tiered approach to education that tailors content to various roles and responsibilities.
- b. Revise Mock Codes to incorporate after death care, resiliency training/education, and incident debriefing.
- c. Develop a hospital-wide support program for staff who work in units/areas which experience a high number of deaths.

6. Implement a standardized follow-up process after the death of a child.

- a. Create guidelines that support staff in setting boundaries around continued involvement and contact with bereaved families.

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:

- a. Through the implementation of hospital-wide memorial services.
- b. Through considering the creation of a recognition wall for the children who have died.

9. Implement facility upgrades to the hospital's morgue and quiet room.

10. Finalize and approve the draft paper: *The Hospital For Sick Children Bereavement Care: An Interdisciplinary Framework for Practice*.

11. Create a model of care that accurately conceptualizes the Task Force's vision for quality paediatric bereavement care that is individualized, family-centred and evidence-based.

Bereavement Care Review Task Force Members: Margaret Keatings (Executive Sponsor), Jackie Hubbert (Project Manager), Mayola Matthew, Maru Barrera, Marie Pinard, Chris Newman, Pam Hubley, Adam Rapoport, Trisha Sutton, Maria Rugg, Ted McNeill, Stephanie Lappan-Gracon, David Brownstone, Susan Cromwell, Michael Marshall, Karima Karmali, Catherine Fenton, and Mitchel Blum.

Organizational Commitment

SickKids is internationally recognized as a leader in paediatric health care. Guided by its core values—innovation, excellence, collaboration and integrity—SickKids is committed to: providing the best in complex and specialized health care for children; creating ground breaking scientific and clinical advancements; sharing our knowledge and expertise worldwide; and championing the development of an accessible, comprehensive and sustainable child health-care system.

SickKids is also known for pushing the boundaries of what is believed to be possible when it comes to saving young lives, or enhancing the quality of life for ill or injured children. For some children and families, the illness or injury is terminal, and enhancing the quality of life that remains is accomplished through providing the best possible palliative care, which includes bereavement care. In some instances, such as sudden, unanticipated death and/or failure to rescue, there is no opportunity to provide palliative care and hospital staff provide only bereavement care. Regardless of whether the death is anticipated or sudden, bereavement care provided to the child, family and loved ones must be of the same standard of excellence as other forms of care provided at SickKids and based on the best available evidence.

Review Objectives

A review of bereavement care at SickKids was initiated in 2009 with the creation of the Bereavement Task Force. The aim of the review has been to conduct a thorough examination of current bereavement practices at the hospital, to undertake an external survey of best practices in bereavement care, and to make recommendations for enhancements to existing practices where appropriate.

This report details key findings of the Task Force, including existing best practices and areas where enhancements will result in improved patient and family care outcomes. Recommendations put forward in the report are informed by the findings of the review. They seek to address some of the identified gaps and to ensure that the standard of bereavement care is consistent across the hospital and with best practices.

Methodology

The review undertaken by the Bereavement Care Task Force included a comprehensive examination of existing practices and resources at the hospital, as well as an external survey of best practices and a literature review. Staff from across the hospital and across disciplines were interviewed, including: 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. Staff were interviewed about current bereavement practices, standards, policies, and protocols.

Staff were also asked to identify families who had experienced the death of a child to be interviewed. Ten families from varying programs and clinical areas across the hospital were interviewed. Six of the interviews were conducted in person; four were conducted by telephone. All of the families interviewed had experienced the death of a child within the past three years, and the ages of the children at time of death ranged from three weeks to 16 years. The families came from diverse backgrounds, and one family required interpreter services to complete the interview. Families were asked to share their experience of bereavement care at the hospital. The interviews were guided by pre-established questions and prompts. (For interview template, see Appendix 2)

The Bereavement Care Task Force acknowledges that providing quality paediatric bereavement care that is individualized and family-centred is achieved by:

- Respecting and honouring the meaning families attach to the concept of ‘family.’
- Identifying each individual family’s needs, hopes, fears, as well as their expectations and ability to cope.
- Applying knowledge of the physical, psychological, social, educational and spiritual levels of childhood development as required.
- Recognizing the unique personal, religious and spiritual values and beliefs of the family.
- Consulting regularly with the family to develop, implement, evaluate, and document a plan of bereavement care.
- Ensuring consensus about the overall goals of bereavement care and the desirability of specific interventions as the child is dying and/or has died.
- Upholding the principles of quality care by maintaining the family’s right to confidentiality and privacy.
- Providing ongoing educational, spiritual, psychological and emotional support appropriate to the needs and circumstances of the family.
- Supporting one another by creating a milieu in which each person’s own spiritual and religious beliefs and insights related to grief and loss are respected.
- Assisting members of the team, including the family, to acknowledge their own limitations.
- Creating an environment in which the family feels it is safe to express feelings that are often difficult to understand and/or not easily shared.
- Openly acknowledging and discussing the child’s imminent or actual death.
- Helping families to maintain a sense of control and to utilize effective coping strategies by meeting their information needs on all aspects of death and dying.
- Actively supporting families in discussing death and dying with the family’s other children.
- Helping families to plan funeral services, burial ceremonies and/or other culturally appropriate rituals (e.g., creating legacies).
- Referring families to appropriate community agencies and resources that provide bereavement care to parents, siblings, and members of the child’s extended family and circle of friends.
- Ensuring parents have access to information about bereavement services in their own community.
- Ensuring a communication system is in place to facilitate a continuous flow of information among all members of the interdisciplinary care team and the family from the time of death through bereavement.
- Ensuring referrals to experts or providers of specialized services in bereavement care occur in a timely and sensitive manner to assist family members with acute and/or chronic grief reactions.
- Ensuring documentation is accessible to all members of the interdisciplinary team, including the family, that summarizes the events surrounding the child’s death, details about bereavement care and follow-up, i.e., the chart should record the name of the person a family is to contact for the results of an autopsy on their child’s body.

