Pediatric Palliative and Hospice Care: Pennsylvania’s Model of Collaboration

Betsy Hawley

At 4 years of age, Sam McConahy, with his huge smile and terrific laugh, was diagnosed with a glioblastoma, an aggressive form of brain cancer. During the next 2 and a half years, Sam had 4 brain surgeries, underwent 6 weeks of daily brain radiation, tried more than 10 different chemotherapies, and was involved in 3 different clinical trials. Despite all of his medical challenges, Sam continued to be a fun-loving and happy little boy. Unfortunately, his brain cancer progressed, and on Christmas Eve 2001, Sam was admitted to home hospice care. After a hard fight against the glioblastoma, Sam died peacefully at home, early in the morning on March 10, 2002, with his parents and brothers at his side.

After Sam died, his bereaved mother embarked on a personal emotional journey that would eventually take her from her son's bedside to the Capitol rotunda in Harrisburg, Pennsylvania. Grateful for the many kind and caring professionals who had walked the path with her, McConahy looked for a way to give back.

That opportunity came when she was asked to serve on the newly formed Pittsburgh Pediatric Palliative Care Coalition (PPGCC), bringing bereaved parents and health care professionals into extraordinary partnership. At that meeting, McConahy learned about another local organization, Helping Hands-Healing Hearts (HHHH), that provides resource information and education to families of children with terminal illness. Knowing she would have the opportunity to be a parent advocate as a member of the PPGCC, she saw a chance to serve in a local, hands-on level with HHHH and joined that group as well.

In the state of Pennsylvania, a collaborative model has been developed for improving pediatric palliative care and end-of-life care services to children with life-limiting conditions and their families. The inspiration and efforts of several bereaved parents provided the initial impetus for this encouraging model. Pennsylvania’s model involves cooperation and collaboration among several groups and initiatives across the state, as well as the integration of parent-professional collaboration at all levels and in each initiative.

The collaborating groups include 1) a volunteer grassroots resource and education initiative, Helping Hands-Healing Hearts; 2) the Pittsburgh Pediatric Palliative Care Coalition, a coalition of concerned parents and experienced palliative and hospice care providers working together to improve service availability; and 3) the Pennsylvania Children’s Hospice and Palliative Care Coalition, which developed as an outcome of a state-level Pennsylvania Pediatric Hospice Care Task Force, and which, among other activities, works with the Pennsylvania Department of Public Welfare and several Pennsylvania legislators on pertinent policy and legislative initiatives.

With McConahy’s help, the two organizations jointly sponsored a workshop that would bring together Pittsburgh area professionals and bereaved parents, as well as, in part, serve as a springboard for the State of Pennsylvania’s Pediatric Palliative and Hospice Care (PPHC) Task Force. This task force was convened by the Honorable Estelle B. Richman, Secretary of Pennsylvania’s Department of Public Welfare, in January 2008. McConahy became a member of that state-wide task force, effectively tying together three palliative and hospice care initiatives.

These three initiatives in Pennsylvania operate on different levels, from grassroots to governmental policy levels, yet together accomplish so much more than each would individually. Figure 1 provides a description of each initiative. This unique intersection and partnership of initiatives has proven to significantly advance pediatric palliative and hospice care in the state. The outcomes of working in a coordinated fashion have included increased accessibility to existing services, the development of comprehensive programs that span across facility barriers, and the implementation of a cohesive unit working to change legislation at the statewide level. 
Figure 1. Description of Initiatives

