Welcome to the 40th issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a PDF collection of articles that explore selected issues in establishing and providing pediatric palliative/hospice care in different settings or in different ways. These articles offer suggestions for and examples of engaging in the important work of providing pediatric palliative/hospice care. Because this is a very important subject, we have decided to devote two issues to these discussions. Even so, we appreciate that no two issues or collections of articles will do justice to these broad topics, but we hope that the articles in this issue and in the one that will follow it will spur discussion, implementation, or expansion of programs in this field as a cooperative enterprise with children, adolescents, their family members, the professionals, and the organizations involved in their care. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-Journal Workgroup, chaired by Christy Torkildson. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy Torkildson at christytork@gmail.com or Charles Corr at ccorr32@tampabay.rr.com.
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A Gift of Grace  p. 5
Scott Newport
This essay memorializes the life of a young girl by offering an example of "paying it forward." Perhaps all who are involved in pediatric palliative/hospice care are basically paying it forward by trying to create a better society for everyone and especially for our loved ones if they should ever need to call upon these types of services.

Developing Your Program through Palliative Care Leadership Center Training  p. 7
Lisa Long, BA, and Sarah Friebert, MD
This article notes that "the skillset necessary for program management is often not part of the training of palliative care professionals." Accordingly, "to develop and sustain a successful and financially viable program so you and your team can provide the care you are compassionate about, and provide it well," it is desirable to take part in the different types of Palliative Care Leadership Center (PCLC) trainings that are described in this article and offered at different locations by the Center to Advance Palliative Care (CAPC).

Integrating Palliative Care into Hospital Care for Children with Medical Complexity  p. 10
Jori F. Bogetz, MD
Here, the author describes issues facing children with medical complexity and the need for more palliative care for both these children and their family members. The article also outlines tiers of integration for broader access to palliative care, challenges to providing such care, and the need for program development. The article notes that following these suggestions can broaden the scope and availability of palliative care services for these children and improve the children's quality of life, while also potentially decreasing healthcare utilization and costs.

Integrating Pediatric Palliative Care into the Pediatric Intensive Care Unit  p. 15
Miriam C. Shapiro, MD, and Renee D. Boss, MD, MHS
This article argues that: "Robust uptake of pediatric palliative care within the PICU promotes consideration of a child’s quality of life throughout a hospital course, whether brief or prolonged, and aids the family and care team in making treatment decisions that take into account the full picture of a child’s life. It is best provided by both improving the capabilities of interdisciplinary care providers within the PICU to deliver care consistent with palliative care principles, and having access to subspecialist pediatric palliative care teams, who can follow children as they transition out of intensive care settings to other medical settings or home."

Building a Successful Perinatal and Neonatal Palliative Care Program  p. 18
Marilyn Fisher, MD
This article describes the development of a perinatal and neonatal palliative care program under the umbrella of a pediatric palliative care program in a large medical center. It shows that: "Creation of a successful Perinatal and Neonatal Palliative Care program involves many of the same baseline resources as used in a Pediatric Palliative Care program, but requires a myriad of other interdisciplinary contact people and assistants to assist the fetuses and neonates suffering from life-threatening diagnoses, and their families."

Stepping Stones: A Home-Based Pediatric Hospice and Palliative Care Program  p. 20
Stacey Jones, MSW, LASW
The author of this article describes the principal characteristics of a pediatric hospice and palliative care program, the only such program in the greater Seattle area. Noted are the benefits of being part of a larger adult hospice and palliative care program.
**Hope for the Journey: The Establishment of Edmarc Hospice for Children**  
Debbie Stitzer-Brame, RN  
This article describes the establishment, history, and current services offered by Edmarc Hospice for Children in Suffolk, VA, "the first hospice in the United States that provides care specifically to children."

**Child Life Specialists in the Pediatric Hospice Setting**  
Magellan Taylor, MA, CCLS, and Stephanie Mishoe, M.Ed., CCLS  
The authors of this article argue for including child life specialists in the interdisciplinary team as a way of best meeting the varied and unique needs of children and their family members. Child life specialists are described as "trained professionals who specialize in play and the developmental needs of children." Detailed examples are offered of ways in which child life specialists can contribute to this type of care.

**Helping Parents Talk to Critically-ill Children about End of Life**  
Mandy Ferguson  
The mission of The Conversation Project, a national public engagement campaign, is to help families overcome communication barriers by ensuring "that everyone’s wishes for end-of-life care are both expressed and respected." The work of the Project began with the Conversation Starter Kit, "a free, downloadable, step-by-step guide that helps adults have “the conversation” about their preferences for end-of-life care." Recently, the Project has responded to requests from adults, parents, and pediatricians, as well as good research, to produce their Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child, an invaluable resource for everyone who seeks to meet the needs of children and families coping with end of life issues.

**Items of Interest**  
In each issue of our ChiPPS E-Journal, we offer additional items of interest.
A GIFT OF GRACE

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“Hey Officer, can I ask you a question?”

The day I asked that question I had woken up at 4:30 a.m. as usual, but that particular morning there was a magnificent sliver of a moon staring at me from the east as I stepped out onto the porch of our two-story home. The clear April morning here in Michigan reminded me of new life and the song of the common wrens popping from a nearby tree made it seem like the day would be OK.

By 10 a.m. I remembered I had a conference call with a few others around the country that had experience with children who have genetic conditions. I hurried home to use the phone and to be able to connect on my computer.

I am a member of the Region 4 Genetics collaborative because my son Evan had Noonan syndrome. My boy lived seven happy years. He never spoke a word but his life was as though a song was always playing through his smile and his zest for life. Participating with this advocacy group helps me to be able to give back.

During our conference call the group was informed one of the well-loved children from Indiana had suddenly died. We were informed, “Grace’s parents would love it if you would pay it forward with a ‘Gift of Grace.’” Not knowing the family personally, I still knew their pain and had to hold back the tears for the rest of the meeting.

After the conference call I went to McDonalds to get a Diet Coke. I was on my way to meet my dad and one of the guys who works for me. I am a carpenter by trade and we were currently putting up drywall in an old 1920s home near downtown Royal Oak.

After I paid my $1.06 I asked the guy at the drive-through window, “How much does the police officer behind me owe?”