**Adapted from the The Hospital For Sick Children Bereavement Care: An Interdisciplinary Framework for Practice*

The Findings

Literature Review and External Survey

The literature review and external survey affirmed some existing best practices at SickKids, while highlighting areas where improvements could significantly enhance bereavement care practices, as well as patient- and family-care outcomes. The following key elements of effective bereavement care are identified in the literature: (For full literature search, see Appendix 1)

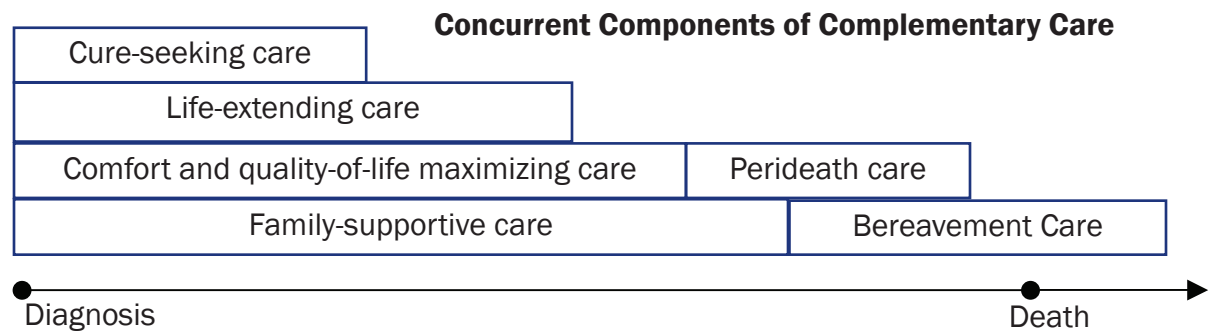
- 1. Effective and compassionate communication:** Parents want to receive information in a timely and compassionate manner, including clarification around circumstances leading to the death of their child. They want to be reassured that everything possible is being done, and that they have made the best possible choices. Families also desire sufficient information to make informed decisions with regard to options, such as organ donation and autopsy.
- 2. Creating meaningful and lasting memories:** Families identify a wish to create memories. These activities may include collecting handprints and footprints, taking photographs, and attending to the unique wishes/rituals of the family and child, such as playing their favourite music and involving siblings.
- 3. Access to support and resources:** All families need support, but each family’s needs are different. Some have their own support networks and resources available to them, others do not. Some families need support and assistance to help coordinate funeral arrangements, support for siblings, translation services (for non-English-speaking families), desired rituals, temporary accommodations, etc.
- 4. Planned follow-up with families:** This is often desired, but not consistently offered. Follow-up activities include letters, phone calls, and hospital memorial services.

Model of Bereavement Care

The literature review and external survey also revealed models of care over the course of life-threatening illness. The model, *Concurrent Components of Complementary Care*, is included in this report because it aligns with some of the key findings and recommendations of the Bereavement Care Task Force. However, the Task Force was unable to find an existing model of care that accurately conceptualized quality paediatric bereavement care that is individualized, family-centred, and evidence-based (see page 1). The Task Force finds the model to have a number of limitations, including the linear depiction of various forms of care.

The model does demonstrates how the principles of palliative care can be blended into a treatment plan aimed at cure. From the time of diagnosis, four arms of treatment begin in parallel: 1) treatment aimed at a cure (if such treatment exists); 2) treatment aimed at prolonging the child’s life; 3) treatment aimed at maximizing and/or maintaining the quality of the child’s life; and 4) education/support of the child’s family.

For children with conditions known to be incurable from the outset, there will be only three arms of treatment. The duration of each arm of treatment will vary with each individual child. As time progresses, it may become clear that a cure is not possible for a child. Life-prolonging treatment may still be continued, in keeping with the family’s goals and the child’s quality of life. With further disease progression, life-prolonging treatment may be stopped. Education and support for the family, at this point, will focus on what is important for the family and child as death approaches. The education and support carries on through the time that the child is dying and into the initial phase of the family’s bereavement.