<table>
<thead>
<tr>
<th>Name</th>
<th>Helping Hands-Healing Hearts</th>
<th>Pittsburgh Pediatric Palliative Care Collaboration</th>
<th>Pediatric Palliative and Hospice Task Force</th>
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</thead>
<tbody>
<tr>
<td>Mission</td>
<td>To promote quality pediatric palliative and hospice care for children with life-threatening conditions in southwest Pennsylvania</td>
<td>To provide leadership and advocacy in understanding and promoting palliative and end-of-life care for children with life-limiting conditions</td>
<td>To review PA's current health care delivery system and (1) identify major challenges that prevent children and families from accessing services, and (2) develop recommendations that will improve the delivery of services in the state of PA</td>
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<td>Structure</td>
<td>Grassroots community service organization made up of bereaved parents and concerned community members</td>
<td>Collaboration of parents, health care providers, policy makers, and community leaders united to improve coordination/continuity of pediatric palliative care</td>
<td>Task Force initiated by PA Department of Public Welfare, composed of health care professionals and parents (both bereaved and currently caring for a child)</td>
</tr>
<tr>
<td>Staff</td>
<td>P/T Director</td>
<td>No paid staff, oversight by Steering Committee</td>
<td>Direction provided by DPW staff</td>
</tr>
<tr>
<td>Activities</td>
<td>• Established Web site for families and health care workers that provides information about available resources • Compiling and distributing resource guide to help families access available resources • Organizing and facilitating educational workshops for healthcare providers and parents • Maintaining resource library • Supporting families with teams of volunteers (pilot project currently underway)</td>
<td>• Provided leadership for PA task force • Meeting monthly to bring together all persons concerned about pediatric palliative care in SW PA • Compiling and distributing care plan books for families • Meeting with state legislators to make recommendations happen (with PA-CHA PPPC) • Working with PA DPW to implement recommendations (with PA-CHA PPPC)</td>
<td>• Met for a period of two years to compile task force report • Organized press conference and launch event at state capital to make legislators and public aware of concerns with pediatric palliative and hospice care • Founded PA-CHaPPC which (1) holds monthly meetings for members across the state and (2) is working with legislators and DPW to implement recommendations (with PPPCC)</td>
</tr>
<tr>
<td>Geographic Scope</td>
<td>Southwest Pennsylvania</td>
<td>Southwest Pennsylvania</td>
<td>Statewide</td>
</tr>
<tr>
<td>Contact Information</td>
<td>Betsy Hawley, Director <a href="http://www.helpinghands.fcpc.us">www.helpinghands.fcpc.us</a></td>
<td>Meghan Murphy, Founder <a href="http://www.pppcc.net">www.pppcc.net</a></td>
<td>Uma Ramaswamy, Executive Director Dr. David Kelly, Chief Medical Officer <a href="http://www.dpw.state.pa.us">www.dpw.state.pa.us</a></td>
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An unusual, and in fact extraordinary, aspect of these three intersecting initiatives lies in the integrated involvement of both families and professionals, at all levels, in addressing the unified goal of promoting palliative and end-of-life care for children with life-limiting conditions. According to Meghan Murphy (bereaved parent, hospice social worker, consultant to HHHH, co-founder of PPPCC, and co-chair of PPHC), this intersection of parent and professional is the key to unlocking the puzzle and seeing the whole picture of the needs of child and family (M. Murphy, personal communication, April 21, 2009).

Parents and professionals look at the issues surrounding pediatric palliative and end-of-life care through their own set(s) of lenses. Professionals get snapshots of the child's experience based on the components of their own discipline(s). Parents see the day-to-day reality as it affects the child and the family. Put these two together, and you can address the whole picture.

Murphy's observation points to the necessity for a family-centered approach in which the parent is included as an integral member of the caregiving team. If both sides of the spectrum are not represented, the overall care plan of the child cannot be effectively implemented. In Pennsylvania, the importance of a family-centered approach is now recognized from the bedside to the policy level.

According to a 2006 study examining parental involvement in a child's end-of-life care, “Parental priorities and recommendations offer simple yet compelling guidance to improve pediatric end-of-life clinical practice and research” (Meyer, Ritholz, Burns, & Truog, 2006, p. 649). With the large
number of professionals involved in the end-of-life care of a pediatric patient, the parent is often the only one holding all the key elements together. While this is a daunting responsibility for a parent, it is, nevertheless, a reality that professionals cannot ignore.

The story of Meghan Murphy’s son, Ellis, provides an example. At the age of 5 months, Ellis was a quadriplegic and ventilator-dependent. To care for him, Murphy had to learn how to suction his trach, use the ambu bag, perform chest physiotherapy, give breathing treatments, and change his tracheostomy tube. There were splints, abdominal binders, positioning devices, and physical and occupational therapies to manage. She learned how to listen to his lungs and problem solve ventilator and pulse-oximeter alarms, as well as how to feed, bathe, and dress him. During this time, she also had to choose a home nursing agency, meet with early intervention therapists, and prepare her home for both the equipment and the many medications.