“It's ah……. $6.47.”

While the cashier guy still held a kind of funny look, I said, “Could you tell the cop I really appreciate his community service?” This was the first time I had ever paid for someone in a drive-through lane. I was obviously an amateur.

As I pulled away from the restaurant I was puzzled by how long the cruiser stayed at the pay window. That was until I told my older daughter about the “Gift of Grace” that evening and what I had done.

She giggled and said, “Dad, that’s how it’s supposed to work. You see, when you pay it forward at a drive-through it’s common for that person to then pay for the car behind them.”

You mean he was paying for someone else’s meal?” I said.

“Yea dad, that’s the hope.”

“Wow, Chelsea, I can’t wait to tell Grace’s family that their daughter's life has even made an impact up north here in Michigan.
Before I end, I guess I should tell you the question I asked the cop I referred to at the beginning of this story, but I won’t. I will tell you that when I walked up to his patrol car he immediately reached to his side. I guess it was for his gun, maybe just a taser. Reflecting back now, that moment reminds me how folks were often not sure about my son Evan because of his unusual appearance. I would guess that maybe Grace’s parents had similar experiences.

Strangers would often step back and protect themselves by avoiding our family. I hope now that cop may have a different view of a stranger just walking up to him in the midst of a drive-through line. I know it may be kind of a stretch of my wish but maybe, just maybe, the “Gift of Grace,” was working then, too.

Grace Susan Akers 5.6.98-4.12.15

http://www.randallroberts.com/tribute/details/2219/Grace_Susan_Akers/obituary.html
DEVELOPING YOUR PROGRAM THROUGH PALLIATIVE CARE LEADERSHIP CENTER TRAINING

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As everyone knows, most professionals go into the field of palliative care because they have a passion for business planning and finance. What? Okay, we all know that’s not true. But it is true that in order to pursue your passion for serving patients with life-threatening conditions and their families, you will likely need to delve into those areas. Top-tier clinical care is, of course, the core of any pediatric palliative care team. However, there are logistics that need to be managed to develop and sustain a successful and financially viable program so you and your team can provide the care you are compassionate about, and provide it well. Despite its importance, the skillset necessary for program management is often not part of the training of palliative care professionals.

That is the purpose of the Center to Advance Palliative Care’s (CAPC) Palliative Care Leadership Center (PCLC) training. Obviously, you have the passion to do this work. Yet the logistics of creating, organizing, running, and funding a program may seem difficult and overwhelming. Or maybe you’ve been doing it but feel like things could be running better, and you are not sure exactly how to improve things.

All PCLC locations have been at that same point sometime in their inception. They started with something that was just an idea and a passion, and took next steps to make a plan. They figured it out and have built long-standing, successful palliative care programs. They are now dedicated to helping other professionals and teams achieve the same thing and can provide some guidance. They’ve undoubtedly made mistakes or missteps along the way, and can help your program avoid some of those.

PCLC training is geared for a small core team of 4-6 people to attend—this can include physicians, nurses, social workers, chaplains, and other clinical people, as well as key stakeholders who will be most involved in the program’s success. There is also a discount in tuition if the team includes a hospital finance person. This is deliberately somewhat vague—depending on how your organization is set up, this could be a variety of people but should be someone who has some role in determining budgeting and expenditures for your team. Joining the training will help the finance person “buy in” to what you are trying to do and learn more about the team. While team building is not the primary goal, it is a positive side effect of spending time away from your home institution, undisturbed, planning your program together. The time apart gets everyone on the same page and focusing on the same goals. It’s important to note that the focus of the training is NOT on how to deliver palliative care in the clinical setting; rather, the goal is to learn how to create, grow, measure, and sustain the program.

There are several different types of PCLC—generally pediatric programs attend PCLC Peds, which covers all the basics to start or enhance your current program if you are seeing primarily pediatric patients or children and adults. Since 2008, CAPC has been offering PCLC-Peds at Akron Children’s Hospital in Akron, Ohio, and at Children’s Hospitals and Clinics of Minnesota in Minneapolis; together we have trained a wide variety of programs including children’s hospitals, pediatric hospitals within hospitals,
hospice and community palliative care programs, and adult programs looking to expand across the continuum. There are also PCLC Custom and PCLC Consult offerings which are for active programs looking for something more customized to their specific needs.

During the 2-1/2 day program, the group works through a modular curriculum as a team; the focus is on small group work with exercises tailored to each program’s needs. The curriculum covers several different areas important to program development:

**Systems Assessment & Mission Alignment:** this module will help you identify who your stakeholders are in the program and how to develop strategies to engage them. This includes patients, families, other hospital staff, administration, and groups in the community. You’ll also take a look at the current situations at your hospital—what are some the ways you can fulfill an unmet need of other providers? What data can be used to show how palliative care would be a benefit? You’ll work on creating or honing your program’s mission statement, making sure it also aligns with your institution’s mission statement.

**Clinical Models & Staffing:** this module will help you decide how your program should run or expand. Should it be a consult service? Should it be inpatient or outpatient or both? How do you dovetail with chronic, complex care offered at your institution? You’ll develop a plan for starting or growing the service, including how a palliative care service fits into your overall organization.

**Financial Case & Sustainability:** in this module, teams will identify how to make the case for palliative care financially, and the key stakeholders. You’ll be introduced to some tools which can help develop the financial case and ways to measure impact. You’ll also talk about billing revenue and philanthropy (an important part of your program’s funding) and how to maximize them.

**Continuity of Care (aka Community Partnerships):** if your program is hospital-based, it’s also important to recognize the need to build relationships and effective communication with community agencies that help provide care once patients leave the hospital. We also talk about transitioning complex patients with long-term chronic illnesses to adult providers, which is not uncommon occurrence in pediatric palliative care—many of our patients are living into adulthood, but still need someone to help manage their complicated and often extensive care.

**Measurement:** as you are starting or enhancing your program, tracking your data and showing results is very important to your program’s future, and gaining future funding and support. You’ll learn about what kind of data to collect and about tools to help you do that. Your team will also learn methods to talk about the data effectively to key stakeholders.