Source: Carter, B., Levetown, M., *Palliative Care for Infants, Children and Adolescents – A Practical Handbook*. The Johns Hopkins University Press, Baltimore and London, 2004, pg. 6

The Findings

Interviews with Parents

Through the interviews, parents shared poignant stories that revealed the profound impact the death of a child has on the family. The interviews also revealed the value and impact of quality bereavement care. The stories included instances and examples of highly effective and compassionate bereavement care practices. They also highlighted significant inconsistencies in the provision of care and services, as well as ways of communicating that can impact a family's overall experience at the hospital. Four major themes emerged from the interviews: (For a list of the interview questions, see Appendix 2)

- Consistency of Care
- Effective and Compassionate Communication
- Continuity of Care and Follow-up
- Advocacy

Consistency of Care

One parent stated that she “did not get pictures, footprints and lock of hair she was promised” and that she was given “no information on what happens to the baby, how to best deal with continued lactation, how to make funeral arrangements, or about counselling services for parents and siblings.”
Parent Interviews 2009

The parent interviews revealed the need for greater consistency in the provision of bereavement care, and services and that the following services are highly valued:

- Providing support/counselling for siblings.
- Providing relevant information in a timely manner (e.g., community resources, lactation consultation, what to expect if an autopsy is needed or if the Coroner is involved, etc.).
- Assisting with funeral arrangements.
- Follow-up care and communication (e.g., phone calls, cards, check-ins).
- Organizing annual memorial services at the hospital.
- Providing personalized legacy-building services (e.g., molds, hand prints or footprints, photographs, locks of hair).
- Providing appropriate and private accommodation/space for family members.
- Availability of interpreter services.
- Advocacy (e.g., when dealing with Coroner's Office, police services).

Some parents indicated that these services were deeply appreciated, meaningful and positively impacted their overall experience of care at the hospital. Others indicated, however, that many of these services were either not made available to them or were inconsistently provided. Interpreter services, for example, although critically important for non-English speakers, were sometimes not available or not utilized. While some families were grateful for opportunities for legacy creation, others indicated that they did not have access to this service. In at least one case, the service had been offered, but not provided, which resulted in the family missing an important opportunity to create specific memories of their child. There was also suggestion in the interviews that access to these services was less available outside of regular business hours.

While some families indicated that they received the information and assistance they needed in navigating specific processes after their child's death (e.g., funeral arrangements), others indicated that this important aspect of care was lacking. More specifically, information with regard to issues such as organ donation, lactation, funeral arrangements, the morgue or Coroner's Office was needed but not provided. Several participants stated that written information they received was out of date, inaccurate and/or irrelevant to their situation.

Effective & Compassionate Communication

“People made themselves totally available to us. They were constantly explaining things. The nurses did molds, it was such a labour of love. Nothing we asked for was denied. The social worker called the funeral homes for us.” Parent Interviews 2009

Having a child in hospital almost always means that parents feel that they have relinquished some degree of control over their child's well-being. As such, open, honest and regular communication with health-care providers is critically important. For parents who are experiencing the death of their child, that communication must also be respectful and compassionate.

Throughout the interviews, families noted what they viewed to be instances of practice excellence in the area of communication. Families clearly desire comprehensive and empathetic bereavement care, including the use of language and tone that is non-judgmental. Some families, however, referred to instances in which dialogue, communication and the sharing of information were focused primarily on procedure and/or were perceived to be insensitive, given the families' circumstances and emotional state. Some families also expressed concern that they had not been given the information they needed in order to make the best possible decisions with regard to bereavement care. Some parents described instances involving incomplete or insensitive communication on the part of hospital staff and its lasting impact on their grieving and the knowledge that they did all they could for their child.

“We were hurt that no one called us and we felt very alone. We were stuck in Toronto for five days waiting for the cremation and not even so much as a secretary called to check on us.” Parent Interviews 2009

Continuity of Care & Follow-Up

Hospital staff often fulfil a critical role for parents who are experiencing the death of their child. In turn, families may develop close and trusting relationships with those staff. In some cases, the hospital and its staff become inextricably linked to families' memories of their children. Parents expressed a deep appreciation for efforts on the part of hospital staff to follow up and maintain contact. The interviews revealed that parents felt “hurt” and “isolated” when hospital staff did not follow-up with them after their child's death. In some cases, parents identified feeling “abandoned” when transferring from one unit to another, or from one service to another, revealing the depth of attachment that often forms between families and staff.

While some parents indicated that they benefited from resources in the community, they noted that the nature of paediatric bereavement is unique from other experiences of bereavement that are often represented in community groups (e.g., bereavement due to miscarriage or the death of an adult). The unique support needs of families who are not from the GTA were also noted. Participants identified the need for meaningful bereavement support available through the hospital, including the possibility of a support group for parents, as well as siblings.

One of the parents explains that they found dealing with the Coroner and police were very difficult because “you're so overwhelmed that you are not capable of advocating for yourself.” They explain that the tone and language used was upsetting and that they were very concerned that “the hospital allowed the Coroner to speak to them in that way.”

Parent Interviews 2009

Advocacy

Parents clearly look to hospital staff as expert advisors and advocates. Some of the parents reported instances of disrespectful and insensitive communication that involved services within and outside (e.g., Coroner's Office and police) the hospital system. Whether within or outside the hospital system, parents indicated a wish to have the hospital's support in dealing with or challenging such communication.

In all cases, parents expressed feeling “lost” as to “what happens next” following the death of their child. Profound gratitude was expressed with regard to the provision of support and guidance by hospital staff throughout this period. A number of parents stated, however, that they would have benefited from having an advocate or liaison to support them or help “walk them through” processes surrounding the death of their child. Some families indicated that they benefitted from having their own resources and support network available to them, and they expressed concern that other families, particularly those that have fewer resources or are from diverse cultural backgrounds, may need greater support.