To care for him, Murphy had to take a Family Medical Leave of Absence. It was only possible due to generous support from her own employer, the Presbyterian Women, a United Way agency that serves children with potentially life-limiting illness and their families, regardless of their ability to pay for services. To learn more, visit www.edmarc.org

Murphy, a single mother, was only able to keep her job by taking a Family Medical Leave of Absence. It was only possible for her to do this because of generous support from her own family. As a professional in the health care field, she is aware that many families do not have the luxury of taking time off due to potential job loss. However, due to the many hurdles in caring for a medically fragile child, such as shortage of nursing staff, multiple medical appointments, or not qualifying for any specialized care at home, many end up losing their jobs anyway. Murphy’s experience, as well as that of less fortunate families, points to the imperative need for grassroots organizations to step in and assist parents with these seemingly insurmountable problems.

Figure 2. Edmarc Hospice for Children

Established in 1978, Edmarc Hospice for Children was the first hospice in the nation designed specifically for children. Edmarc is the only pediatric hospice in Hampton Roads, Virginia. Edmarc was founded by the members of Suffolk Presbyterian Church in Suffolk, Virginia, along with their minister, who was dying of cancer, and a young couple whose only son was dying of a progressive neuromuscular disease. The minister’s name was Edward and the boy’s name was Marcus. The agency is named in their memory.

In 1982, Edmarc Hospice for Children received a $300,000 grant from the Presbyterian Women. This generous community gift funded the development and expansion of hospice, home health care, and bereavement support services. Edmarc Hospice for Children is a United Way agency that serves children with potentially life-limiting illness and their families, regardless of their ability to pay for services.

To learn more, visit www.edmarc.org

Community concern about this feeling of overwhelming responsibility for families of children with life-limiting conditions led to the formation of Helping Hands-Healing Hearts (HHHH) at Fox Chapel Presbyterian Church in Pittsburgh, Pennsylvania. In 1975, church members Joan and Allen Hogge had lost their son Marcus at 7 and a half years of age, to a rare, incurable genetic disorder called metachromatic leukodystrophy (MLD). After Marcus died, Joan and Allen were consumed with a passion to make the road they had just traveled easier for other parents. They lived in Virginia at the time and helped establish the nation’s first free-standing pediatric hospice. Edmarc, in the Tidewater area of Virginia (see Figure 2). Inspired by the story of the Hogge family, members of Fox Chapel Presbyterian Church established HHHH, with the mission of promoting quality hospice and palliative care for children with life-threatening conditions. A commitment to help other children and their families encouraged bereaved parents, as well as other concerned community members, to become part of HHHH.

In a first step toward helping families access area resources, HHHH volunteers worked together with health care professionals to develop a comprehensive guide to resources for pediatric palliative and hospice care in southwest Pennsylvania. This resource guide, as well as a more in-depth Web site (www.helpinghands-swpa.com), was made available to families so they would not have to search for all the available resources on their own. McConahy, a key contributor to the formation of the guide, comments as follows:

The HHHH resource guide is such a wonderful tool for families. It is small and easy to have with you all the time, but it contains a wealth of information and gives you a place to go when you need answers. It is an essential tool for anyone facing the challenges of caring for a medically fragile child (McConahy, personal communication, October 8, 2009).

All agencies listed in the guide receive copies for distribution to the families they serve. The guide is also distributed throughout southwestern Pennsylvania in many public locations, such as libraries and community centers. Families who have used them often keep a supply on hand to pass on to others. McConahy notes, “I have given many of them away, and everyone is always so pleased to have information about where to turn” (McConahy, personal communication, October 8, 2009). (The guide is available, free of charge, by contacting Helping Hands-Healing Hearts at helpinghands@fcpc.us or 412-963-8243.) As the HHHH experience shows, it is through the important collaboration of family advocates and professional health care workers that such invaluable resources can be made available for families in their time of need.
Pittsburgh Pediatric Palliative Care Collaboration

To better serve the families in southwestern PA, HHHH works with the PPPCC to bring together pediatric palliative care professionals and parent advocates who have experienced the particular challenges involved in caring for a chronically ill child. PPPCC was founded by Murphy because of her experiences both as a bereaved parent and a social services professional. Murphy recognized the need for a coordinated effort on the part of her professional colleagues, as well as other bereaved parents, in the field of pediatric palliative and hospice care. While there are many wonderful pediatric palliative care resources in the Pittsburgh area, most were working in their own isolated world. Murphy saw that the first step was to bring them together, along with parents, to identify the greatest needs and tackle them as a group.