**Internal Marketing:** this module will help you develop a strategy for marketing palliative care services to other stakeholders such as clinical staff, administrative leadership, and donors, as well as evaluating how you communicate your program’s services to patients and families.

**Palliative Care Education:** What should we teach? How should we teach it? What are the core competencies that palliative care professionals need to be expert in their fields? In addition to being well educated themselves, palliative care teams are often called upon to provide basic palliative care education to other staff in your institution; doing this well will help empower your team members in palliative situations. You’ll learn more about different methods of health education and what might work best in your organization, and your team will develop an educational action plan.

**Program Implementation:** The last module in the curriculum is where the rubber meets the road. Your team will identify barriers and resources to overcome those obstacles to implementing or expanding a palliative care service at your organization. Your team will develop a timeline for implementing your palliative care program, identifying specific goals at one month, three months, six months, and one year, together with steps to achieve those goals.

In addition to these, our PCLC in Akron also includes the topic of **Team Health.** Interpersonal conflicts
and issues can be a barrier to program success and are often difficult to discuss and manage. Team wellness and sustainability are key ingredients for successful implementation and growth.

After PCLC training, teams receive a year of mentorship from the host site. PCLC faculty plan follow up phone calls with your team one month following the training and then every three months, to help keep you on track. To learn more about attending a PCLC training, visit https://www.capc.org/palliative-care-leadership-centers/.
INTEGRATING PALLIATIVE CARE INTO HOSPITAL CARE FOR CHILDREN WITH MEDICAL COMPLEXITY

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Describing Hospital Care for Children with Medical Complexity

In the United States there is a growing population of children living with increasingly severe and complex chronic health conditions due to advances in intensive, surgical and home care. Children with medical complexity (CMC) have significant health needs that require many types of care providers and services. These children have conditions such as cerebral palsy and severe congenital heart disease. Throughout their lives, many of these children develop secondary comorbid health conditions that increase their need for hospital care to treat acute illnesses or exacerbations of chronic conditions. This has led to significant increases in hospitalization rates. Over the past 15 years, CMC were the fastest growing population of patients to utilize children’s hospitals where they accounted for nearly one-third of patients and one-half of inpatient costs. In 2009, CMC accounted for over 19% of patients, 27% of discharges, 49% of hospital days and over 53% of hospital charges at dedicated children’s hospitals nationally, with charges equated to over $9 billion dollars. One study determined that despite comprehensive care programs, CMC continued to experience hospitalizations and readmissions for issues such as major surgery (47%), medical technology malfunction (9%), aspiration pneumonia (4%), vomiting/feeding difficulty (3.5%) and asthma (2%). Changes in the most common chronic conditions found in hospitalized children in the US are shown in Table 1.

To complicate matters, CMC and their families often experience unsuccessful transitions away from the hospital, with 30-day rates of unplanned readmission at 7% nationally. One study looking at readmissions of medically complex children over a one-year period found rates to be as high as 22%, with nearly 3% of children being admitted four times in a one-year period. Factors associated with increased hospitalization rates included greater complexity of care (from 22.3% to 89%) and technology dependence (from 5.3% to 52.6%). A study of nearly 350 caregivers found that readmission rates were as high as 30% in children whose families did not feel that their child was healthy enough to be discharged. It is clear that many CMC experience multiple recurrent hospitalizations because of their ongoing fragile health status and suboptimal care planning. Engaging hospital providers during critical changes in a child’s health status provides an opportunity to involve the family’s perspective and curtail some of the frequent hospital use associated with care that is not goal directed.

The Need for More Palliative Care: Understanding the Family Experience

Despite medical advances and the significant use of hospital-based care, families of children with medical complexity continue to struggle to meet their everyday needs. On average, families supply 20 hours per week of direct care and 2 hours per week of care coordination for their medically complex child. Furthermore, over half of families report the need to stop working often resulting in subsequent financial difficulties because of their child’s care. Many families admit to significant social isolation, strained relationships with peers, and frustration with the healthcare and educational systems because of their children’s care needs. Many of these families also report sleep deprivation, stress, anxiety, anger, guilt and frustration as part of their caregiver experience. One study of over 100 families of children with developmental disabilities found that a significant number of families thought that their care providers did not understand how their child’s health impacted their family’s life.
More recent studies have shown even higher numbers of families reporting unmet healthcare needs and trouble accessing community services for their medically complex children. Although family caregivers consistently report wanting clear communication and continuity of relationships with multiple types of care providers (including doctors, nurses, social workers, case managers and community agencies) this often is not accomplished. When asked about their attitudes towards care planning, 99% of families wanted information shared with them regardless of how serious or potentially upsetting the information was perceived to be by healthcare providers. Frequent hospital readmissions, high healthcare costs and significant family caregiver burdens have created the impetus to develop more effective and efficient strategies to help CMC. One of these strategies is the early and ongoing integration of pediatric palliative care into hospital-based care for CMC.

**Tiers of Integration for Broader Access to Palliative Care**

Pediatric hospital providers are critically positioned to change the way care is delivered to CMC and their families. Hospital providers interact with families at crucial times during acute illnesses, chronic disease exacerbations, medical interventions and health status changes. Hospital providers can have a dramatic effect in the way they operationalize palliative care for CMC and can have an enormous impact on a child’s long-term care and on family functioning even during a single hospitalization. A tiered system in which palliative care is provided by teams with various levels of palliative care training based on medical and psychosocial complexity is shown in Figure 1.

To provide the highest quality medical care to CMC, pediatric healthcare providers should consider the child’s overall health status and their long-term disease trajectory. This includes an appreciation of the multiple care settings, healthcare transitions and service providers families interact with over their child’s life. This can be accomplished by (1) framing care decisions based on families’ concerns and patient-centered goals of care, and (2) linking between various care systems (hospital and community) to support communication and continuity. The tasks listed in Table 2 can be helpful to hospital providers when assessing for these concerns. Table 3 summarizes a set of example questions for healthcare providers to consider when providing palliative care. These models and other palliative care practices can be taught more broadly to hospital providers across the education continuum, regardless of specialty to increase access to palliative care for CMC.