The Findings

Environmental Assessment and Staff Interviews

The environmental assessment and interviews with hospital staff occurred early in the review process and revealed significant gaps within and across clinical units and areas. Examination of all the findings can be categorized into four key areas:

- Effective and compassionate communication
- Consistency of care and policy development
- Continuity and follow-up
- Enhancing knowledge

Environmental Assessment Findings

Sixteen areas were assessed for current bereavement practices and resources. The following is a brief summary of findings (for the full report see Appendix 3):

- Five areas identified having a dedicated bereavement coordinator/staff and/or committee.
- Nine described current bereavement practices that are related primarily to legacy building (e.g., providing molds of hands and feet, locks of hair, photographs, ceremonies, CDs or DVDs, etc.).
- Eleven areas identified having resources available, such as written information, physical space (i.e., quiet rooms), staff, complementary therapies (e.g., art, music, therapeutic clowns, and other therapies).
- Ten identified follow-up practices, including sending cards at specific time intervals, holding memorial services, verbal “check-ins” with families, etc.
- Ten identified routine bereavement practices and care provided at time of death.
- Four identified having “no deaths” and, therefore, have no bereavement practices/plans in place.

Staff Interviews Findings

There are important similarities between the key themes that emerged from parent interviews, staff interviews and the environmental assessment. The following is a list of enhancements that interviewed staff suggested might contribute to significantly improved bereavement practices across the hospital:

- Greater consistency in bereavement care across programs.
- Specialized resources related to bereavement care for non-English-speaking families.
- Adequate communication between the Coroner and family.
- Written consent from families for legacy building; upon the family’s consent, the services need to be implemented consistently.
- Enhanced documentation of after-death plan-of-care.
- More effective processes and systems of communication for informing all involved staff of a patient death.
- Guidance around the length of time the deceased child’s body and their family can stay on a unit.
- Clear guidelines around staff attendance at funerals.
- A bereavement follow-up policy to ensure a consistent standard of bereavement care is provided for all families.
- An effective process for families visiting the morgue.
- A formal debriefing policy that contributes to care and support of staff.
- Mentors for staff at the time of death.
- More practice-based training for residents.
- Enhanced knowledge of diverse cultural bereavement practices.

Actions Taken

While the review was underway, it became apparent that the Task Force could begin to implement certain enhancements immediately. The following is a list of enhancements already undertaken:

- Members of the Task Force initiated meetings with the Coroner's Office to review current practices and procedures and to build a closer working relationship in support of families experiencing the death of a child in hospital.
- Maria Rugg, APN, Palliative and Bereavement Care Services, was seconded for one year to the Coroner's Office to help build enhancements in terms of the care they provide families and to act as a liaison between families, the hospital, and the Coroner's Office.
- A "bereavement checklist" was created to support greater consistency around the provision of legacy building services and obtaining consent for services.
- A working group developed an End of Life clinical practice guideline.
- Education opportunities were developed to enhance cultural competence in the area of bereavement care.
- Existing written materials have been updated to be more reflective of current bereavement practices, and work is underway with the NISN to translate the materials into nine languages.
- A number of Task Force working groups were created to focus on multiple areas, including: Policies and Procedures, Clinical, Education, Research, and Resources and Partnerships.
- Stakeholder feedback was provided to the proposed RNAO Best Practice Guideline on Bereavement Care.
- Enhancements have been made to the environment within the morgue and the processes associated with care of the child after death.
- Partnerships have been established with academic and health-care institutions to study the implementation of bereavement BPGs.

Enhancing Cultural Competence in Bereavement Care

In April 2009, SickKids received government funding from Citizenship and Immigration Canada to establish the New Immigrant Support Network (NISN). The primary goal of the NISN is to enhance the delivery of culturally competent care to patients and families through education for health-care providers and the translation of patient education material into up to nine languages.

A key area of focus for the education program, which has been attended by over 1,700 clinicians, and which has been very well received, is on bereavement practices across cultures. An e-learning module on cultural considerations in bereavement care is also being developed for staff. Additionally, as the Bereavement Task Force reviews hospital policies and procedures related to death and dying, language pertaining to the consideration of, and respect for, diverse cultural and religious practices is being strengthened.

Recommendations

The interviews with staff and families, as well as the literature review, revealed both strengths and gaps in terms of existing bereavement care practices at SickKids. Based on the data gathered, the Task Force has put forward recommendations that address a number of areas, including: enhancements to staff education and resources in the area of bereavement care; the need to challenge existing beliefs and attitudes about death as a care outcome and the potential for a dignified death to support a positive bereavement process; and the development of policies and procedures where needed to ensure consistency of bereavement care across the hospital.

1. Develop a strategy to ensure consistent bereavement care is delivered at all times, in all settings.

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- b. Implement and evaluate a triage model to identify families at high risk for post-traumatic stress following the death of a child.
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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.

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- b. Ensure this program is responsible for the implementation and evaluation of all recommendations put forth by the Task Force.
- c. This program is to assume accountability for implementing best practice guidelines throughout the hospital.
- d. The Bereavement Task Force is to be reconstituted to become an advisory to the Bereavement Program.
- e. Utilize TRAC-PG (Team for Research in Adolescence and Children in Palliation and Grief) as an overseeing body for research development and implementation in the area of palliative and bereavement care.
- f. Integrate bereavement work with other hospital initiatives, such as the New Immigrant Support Network (NISN) and interprofessional practice initiatives.
- g. Examination of the bereavement experiences of families from diverse cultural and religious backgrounds is to be considered a priority for further research.