In September 2004, the first meeting of the PPPCC was held. The goal of the PPPCC, composed of bereaved parents and pediatric health care professionals, was to develop a combination of active and compassionate therapies in Western Pennsylvania – providing pain and symptom management of terminally ill children, and utilizing support services to assist children and families to fulfill their physical, psychological, social, and spiritual goals. The aim of the PPPCC is to develop services that are sensitive to the personal, cultural, and religious values of children and families. One outcome of the first PPPCC meeting was the development of a grid reflecting both the current programs and the future outlook for service delivery for children with life-limiting illnesses and their families. Additionally, a subcommittee of parent advocates and health care professionals designed a needs assessment survey for families and community organizations to better quantify the needs of this population. The results of this comprehensive survey identified a number of key issues, highlighted by a community need for respite, case management, and patient/family advocacy. PPPCC continues to use the framework of this survey to address the needs of children and families they serve.

Pediatric Palliative and Hospice Care Task Force

As a result of the PPPCC’s efforts in southwestern Pennsylvania, as well as the work and dedication of the Liam Lawson Foundation in eastern Pennsylvania (see Figure 3), the Department of Public Welfare convened a state-wide Pediatric Palliative and Hospice Care (PPHC) Task Force. This task force was just the statewide forum that Kathryn Lawson, bereaved mother and vice president of the Liam Lawson Foundation, was looking for to promote her campaign for improved end-of-life and palliative care. Lawson recalls:

The PPHC Task Force brought together close to 200 people from across Pennsylvania. The task force was [composed] of almost 200 members across many disciplines, including doctors, nurses, social workers, clergy, hospice professionals, homecare professionals, educators, administrators. Of course, the task force also included parents and family members who live or have lived with a child with a life-threatening, life-limiting illness or condition. Without this unique combination of insightful, compassionate, and experienced members, this task force report would not be nearly as thorough or compelling. I am so proud to have been a part of this groundbreaking work for all the children and families involved (Liam Lawson Foundation for Pediatric Palliative Care, n.d.).

One compelling aspect of the PPHC Task Force was the strong involvement of families and caregivers, as well as dedicated professionals. As noted in the Final Task Force report, “the majority of our PPHC Task Force has experienced what it is like to love and care for a child with a life-limiting illness/life-threatening condition and coped with the impact the resulting circumstances have on a family’s day-to-day living” (Pennsylvania Department of Public Welfare, n.d.). The report also commends the health care, human services, and medical professionals “who have often stood side-by-side with our youngest patients and advocated for their rights to palliative and hospice care” (Pennsylvania Department of Public Welfare, n.d.). This dynamic combination of parents and professionals gave the Task Force a breadth and depth not often accomplished in a governmental undertaking.

Figure 3.
The Liam Lawson Foundation for Pediatric Palliative Care

Liam Lawson was diagnosed at the age of 4 months with a condition known as Lissencephaly. After being told there was no cure or treatment for Liam’s rare condition, his mother, Kately Lawson, recalls the grim reality made clear by the diagnosis.

We understood that his condition would likely run its course of allowing Liam’s body to grow physically while his developmental age would remain at 3 to 4 months. Eventually, his body would outgrow the capacity of his brain to function. He would lose what little function he did have, like the ability to eat or digest food. We also understood that we were going to be facing caring for Liam as he died.

It was clear from the beginning that the number-one priority would be Liam’s comfort. With the help of family, friends and Liam’s medical team, Lawson worked to keep Liam as comfortable, pain-free, and happy as his condition would allow until his death at age 2.

Liam’s story and the tireless efforts of his family played an important part in creating the impetus for Secretary Richman to initiate the PPHC Task Force.

To learn more, visit www.liamlawsonfoundation.org

Liam Lawson
The PPHC Task Force was composed of 12 subcommittees:
- Patient and Family Issues.
- Pain and Symptom Management.
- Research.
- Hospital Care.
- Hospice Care.
- In-home Care.
- Care in Alternative Residences/Facilities.
- Systemic Financing and Funding.
- Education, Training, and Certification of Professionals.
- Medical Ethics.
- Community Resources and Systems Enhancements.
- Quality of Life Enhancement Areas.