Involving dedicated palliative care teams in the care of CMC in the hospital provides an added group of healthcare providers with diverse skills who can coordinate care outside of the hospital setting and provide continuity as other care team members change throughout a child’s life. Furthermore, discharge planning that includes community based pediatric palliative care programs have been shown to have benefits for CMC at the end of life. In these situations, community based palliative care has led to a one-third decrease in hospital days, an 11% decrease in healthcare spending and an improved quality of life for the child and family. Most importantly, studies have shown improved patient and family satisfaction with their care and enhanced communication with healthcare providers when palliative care services are provided. Although the needs of CMC and their families are unique and diverse, palliative care services can support many of the self-identified needs of these families. These needs include help with care coordination and home care services. Incorporating palliative care services early on may be beneficial to support medically complex children, their families and providers.

Thoughts about prognostic uncertainty and unpredictable setbacks are the norm for families with CMC. Integrating palliative care services at the hospital provider, palliative care team and community level can more broadly and routinely provide better care for this population of children and can better support their families.

**Challenges to Providing Palliative Care and the Need for Program Development**

There are many challenges to providing comprehensive palliative care to CMC. These challenges include
misconceptions about the benefits and services of palliative care for patients who are not in the end stages of their disease trajectory. Determining when palliative care teams should become involved with patients is also difficult for healthcare providers when disease trajectories are uncertain. Having difficult conversations can also be tough for healthcare providers and there is still a limited workforce trained in pediatric palliative care.\(^\text{14}\)

Ways to mitigate these challenges include offering more education to healthcare providers and supporting pediatric palliative care program development. Stakeholders in these important projects include hospital administrators, multidisciplinary care providers and family advocacy groups. Developing patient registries, tracking utilization, and reporting patient’s stories can encourage stakeholders to support education and program development in palliative care. Integrating palliative care into the everyday treatment of CMC should be a priority in delivering the highest quality of care to these children and their families.

**Summary**

All pediatric hospital providers are critical to enhancing palliative care for CMC by establishing goal directed care, coordinating services with the community and focusing decision-making on a child’s quality of life. Furthermore, palliative care has the potential to decrease healthcare utilization and costs. Tiered systems can incorporate pediatric hospital providers who can broaden the scope and availability of palliative care services for CMC and their families.

**References**


9. Liptak GS, Orlando M, Yingling JT, et al. Satisfaction With Primary Health Care Received by


### Table 1: Changes in the Most Common Primary Chronic Conditions of Children Hospitalized in the United States Between 2005-2009

<table>
<thead>
<tr>
<th>Chronic Condition</th>
<th>Percent Increase (+%)</th>
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<tbody>
<tr>
<td>Complex chromosomal anomaly</td>
<td>60.5</td>
</tr>
<tr>
<td>Significant craniofacial anomalies</td>
<td>52.5</td>
</tr>
<tr>
<td>Major congenital heart disease</td>
<td>51.9</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>43.9</td>
</tr>
<tr>
<td>Anomalies of trachea, larynx or bronchus</td>
<td>43.9</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>43.4</td>
</tr>
<tr>
<td>Coagulation disorders</td>
<td>42.2</td>
</tr>
<tr>
<td>Bronchopulmonary dysplasia</td>
<td>41.7</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>36.1</td>
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</tbody>
</table>

### Table 2: Pediatric Palliative Care Tasks for Hospital Providers

<table>
<thead>
<tr>
<th>Task 1: Assess the child’s short and long-term prognosis and quality of life at every admission</th>
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<tbody>
<tr>
<td>• Consider how primary diagnoses and comorbidities contribute to child’s overall health</td>
</tr>
<tr>
<td>• Speak with continuity providers outside of the hospital setting</td>
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<tr>
<th>Task 2: Ensure that families are truly involved when making decisions about hospital care</th>
</tr>
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<tbody>
<tr>
<td>• Create opportunities to discuss treatment options with families and how they relate to goals of care</td>
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<tr>
<th>Task 3: Maximize the family’s understanding of their child’s health and well-being</th>
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<tbody>
<tr>
<td>• Ask families what they understand about their child’s illness</td>
</tr>
<tr>
<td>• Ask families to elaborate on their quality of life concerns, hopes, and worries</td>
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<tr>
<th>Task 4: Address factors that influence the child’s well-being and care planning after discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assess feasibility and effectiveness of care plans</td>
</tr>
<tr>
<td>• Assess and address caregiving burden needed to keep the child healthy at home</td>
</tr>
</tbody>
</table>
Table 3: Example Questions for Hospital Providers to Use When Engaging Families of Hospitalized Children with Medical Complexity in Palliative Care Conversations

<table>
<thead>
<tr>
<th>Conversation Topic</th>
<th>Example Questions</th>
</tr>
</thead>
</table>
| Prognosis          | What is your understanding of your child’s health problems?  
How often are you worried or concerned about your child’s health?  
What are your expectations about your child’s health in the future? |
| Quality-of-life    | Can you tell me about your child as a person?  
How does your child communicate with you and with others?  
What makes your child happy? Upset?  
Tell me about how your child’s illness impacts your family? |
| Goals of Care      | What activities are the most important to your child?  
What are the most challenging aspects of your child’s care?  
What care needs are not being met for your child? |
| Advance Care Planning | While we continue to hope for improvement, how can we prepare for other possibilities?  
What are your hopes for your child? |

Figure 1: Tiered System to Integrate Providers with Various Training in Palliative Care Based on Medical and Psychosocial Complexity
INTEGRATING PEDIATRIC PALLIATIVE CARE INTO THE PEDIATRIC INTENSIVE CARE UNIT

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From infancy through young adulthood, children who face life-threatening illnesses or injuries are often cared for in pediatric intensive care units (PICUs), where the primary approach to care is to save children’s lives and restore them to normal functioning [1]. The initial focus of care provided in the PICU typically involves medical stabilization using highly technological and invasive interventions. Care may initially be fast paced, and diagnoses and prognoses are often uncertain at the outset of illness or injury. Within the PICU, care is delivered by a large multidisciplinary team and often involves consultation by an ad-hoc assembly of medical subspecialists, surgeons, rehabilitation therapists, and others.