3. Develop new resources to promote best practices in bereavement care including bereavement care across cultures, such as:

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- b. Parent-to-parent support program.
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4. Link with available community resources to optimize their use, foster existing relationships, and create opportunities to develop new partnerships.

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8. As is appropriate, continue to engage our bereaved families:

- a. Through the implementation of hospital-wide memorial services.
- b. Through considering the creation of a recognition wall for the children who have died.

9. Implement facility upgrades to the hospital's morgue and quiet room.

10. Finalize and approve the draft paper: *The Hospital For Sick Children Bereavement Care: An Interdisciplinary Framework for Practice*.

11. Create a model of care that accurately conceptualizes the Task Force's vision for quality paediatric bereavement care that is individualized, family-centred and evidence-based.

Conclusion

This report describes the work and findings of the Bereavement Care Task Force with regard to the current state of bereavement care at SickKids, as well as current thinking and evidence on bereavement care best practices. Both the strengths and gaps, with respect to the bereavement care being provided at the hospital, have been investigated and documented. The report recognizes that families value many of the existing bereavement practices, such as legacy creation, follow-up, active support, and timely and compassionate communication. It also indicates that there are considerable and problematic inconsistencies in the quality of bereavement care being provide to children and families. Additionally, other insights, such as the need for support for staff who are impacted when a child dies, have surfaced as a result of the work.

Based on these findings, the report offers a number of recommendations that seek to build on successes and strengths, while addressing identified gaps and inconsistencies. Where possible, the Task Force has already begun implementing recommendations, such as building closer working relationship with the Coroner's Office. A key recommendation of the Task Force is the creation of a hospital-wide, comprehensive bereavement program. The Task Force members are committed to continue working with stakeholders and partners within and outside of the hospital to develop and promote best practices in bereavement care at SickKids and beyond.

"This is incredibly important work. Comprehensive and meaningful bereavement care is a critical component of the care we provide children and their families. When done well, bereavement care can help to support the bereavement process for all whose lives have been touched. Families, friends and the interprofessional staff all participate in providing care and support and all can be deeply affected when a child dies. Seamless, comprehensive bereavement care and knowing that we've done the very best that we could may assist all of us to heal following the death of a child. I'm deeply grateful for the tremendous work of our staff in this area, supporting children, families, loved ones and each other as they move through the experience of death."

Margaret Keatings, Chief Interprofessional Practice & Chief Nurse Executive

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Appendices

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Appendix 1 - Literature Review

(Special thanks to Kim Widger for sharing this literature review.)

Bereavement care began at the time of death often with the collection of mementos such as pictures, locks of hair, and hand/footprints (Aherns et al., 1997; deJongBerg & Kane, 2006; Laakso & Paunonen-Ilmonen, 2001; Macnab et al., 2003; Meert et al., 2005; Oliver et al., 2001; Pector, 2004b; Rini & Loriz, 2007; Skene, 1998; Widger & Picot, 2008). Some families later regretted not taking mementos (deJongBerg & Kane, 2006), but others were distressed when mementoes, particularly pictures, were taken against their wishes (Skene, 1998). Some parents expressed appreciation for assistance with or information on arranging funerals (Dangel et al., 2000; deJongBerg & Kane, 2006; Macnab et al., 2003; Pector, 2004a; Rini & Loriz, 2007). When options for autopsy and organ/tissue donation were not discussed with parents, some had lingering regrets that an opportunity to help another child or to answer some questions about their own child's death was missed (Aherns et al., 1997; Macdonald et al., 2006; Oliver et al., 2001; Widger & Picot, 2008). When autopsies were done, parents wanted the results in a timely and compassionate manner (Macdonald et al., 2006; Meert et al., 2007; Rini & Loriz, 2007; Wisten & Zingmark, 2007).

Follow-up care after the child's death was identified as important in several studies, yet it was often lacking (Aherns et al., 1997; Collins et al., 1998; Contro et al., 2002, 2004; D'Agostino et al., 2008; Dangel et al., 2000; Davies & Connaughty, 2002; Davies et al., 1998; deJongBerg & Kane, 2006; Dent, 2002; Hannan & Gibson, 2005; Heller & Solomon, 2005; James & Johnson, 1997; Kreichbergs et al., 2005; Macdonald et al., 2005; Macnab et al., 2003; McHaffie, Laing, & Lloyd, 2001; Meyer et al., 2002, 2006; Parker et al., 1999; Pector, 2004b; Sirkia et al., 1997; Widger & Picot, 2008; Wisten & Zingmark, 2007; Woodgate, 2006). Parents sometimes felt abandoned after the death which added to the grief they experienced (D'Agostino et al., 2008; deCinque et al., 2006; Heller & Solomon, 2005; Meert et al., 2007; Spooren et al., 2000; Widger & Picot, 2008).