Each subcommittee included both parents/caregivers and professionals and addressed three areas of service delivery systems analysis:
- The current state of pediatric palliative and hospice care provision throughout Pennsylvania through the collective personal and professional experiences of the Membership of the PPHC Task Force.
- The major themes and challenges associated with accessing and providing pediatric palliative and hospice care services throughout Pennsylvania.
- The ideal solutions and recommendations that address any challenges to accessing and providing comprehensive pediatric palliative and hospice care throughout Pennsylvania (Pennsylvania PPHC Task Force, 2008).

Each subcommittee submitted a report of their findings, which the Steering Committee then compiled to formulate a common list of Barriers and Recommendations (see Figure 4). This final Executive Summary was unveiled at a rally in the Rotunda of the State Capitol in Harrisburg, Pennsylvania. After the presentation, Task Force members met with state legislators to garner support for the recommendations suggested.

**Pennsylvania Children’s Hospice and Palliative Care Coalition**

One of the five recommendations put forward in the Executive Summary of the PPHC Task Force was to establish a statewide Pediatric Palliative and Hospice Care Coalition. The formation of this coalition, Pennsylvania Children’s Hospice and Palliative Care Coalition (PA-CHaPCC) has already begun. The mission of PA-CHaPCC is “to provide advocacy, support, and education to children and families facing life-threatening or life-limiting illnesses/diagnoses to enable them to experience the best possible quality of life throughout the course of the illness/disease” (PA-CHaPCC, n.d.).

As with the Task Force, PA-CHaPCC is composed of parents, families, and caregivers, as well as health and human service professionals. With the help of the Department of Public Welfare, PA-CHaPCC and the PPPCC are working together to ensure that all five recommendations in the Task Force report will come to fruition for families and children throughout the state of Pennsylvania.

While much has been accomplished, much more needs to be done. PA-CHaPCC continues to grow and to carry out the findings presented in the Pennsylvania Pediatric Palliative and Hospice Care Task Force report. PA-CHaPCC is already working with the Pennsylvania Department of Public Welfare and several Pennsylvania legislators on spe-

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**Figure 4. Pennsylvania PPHC Task Force Barriers and Recommendations**

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<tr>
<th>Barrier</th>
<th>Recommendation</th>
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<tbody>
<tr>
<td>• Current health care and human services delivery systems do not adequately address the urgent yet unmet needs of children with life-limiting illnesses/life-threatening conditions and the needs of their families.</td>
<td>• Establish a Permanent Bureau or Division under the medical director’s office within the Office of Medical Assistance Programs that is responsible for pediatric palliative and hospice care services.</td>
</tr>
<tr>
<td>• The current health care system for children with life-limiting illnesses/life-threatening conditions is impaired by poor coordination, poor communication, and limited access.</td>
<td>• Establish a statewide Pediatric Palliative and Hospice Care Coalition composed of family members and professionals for the purposes of advocating for the needs of children with life-limiting illnesses/life-threatening conditions and their families, raising public awareness, and disseminating information.</td>
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<tr>
<td>• Pediatric palliative and hospice care services are inadequate and unavailable due to lack of education and training for health care professionals and the medical community at large.</td>
<td>• Establish a statewide network of pediatric palliative and hospice care regional centers of expertise across Pennsylvania to provide leadership in pediatric palliative and hospice care regarding clinical consultation, family advocacy, education, professional development of clinicians, and research.</td>
</tr>
<tr>
<td>• Families experience isolation and tremendous guilt while making challenging and painful decisions throughout their child’s course of care due to a lack of support, information, and options.</td>
<td>• Establish, provide, and facilitate funding for program development and maintenance, direct patient care, and family support.</td>
</tr>
<tr>
<td>• Children and families do not get the medical care and financial services they need and deserve, and are at high risk of becoming financially devastated due to inadequate financial assistance and poor funding for programs and services.</td>
<td>• Improve the quality and enhance the availability of services related to pediatric palliative and hospice care.</td>
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**Source:** Pennsylvania PPHC Task Force, 2008.
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*continued from page 65*

cific initiatives to improve the lives of children and families with life-threatening illnesses. In addition, the other two groups continue working on their own initiatives: HHHH is using hands-on volunteer work to bring education and aid directly to families; and the PPPCC is aiding in the state-wide initiative, as well as continuing to find ways for Pittsburgh organizations to work together to directly help children and families.

References