In their policy statement on pediatric palliative care published in 2000, the American Academy of Pediatrics advocated that pediatric palliative care should be "offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death" [2]. There is an obvious role for palliative care in the PICU, to provide expertise in symptom management, complex communication, establishing and adjusting goals of care, facilitating transitions to other sites of care, and aiding in end of life management. Data suggest that integration of palliative care into ICU settings improves patient outcomes without affecting mortality [3].

As described by Boss et al, there are three approaches to initiating pediatric palliative care services in the ICU setting: consultative, which relies on a subspecialty palliative care team; integrative, in which palliative care principles are incorporated into standard care delivery in the ICU; and mixed models, which draw on features of both [4]. Depending on the hospital and community resources, a combination of these methods will need to be used to incorporate pediatric palliative care services in the care of pediatric ICU patients.

There exists overlap between some services provided by pediatric palliative care specialists and those provided by pediatric ICU care teams, which may reduce deliberate utilization of palliative care services. One important way to promote uptake of pediatric palliative care in the PICU is to support and facilitate intentional incorporation of palliative care principles into usual PICU practices. Identifying palliative care advocates among PICU staff can facilitate broader acceptance and training of PICU providers in palliative care. As this integrative approach offers immediate palliative care supports to children upon PICU admission, it could lead to earlier and broader delivery of palliative care to critically ill children.

One potential drawback to reliance solely on an integrative model is the possibility that activities or interventions deemed palliative care would be sacrificed when ICU resources are limited. Another barrier to early integration of palliative care in the PICU, on the part of clinicians and families, may be the assumption that it requires forgoing ICU treatments or technologies. Though the Concurrent Care for Children Requirement (CCCR) of the Affordable Care Act was signed into federal law 5 years ago, many in the professional and lay communities need greater awareness of the implications for regular integration...
of palliative care alongside ongoing medical treatment intended to cure disease or prolong life [5].

Additional components of palliative care, which can be more effectively provided by a subspecialty consult team, include the abilities to focus directly on more complex palliative care issues, to provide a perspective from outside the ICU, to follow patients across multiple settings and facilitate continuity of care and decision-making, and knowledge of and access to a variety of resources that exist outside of the hospital setting. The most comprehensive delivery of palliative care to critically ill children can be realized through a mixed-model approach, wherein ICU teams actively engage palliative care principles as a standard of care, and these resources are supplemented by the expertise of subspecialty palliative care consultants, who can follow patients both in and outside of the ICU.

As we explore the role of consultative palliative care services in the PICU setting, it is important to consider how to identify those children who should be at highest priority for receiving these services. Nelson, et al evaluated multiple approaches to identifying which adult ICU patients should receive palliative care involvement and found that using specific criteria to prompt palliative care consultation resulted in increased uptake of palliative care services and reduced utilization of ICU resources, without affecting mortality [3]. Such criteria have not yet been studied in children, but are an important area of inquiry.

Two pediatric populations deserve special consideration: the growing number of children with complex chronic conditions who have frequent ICU stays, and the subgroup of chronically critically ill children whose chronic care needs make them ineligible for discharge from the ICU for months or even years. As medical science and intensive care capabilities have improved, the population of children who are living longer despite life-limiting conditions has increased [6]. These children have unique needs, including coordination of complex medical care, coordination of non-medical services, and support for families as they care for their children at home. Those children who move between home, clinic, and hospital settings require close attention to care coordination, of the sort provided by a medical home. Palliative care involvement can help assure that, when these children are admitted to the hospital, acute care decisions are consistent with both longitudinal goals of care and existing advanced directives. With the knowledge of a child’s life and care outside of the inpatient setting, palliative care teams can be instrumental in negotiating the communication and decision-making around changes in condition and reevaluation of goals of care for medically complex children.

Children who have not been able to leave the ICU for months or years may lack a meaningful outpatient medical home. Palliative care may be particularly important in the complex quality-of-life considerations for these patients, as we attempt to balance benefits and burdens of prolonged ICU treatments and to support the families who face a great deal of uncertainty, distress and stress. The pediatric palliative care team could serve as a primary care provider for this type of patient, providing the role of an in-hospital medical home and ensuring continuity of care. Palliative care providers also bring valuable knowledge of what can be done for medically complex children outside the walls of the ICU, or even the hospital, and may facilitate hospital discharge with appropriate goals for children who have been otherwise “stuck” in an ICU setting.

**Conclusion**

Palliative care within the PICU may seem different from palliative care provided in other clinical environments, as it often co-exists with highly technical medical interventions that may prioritize cure. Robust uptake of pediatric palliative care within the PICU promotes consideration of a child’s quality of life throughout a hospital course, whether brief or prolonged, and aids the family and care team in making treatment decisions that take into account the full picture of a child’s life. It is best provided by both improving the capabilities of interdisciplinary care providers within the PICU to deliver care consistent with palliative care principles, and having access to subspecialist pediatric palliative care teams, who can follow children as they transition out of intensive care settings to other medical settings or home.
References

BUILDING A SUCCESSFUL PERINATAL AND NEONATAL PALLIATIVE CARE PROGRAM

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The development of our Perinatal and Neonatal Palliative Care Program, under the umbrella of our Pediatric Palliative Care Program, came about slowly, with the gradual realization that we needed a team of individuals who could assist fetuses and babies facing a life-limiting medical condition, and their families. Recognition of need for such a program was the first requirement to forming the program. In our institution, certain maternal-fetal dyads were identified as being at particularly high risk, but, because we did not initially have a Perinatal Palliative Care program; one particular neonatologist took on the task of providing that aspect of care. This was a first step to providing perinatal palliative care, but a one-hour prenatal consultation alone, even though it might include creation of a birth plan, did not constitute ongoing support, nor did it necessarily provide an ongoing connection with the family.

The high-risk situation faced by certain fetuses and their families is generally identified by the community obstetrician or family practitioner, obstetric nurse practitioner, or academic center obstetrician. Subsequent referral to our Perinatal Palliative Care Program can occur as long as each of these health care providers is aware of the existence of the program and considers making such a referral. We advertised our program by means of presenting Obstetrics Grand Rounds at the medical center as well as at community hospitals. We also created colorful informational flyers and mailed them to the birthing centers of community hospitals and to the offices of community obstetricians and family practitioners, as well as to the Obstetrics/Maternal-Fetal Medicine Department of our institution. Within the hospital, Palliative Care flyers are easily accessible at the front desk of the Obstetrics unit. We make ourselves visible within the hospital and in the obstetrics office by meeting patients and involving the health care professionals in these discussions. We attend the bi-monthly Maternal-Fetal Medicine meetings where high risk pregnancies and their management are discussed. At these meetings, we learn of future patients who may benefit from our services and have an opportunity to make recommendations to the other health care professionals as to whether Perinatal Palliative Care should be offered to these families, and, if so, what will be the management options. These various advertising and networking methods serve to remind our health care professional colleagues of our existence and of how we may benefit their patients.