Similar components of care prior to the death were also important in follow-up care, such as compassion, good communication skills, sharing information, supporting decisions, and demonstrating personal interest in and respect for the family (Dent, 2002; Meert et al., 2007). Parents often wanted to meet with health professionals after the death to discuss autopsy results, clarify the events leading to and the circumstances of the death, and be reassured that everything possible was done and the right decisions were made (Brosig et al., 2007; Kreichbergs et al., 2005, 2007; Macdonald et al., 2006; McHaffie et al., 2001; Oliver et al., 2001; Pector, 2004a, 2004b; Spooren et al., 2000; Wisten & Zingmark, 2007; Woodgate, 2006). However, returning to the hospital can be very difficult for some parents so holding the meeting in another location or ensuring proper supports for the parents are in place is important (Davies et al., 2007; Macdonald et al., 2005; McHaffie et al., 2001; Meert et al., 2007).

Other bereavement follow-up activities such as letters, calls, hospital memorial services, and health professional attendance at the funeral were important means of support by showing parents their child and family truly did have an impact on the health professional (Davies et al., 2007; deCinque et al., 2006; deJongBerg & Kane, 2006; Kreichbergs et al., 2005; Macdonald et al., 2005; Meert et al., 2005, 2007; Pector, 2004b; Widger & Picot, 2008; Woodgate, 2006). Written information about grief or other sources of support for all members of the family were important (D'Agostino et al., 2008; deCinque et al., 2006; deJongBerg & Kane, 2006; Pector, 2004a; Rini & Loriz, 2007), as well as information to share with extended family and friends on how to support bereaved parents (deCinque et al., 2006; deJongBerg & Kane, 2006). The importance of bereavement support groups was mentioned in a few studies with parents noting the need for a safe place to express emotions and meet others who were effectively coping with grief (D'Agostino et al., 2008; Davies et al., 2007; deJongBerg & Kane, 2006; Laakso & Paunonen-Ilmonen, 2001). However, such groups certainly were not a fit for every parent, and may not even be available due to geographic distances between bereaved families (deJongBerg & Kane, 2006).

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Appendix 2 – Family Interview Questions

1. Was (child's name) death expected or not?
2. Were you prepared for what to expect at the time of death?
3. What services did you think you would receive when dealing with the death of your child? (expectations)
4. What were the bereavement services you did receive at the time of death? (Is there a difference between what you expected and what you received?)
5. At the time, what did you find most useful/helpful?
6. What was not so useful/helpful to you?
7. What was the hardest issue/thing to deal with?
8. What did you find was missing or not useful?
9. Did you feel you had appropriate space that supported the grieving process here at SickKids?
10. Did you have a conversation about your cultural practices and were they incorporated into care?
11. Was support provided or available for your entire family, i.e., siblings?
12. Do you think this could have been done differently?
13. Did you have any legacy building for your child? What was done? Did you find it meaningful?
14. Did you feel involved in legacy building and care at time of death?
15. Was your child taken to the morgue and what support was offered to you while in the morgue?
16. Were you helped with funeral arrangements?
17. Did anyone from the hospital contact you after you left the hospital? When, who and how often?
18. Were you connected to community resources? What were they and how long after (child's name) death did that happen?
19. At that time, what resources did you find useful?
20. Did you feel you received enough support from the hospital?
21. Thinking back on your experience is there anything you wished had been different?
22. Overall, how would you rate communication between the HCT and yourself? (0 to 10)
23. How would you rate your overall experience surrounding your child's death? (0 to 10)
24. Is there anything else you would like to tell us?

Appendix 3 – Environmental Scan

Bereavement Practices

page 1

Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
Oncology Committee 8A & 8B	Abby Bezant	7-Apr-09	Co Chair bereavement committee	Do molds and pictures often try to do them before the child dies. Only done if the family consents.	Have bereavement bags they give to families with books and resources 6 months after the death.	Nurse put in a one to one assignment.	Families may accompany child to the morgue with nurse. They can comeback to palliative care room after if needed.	Send hand written cards at 3 / 6 / 12 months after death.	APN's or Manager facilitate a debriefing after a few deaths have occurred.	Committee looking into purchasing bereavement cart with sound machine / video (KICKS fundraising)
					Child life and social work will be involved with the family and often see the siblings.	Will discuss with the family prior as to their wishes and practices at the time of death. Plan is to be documented in care plan but not done routinely.	Majority of patients do not go to the morgue arrangements are made for the funeral home to pick the patient up from hospital room.	Yearly memorial outside the hospital.	6 months after they start work on 8A education is provided on palliative care.	
					Have palliative care suite with parent lounge (fund raising police KICKS and high school).	Family can stay for several hours after the death.			Difficulty informing all of the staff of patient death	
					Medical care is assigned to an APN if possible.	2 nurses will work together to bath the patient and remove lines and dress them followed by shrouding. Family may also assist.				
						Bereavement cart from Tim Horton's is provided.				
Critical Care Coordinator	Darcy Farrell	7-Apr-09	Bereavement Co-coordinator .5 FTE	Have a legacy package with ink prints etc. Will do hand molds, hair locks, pictures. Verbal consent prior.	On follow up calls often provide information on how to access community resources.	Wash, cream and shroud patient and remove lines if possible. Usually 2 nurses work together.	Parents can accompany child to the morgue. Not sure who would accompany if family returned to morgue.	Call family one week after death and then again in one month.	Bereavement coordinator provides education during orientation on how to care for the body.	
			Attend Palliative Care Teams weekly meetings	Butterflies are made for some of the families that hang over the bed and all the staff involved in care sign it.		Have bereavement gowns for patients if family would like.	Almost all patients go to the morgue and then picked up by funeral home.	They are sent a card with contact info for bereavement coordinator at 1 / 3 / 6 / 12 months.		

Bereavement Practices

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Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
			Is notified by RN's of all deaths either at the time or next day. Use to be called in in the middle of night to support families.	Religious ceremonies if requested		Shroud in hospital sheet. Tie wrists and ankles naked unless family requests clothing.	Have facilitated families to take the body home.			
						Prior to death or at the time ask family of the cultural / religious practices they would like honoured.				
						nurse usually in 1:1 assignment even after death until next shift or resources are needed for other patients.				
						In high profile cases can never leave the family alone with the body.				
NICU Coordinator	Lori Ives-Baine	17-Apr-09	Bereavement Coordinator	NILMTDS - volunteer photography. Pose guide available. Provide CD /DVD to music.	Each family receives a folder full of information (maternity leave, how to plan funeral, breastfeeding, how to care for molds, grief etc)	Provide nurse with a one to one assignment if possible.	Majority of patients go to the morgue.	Yearly memorial at hospital in November	Comprehensive guide created for nurses.	
			Available by pager 24/7 to provide phone support if required.	Molds (siblings and parents), pictures, ink prints, lock of hair, video camera, hand painting, teddy bear angels, certificate of life. Have nice boxes for all of the items to be placed in.	Will send resources in the mail if they didn't get them while at hospital.	Wash, cream and shroud patient and remove lines if possible. Usually 2 nurses work together. Baby is dressed then shrouded in plastic and then wrapped in blanket.	Have facilitated families to take the body home, mosque or synagogue.	Newsletters send at 3 / 6 and 12 months. Along with the newsletter they are sent a personal note. On anniversary letter let family know formal follow up is complete.	14 RNs comfortable and capable with end of life care who function as mentors.	

Environmental Scan

Bereavement Practices

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Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
			Teaches the hospitals bereavement classes as well as in the community.	Keepsakes are also offered; measurements of baby, sat and temperature probe, scrap booking. Siblings are send personalized workbook.	Are provided information on all community resources and recommended counselors.	As changes occur to the body the nurses provide education to the families so they are prepared for the cold and stiffness.		Call with in first 4-6 weeks	Encouraged to take What do I say and Legacy building class.	
			Also follows retro transfers and transport deaths.	Religious rituals if requested.		Family can stay in the room as long as they like		Facilitate autopsy report meetings. Will take notes for the family	Sends out an article of interest every month.	
				Can provide gowns, blankets, hats and booties.				Provide support with subsequent pregnancies (will attend genetics meetings).	Provides debriefing with staff following a particularly traumatic death.	
Palliative Care Team	Gurjit Sangha and Marie Rugg	9-Apr-09	To access team a referral is sent. Team rounds weekly on all in and outpatient families they follow.	Certificate of life - documents patients life. Try to complete while patients is still alive but often done after they die.	On follow up calls will offer resources and to prepare a certificate of life. Will link to community resources.	Don't usually provide care at time of death. Occasionally called to support at an unexpected death.	Occasionally called by pathology to sit with a family (perhaps not HSC patient). Will provide support / resources. The coroner's office may not explained fully the reason for autopsy and team will facilitate.	Will try to attend funeral of families they follow	Hold education rounds 6 times a year.	
			yellow copy of bereavement checklist gets sent to Palliative care team so they know to begin follow up contact.	offer photos and molds following verbal consent.	Have access to complimentary therapists - message, art, music, clown and counseling for both patient and siblings. May provide during bereavement period as well as after.		Most patients followed by team who die as inpatients are transferred to the morgue.	will call and send card to their families right after death then again at 1 month and 1 year.	Provide "What Do I Say" Legacy Building class offered by the Centre for Nursing.	
				Have a mobile bereavement cart that CHS Administrators have access to after hours.					Offer 4 day workshop - 1 day is dedicated to bereavement and care of the care giver.	

Bereavement Practices

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Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
								One bereavement visit first few months following if family desires.	Provide orientation in RN general orientation as well as to residents and fellows.	
								Do follow up on all families they follow except oncology families they do their own follow up.		
General Pediatrics 7A,B,C,D	Melissa Skinner	8-Apr-09	No coordinator or committee	Provide molds / hair pictures if family consents. Get written consent for pictures.	Usually have planned deaths so they collaborate with palliative care team.	Prior to death we discuss with families their wants and wishes. Usually done by Palliative Care Team.	carry child to the morgue or order up special stretcher from transport.	usually done by Palliative Care Team. If not a PCT patient unsure if follow up occurs.	Nurses encouraged to take the class offered by the Centre for Nursing	
					May provide room for family if possible.	Bereavement cart from Tim Horton's	Nurse will accompany patient to morgue family can accompany if they desire.		Informal debriefing process done often after a death. Led by MD, CSN, CCRT.	
					May provide special meals to be brought up for the family.	Decrease nurse's assignment.	Nurse will not stay to provide support in quiet room social work is usually utilized.			
						Prior will try to turn off all monitors take off Ivs.				
						Family can stay as long as they need after.				
						2 nurses will wash and prepare body. Shrouded in plastic one provided by hospital naked.				
General Surgery 5B	Maria Plastina	8-Apr-09	no deaths no plan							
5A	Catherine Eadie	9-Apr-09	almost no deaths no plan							