We have identified champions of the Perinatal Palliative Care Program, including self-selected nurses and nurse practitioners in the Department of Obstetrics/Maternal-Fetal Medicine, genetics counselors, social workers, case managers, obstetricians, and neonatologists. These health care professionals watch for fetal patients who may qualify for palliative care services on the basis of prenatal diagnoses that may be incompatible with life, and notify us for consultation when such a patient is identified.

Since our Pediatric Palliative Care program already was in existence, there was very little start-up money required to branch out our services to providing support for families requiring Perinatal or Neonatal Palliative Care. There was a small cost of printing informational flyers. The champions of the Perinatal Palliative Care Program carry on their normal job responsibilities, simply keeping alert for certain patients who may benefit from Palliative Care referral, and making the contact with the Palliative Care team if a potential patient is identified. Paid Pediatric Palliative Care team providers, consisting of chaplains, social workers, nurses, and physicians make themselves available via e-mail, pager, and/or cell phone to provide perinatal care and counseling when needed. Therefore, Perinatal Palliative Care team members must be available 24/7 to provide support to families whose sick fetus has died in utero, and to attend high-risk deliveries or prenatal physician appointments if requested to do so by the family. The Perinatal Palliative Care team may assist the family with understanding the medical situation facing their fetus, with
creation of a birth plan and a plan for funeral or other ceremony as the family desires, and may help to provide care and support to the family and the sick newborn if and when crises ensue. This support is offered, not only during the initial face-to-face consultation, but with each outpatient visit to the obstetrician, as well as during telephone discussions as the family desires. Health care providers in the field of obstetrics may also feel uncomfortable dealing with fetal end-of-life issues. Our Perinatal Palliative Care team is likewise available to provide education and support to them.

After birth, a sick newborn who qualifies for palliative care may be cared for in the loving arms of his or her parents, under the careful watch of the Labor and Delivery staff and the Perinatal Palliative Care team. The parents may desire creation of a memory book and photographs at this time, which our team can assist with. If the sick neonate survives for some length of time, accompanying his mother to the postpartum suite, or if he is transferred to the Neonatal Intensive Care Unit (NICU) for therapeutic measures, the Neonatal branch of the Pediatric Palliative Care team will follow him. Just like the Palliative Care team supporting families carrying sick fetuses in utero, the Palliative Care team supporting sick neonates and their families has its champions, including NICU and delivery room nurses, physician assistants, neonatal nurse practitioners, social workers, case managers, and neonatologists. Many of the same Pediatric Palliative Care team members that work with the perinatal patients provide seamless continuity by following these patients throughout the neonatal period. Support rendered to the sick neonate and his family may include being physically present for families during difficult periods, helping to interpret data presented by the health care professionals, helping families to weigh options, helping families to utilize resources available to them, serving as a liaison between inpatient physicians and outpatient physicians, and helping to open lines of communication between families and health care professionals. In the event that a neonate with a life-limiting condition is preparing to go home from the hospital, the Neonatal Palliative Care team can offer to provide information, suggestions, and a medical care plan to the outpatient physician, and can set up the family with appropriate community supports such as professional photography, parent support groups, and hospice care. The health care providers of neonates, within the hospital or in home hospice organizations, as well as some community pediatricians and family practitioners may be relatively unfamiliar and inexperienced with babies dying at home; therefore, our Neonatal Palliative Care team can offer support and education for those care providers as well.

Our Perinatal and Neonatal Palliative Care teams can also work with the siblings of the affected fetus/neonate to provide age-appropriate explanations and grief management. In both the prenatal and the postnatal realm, we can help families to deal with their grief and to find resources to address this. We can also help to find interdisciplinary agreement between the health care professionals, so that news presented to families by various health care providers is consistent and less confusing.

Creation of a successful Perinatal and Neonatal Palliative Care program involves many of the same baseline resources as used in a Pediatric Palliative Care program, but requires a myriad of other interdisciplinary contact people and assistants to assist the fetuses and neonates suffering from life-threatening diagnoses, and their families.
STEPPING STONES: A HOME-BASED PEDIATRIC HOSPICE AND PALLIATIVE CARE PROGRAM

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Providence Hospice of Seattle and Palliative Care is a not-for-profit, community-based hospice and palliative care organization that serves patients in King County, Washington. We provide physical, emotional, and spiritual care to children and adults with life-limiting illness, including support for their families and friends. Our programs include:

- Hospice of Seattle – Adult Hospice Program
- Transitions – Adult Palliative Care Program
- Stepping Stones – Pediatric Hospice and Palliative Care Program
- Safe Crossings – Children’s Grief Support Program

This article focuses on how we organize and manage our Stepping Stones program. The Stepping Stones program began in the mid-1990s and has developed over the years into a comprehensive, interdisciplinary approach to care for children with life-limiting illness and their families. The program was named Stepping Stones in 2004 after receiving feedback from parents and providers about the difficulty of using the word “hospice” when explaining the program to families. The Stepping Stones program has grown each year in the number of children served. In 2014 the program served 88 children.

The Stepping Stones program is the only children’s pediatric hospice and palliative care program in King County (the greater Seattle area). We work closely with Seattle Children’s Hospital and clinics in our area. While most of our referrals come from Seattle Children’s Hospital and clinics, we also receive referrals from other area hospitals, public home health nurses, community children’s programs, and families themselves.

We work hard to foster and maintain good relationships with our referral sources. We provide education about our program, services, and end-of-life care. We do this by 1:1 consultation, participation in hospital discharge planning conferences, educational sessions, and panel discussions. Most recently, our team participated in the Schwartz Rounds at Seattle Children’s Hospital as part of a panel to review a child’s care over the care continuum. This supported hospital staff to better understand that children and their families can be given the option to go home from the hospital and have good end-of-life care in a home setting, even with a complex medical situation.