Environmental Scan

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Bereavement Practices

Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
Burns and Plastics 8C	Rosemary Dymond	8-Apr-09	no deaths no plan							
Neuro Trauma 5C	Susan Stinson-Lyska	8-Apr-09	No coordinator	Will provide printing, hair, pictures, molds if family consents verbally.	Have bereavement kit and information at nursing station.	Social work would be called as well as Chaplaincy or anyone else family requested.	All patients go to the morgue	Done by Social Work if unexpected death. Palliative Care Team if expected.	Nurses encouraged to take the class offered by the Centre for Nursing	
						Limit the assignment of nurse	RN will accompany patients to morgue		Debrief is held after trauma patients usually led my Social Work.	
						CSN would help RN with the washing and preparing of the body.	Family can go to the morgue if they like.			
						Family can stay as long as they need after.				
Emerge	Cindy Capstick	8-Apr-09	No committee or coordinator	will provide photos, hair, mold with verbal consent from family	Have a bereavement box	Prior to death would ask family what practices they would like at the time of death.	RN takes patient to morgue. Will carry if small enough.	Send card at one week following but only done sporadically.	Nurses encouraged to take the class offered by Centre for Nursing	
				Offer keepsakes like blankets.	Often coroners case need to get permission to move or prepare the body.	Core nurse is assigned 1:1 assignment with patient.	Family can accompany			
				Utilize mobile bereavement trolley have to call CHS Administrator for access.		Put sign on door so no unnecessary interruptions.	RN will not stay with family in the quiet room CHS Administrator would be called to find someone to sit with family.			
						Family can stay as long as they need after.				

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Bereavement Practices

Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
						2 nurses will wash and prepare body. Shrouded in plastic one provided by hospital naked unless family requests cloths.				
6A	Stephanie Laivenieks	12-Apr-09	Bereavement Committee of 2 people. One member just received Palliative Care Certificate	Provide molds, hair, pictures after verbal consent.	Have a bereavement drawer at nursing station with every thing needed.	Nurse is given 1:1 assignment	RN accompanies patient to morgue can usually carry patient.	Done by Palliative Care Team.	Nursing education day once a year in that session on bereavement	
					Often it is a planned death and Palliative Care Team is involved.	Patient in private room may provide extra room for family if possible. Have small quiet room on unit.		Committee members will send at least one card to family from 6A	Often committee nurses called at home for support	
					Will call up bereavement cart from diet office.	2 nurses wash and prepare body.			Debrief held after most deaths lead by committee members.	
						Wrap in HSC blanket do not shroud			Have bereavement list of who wants to be called at home when patient dies.	
						Family can stay as long as they need after.				
PACU	Theresa Bruno	14-Apr-09	no deaths no plan							
Cardiac 4D	Allison Pumell	14-Apr-09	Currently no functional bereavement committee/coordinator on the floor as there are almost no deaths on the floor. Had one, for a brief period over a year back	Over a year back provided basics like hand/foot prints, basic support pamphlets, photos. Verbal consent for prints; written consent for photographs	Material provided by Child Life Dept. Bereavement notice board on the floor announcing deaths of patients in the cardiac program, in patient and out patient.			Schedule was made with committee members taking turns to send cards/letters soon after death and on birthdays.		

Environmental Scan

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Bereavement Practices

Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
Pathology / Autopsy	Susan Cromwell	6-Apr-09	Claim no involvement with families except perhaps a call from family to ensure all body parts are berried with the body. Coroner's office has all the communication with families.							
Protection Services / Morgue	John Bond	9-Apr-09	Looking into if families are ever left alone in quiet room with only security.	Have a quiet room where families can sit with their child. Cold room and an ante room behind cold room where you can prepare the body for viewing.	If family coming for scheduled visit they will have quiet room cleaned by housekeeping prior.	Security stays during entire visit. Must have RN or SW there as Officer will not touch the body or bring it in or out of cold room.	Protection Services meets nurse at morgue when patient is being transferred down. Only pathology and protection services have access to cold room.			Need better access to lauding dock. Larger patients requiring stretcher have to be taken down hall and outside for pick up.
				There are gowns, diapers, blankets and stretchers to prepare body for visit from family.		If family comes for unexpected visit will page Social Worker on call to facilitate.	If there is an empty crypt nurse is to place patient in it.			
							Patient can only be in morgue 14 days. After will call HR to call internal lead for the case to contact family re arrangements.			
Chaplain	Michael Marshall	15-Apr-09	Attend Palliative Care Rounds		On call Chaplain if urgent and unexpected.	Encourage families to bring in community clergy.		Attach families to their local clergy for follow up.		
			Attend Neuro and trauma rounds		Chaplains available 24/7 - Catholic, Protestant, Jewish, Muslim? Part time Buddhist, Hindu, Pentecostal, 7th Day Adventist, Presbyterian.					

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Bereavement Practices

Department	Person	Date	Bereavement Coordinator / Committee	Legacy Building	Resources	Care at time of Death	Transfer of Care	Follow up	Staff Support	Future Plans
Clinical Psychologist /Senior Scientist	Maru Barrera	24-Apr-09	Hematology/ Oncology Research Institute							Support groups for siblings of patients that have died of cancer