The word “palliate” means to ease symptoms of an underlying disease. All children with a life-limiting illness can benefit from palliative care. Our program supports children from birth to age 22 with a life-limiting illness. In the home setting, both hospice and palliative care focus on quality of life, provide pain and symptom management, and provide an interdisciplinary team approach. A child is admitted under hospice or palliative care based on certain criteria. For children admitted to hospice, a physician must certify a child has less than 6 month to live. For children admitted to palliative care, the only criterion is the child has a life-limiting illness where the outcome or life expectancy is uncertain. Children with the following diseases are often referred to our program: cancer, chromosomal/genetic anomalies, osteogenesis imperfect, congenital cardiac defects, neuromuscular disorders, and anoxic brain injury.

The Stepping Stones team includes experienced professionals who specialize in working with children and families. The team includes registered nurses, social workers, a chaplain, and a medical director. Registered nurses provide symptom management, end of life education, and care coordination. Social workers address emotional needs, caregiving needs, financial and legal concerns, and funeral planning.
They also help connect families with community resources. The chaplain offers non-denominational spiritual support to both the child and family and supports spiritual leaders in their service to child and family. The medical director provides physician oversight of the team. The team meets on a weekly basis to review patient/family situation, patient/family goals, and to develop a continued plan of care. There is also a time to reflect on those who have died and what the team has learned or will take away from serving each patient and family.

There are many benefits to being part of a larger hospice and palliative care organization. As part of the larger organization, we are able to utilize many resources that are also available to the adult patient population that we serve. These resources may include hospice aides, physical, occupational and speech therapies, volunteers, adult grief support services, and children’s grief support services. Hospice aides provide assistance with a child’s personal care. Physical, occupational, and speech therapy assist in promoting independence, quality of life, and safety of the child. Volunteers provide companionship for the child and respite for parents. Adult grief support services provide grief support to family both before and after death of the child, as well as organize a yearly grief program for families who have experienced the death of a child. Children’s grief support services provide individual counseling, support groups, school groups, education, and grief camp to siblings and other important children in a child’s life before and after death of the child.

Our team is also supported by the organization’s after-hours staff. We are able to offer access to nursing, social work, and chaplain services 24 hour a day, 7 days a week for both our hospice and palliative care patients. Our after-hours staff provides both telephone and visit support as needed.

When a referral is made to the Stepping Stones Program, the referral source, Stepping Stones team, and family determine whether the patient will be admitted to the hospice or palliative care service. A nurse and social worker make joint admission visits for all our hospice patients and, if possible, with our palliative care patients as well. A plan of care is developed with family at time of admission and visit frequency is determined. This plan of care and visit frequency is consistently reviewed and can change over time based on the child and family needs. The team may see patients as much as daily or as little as once a month depending on needs.

Our services are covered by Medicaid, private insurance, or charity care. Medicaid and some private insurance plans offer a palliative care benefit. Medicaid and most private insurance plans offer a hospice benefit as well. If a child has no insurance or limited coverage, we will determine the amount of charity available to family based on income. Transition between hospice and palliative care is possible, depending on the needs of the child and prognosis. A child may transition off of our services at any time.

Our organization is a strong supporter of our program as it enhances the services our hospice and palliative care organization provide to our community. Our vision is to continue to provide excellent care to children with life-limiting illness and their families and to educate our community of the benefits of supporting children in the home setting.
HOPE FOR THE JOURNEY: THE ESTABLISHMENT OF EDMARC HOSPICE FOR CHILDREN

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In 1977, the shell of what would later become Edmarc Hospice for Children was envisioned by W. Allen and Joan Hogge with the help of their minister Reverend Edward Page, Jr. It is considered the first program in the nation created to provide end-of-life home care to children. Edmarc was founded by a group of church members of the Suffolk Presbyterian Church in Suffolk, Virginia. The needs of Edward, the parish minister, and Marcus, a young boy who was a member of the congregation, are what ultimately inspired the group. The agency is named in their honor and memory.

As the story is told, sadly, one of the Hogge’s children, Marcus, was suffering from a rare, progressive, and ultimately terminal neurological disease. Dr. Hogge and his wife realized early in their six-year-old son Marcus’ diagnosis that there were no support systems available at the time to assist them in caring for their son. The Hoggess, desperate for support, turned to a young minister at the Suffolk Presbyterian Church by the name of Edward Page for assistance. Reverend Page, who incidentally was also terminally ill with cancer, in turn asked for volunteers from the congregation to assist the Hoggess during the family’s time of need. Reverend Page lost his battle in April of 1979. The outpouring of support from the congregation was tremendous and successful in alleviating stressors and meeting the needs of the Hogge family, until Marcus passed away in February of 1980.

Over the next few years, the volunteer services that were initiated by the congregation in 1978 slowly became more organized and the group, many of whom were either nurses or doctors, began to envision their services extending further into the community. With that realization, the establishment of Edmarc began. The congregation decided to leave the naming of the organization to the children of the parish. In doing so, the children thought that it should be called Ed & Marc, after the two who inspired its creation, and Edmarc Hospice for Children was born. Edmarc’s logo depicts Edward and Marcus holding hands on the journey they took together.

Initially, regular meetings for all Edmarc Hospice for Children volunteers were held in the den of the Hogge’s home. However, with the expansion of services to the community, the official hospice for children headquarters moved from the Hogge family den to a classroom of the Suffolk Presbyterian Church. They continued to work out of the Presbyterian Church until the mid-1980s.

To achieve their vision of servicing the sick children and families within the greater Suffolk, Virginia, community, the volunteers began submitting applications for funding to local agencies. Successful in the application process, the funding received from these local state grants made it possible for Edmarc to offer assistance to families with disabled and/or mentally retarded children. Initially, Edmarc tried to do all and be all, caring for kids with acute illnesses and chronic illnesses, on a variety of different short- or long-term therapies…not just end-of-life care. However, the desire to meet the needs of all these children in the community ultimately spread the organization and their resources thin.

In an effort to improve and stabilize the resources and services available to the community, as well as allow for continued growth of the pediatric hospice services, the group decided they would need more funding. They decided to write a grant for the Birthday Offering sponsored by the Presbyterian Women. The Birthday Offering is a grant that was established in 1922 to celebrate the 10th anniversary of the Woman’s Auxiliary of the Presbyterian Church of the United States. Funding provided from this grant must be used to enhance the quality of life for women, children, young adults, racial-ethnic people, and/or persons with disabilities. In 1982, the volunteers of the Suffolk Presbyterian Church received a grant in
the amount of $300,000 to officially begin providing hospice, home health, and bereavement services to
the children and families of their community, as well as neighboring areas.

For the first decade Edmarc continued to grow and prosper. In addition to the Birthday Offering Grant,
Edmarc also received Medicare certification which allowed it to begin billing for services provided. This
reimbursement made it possible for Edmarc to add to the permanent nursing staff on payroll, an
Executive Director, secretary, and part-time Family Services Coordinator. Local chaplains continued to
provide services on a voluntary basis.

Then in early 1990’s when reimbursement for managed care was hit hard by the federal government,
Edmarc’s Board of Directors decided if they were going to sustain the program they had to scale back
their services and make adjustments in the current system. Edmarc decided to approach Children’s
Hospital of the King’s Daughters who had a home care program for children and ask for assistance. The
King’s Daughters agreed to partner with Edmarc by offering them a small site free of rent, which would
allow them to get back on their feet and become financially secure.

By 2000, Edmarc was able to provide services completely under the organization again, having regained
financial security, with an annual operating budget of approximately $480,000. A total of 35% of the cost
for services were reimbursable at this time, leaving the remaining 65% to be funded through philanthropy.
Today, Edmarc’s operating expenses are approximately $1,000,000 per year with a mere 10% of these
costs qualifying as reimbursable expenses under current health care. We continue to honor our mission
to serve all children with life-limiting illnesses and their families without regard for their ability to pay for
services. Costs are met through fundraising events and the generous support of community at large.

Edmarc has faced many barriers to pediatric end-of-life care over the years. Those barriers include:
uncertainties in prognosis and discrepancies in treatment goals between staff and family members;
questions about when to make the referral; misconceptions and clarification on eligibility; education of
both healthcare professionals and the general public; recruitment and retention of qualified staff; building
partnerships with physicians and hospitals; and improving funding.

**Services Provided by Edmarc Hospice for Children**

For the first eight years of Edmarc’s establishment it was primarily a nursing agency offering both skilled
and private duty care. The skilled nursing was provided on a per visit basis by registered nurses, while
the private duty care was done on an hourly basis by licensed practical nurses. In addition, if family
circumstances required non-skilled care, a home health aide was available for assistance.

In addition to the specific nursing care needs, Edmarc offered a variety of therapy services, including
speech, occupational, and physical therapists, to children under their care as needed. Social services
were available to provide short-term counseling, family assessments, information gathering, and referral
services, as well as funeral planning. The social worker also organizes sibling support groups and social
events for families. From the beginning, Edmarc also has provided bereavement services for families,
including mom and dad support groups, annual Memorial services, and bereavement retreats. Volunteer
chaplains were available as needed.

Over time, Edmarc added to the hospice, home health, and bereavement services it had always offered.
Specifically, such additions included perinatal care and hospice support. Nursing care continues to be
provided by registered nurses who have intensive care and/or end-of-life training. Each of the services
was created to ensure that the needs of all children with life-limiting illnesses within the community were
being met.

Perinatal care was designed to care for pregnant women who either were at high risk for delivering a
stillborn child or whose child would likely not survive long. Specific care to these women includes support
during pregnancy and funeral planning. In addition, after the birth of the child there is a transition to a
bereavement support group.
The home care program is for children who leave the hospital but still have acute care needs. Nursing staff visit the home to provide assistance with medication administration as well as intravenous infusions including antibiotics, blood products, and even in some instances chemotherapy. All children diagnosed with a life-limiting illness requiring medical assistance will qualify for home care, however much of that care is not reimbursable. This is precisely why the organization was established as a charity model as opposed to the traditional hospice fee-for-service model.

The true hospice care that Edmarc provides is non-residential and essentially fulfills the healthcare needs of children in their homes. This reduces/eliminates the separation of the child from its home and family, thus keeping the family together. The families in this model are the center of care and are supported all the way from early involvement through funeral planning to bereavement.

Finally, hospice support was created as a catch all for children who do not qualify for actual pediatric hospice services. Today, it is utilized for active patients who require intermittent care outside of Edmarc’s service area. The staff at Edmarc does all they can for all families in the community with sick and dying children. This goes beyond nursing care to include providing groceries for families that may be struggling financially and so much more.

Edmarc Hospice for Children is recognized as the first hospice in the United States that provides care specifically to children. Since 1978 we have served nearly 2,000 families within our community. Beginning early in our establishment and continuing through periods of growth and re-organization, Edmarc services and mission have served as a model of care for the pediatric hospice community. The challenges we have faced over the years have been many. Nevertheless, we have held true to our mission of providing care and support while also easing the amount of stressors present in the lives of families and their dying children.
Caring for a child with a complex and chronic medical condition requires an interdisciplinary team approach to best meet the varied and unique needs of the child and family. One vital member of this team is the Child Life Specialist. Child Life Specialists are trained professionals who specialize in play and the developmental needs of children. They provide expertise in assisting children and families to overcome life’s most challenging events by providing support and encouraging positive experiences. Child Life Specialists also educate caregivers, administrators, and the general public about the needs of children under stress. With a focus on the unique needs of a child, they promote coping through play, preparation, education, and self-expression activities.

Child Life Specialists in the pediatric hospice setting play an integral role in providing the highest quality of care for children and families. This care for the patient and siblings includes: (1) Facilitating opportunities for memory making with unique pieces of art; (2) Encouraging expressive art and therapeutic play for coping; (3) Assisting to fulfill a patient’s final wishes through wish foundations and community support; (4) Providing individualized support for siblings; (5) Offering education on facilitating end-of-life discussions with a child; and (6) Making bereavement services available.

A pediatric hospice team provides quality care and expertise for children with life limiting illnesses. Hands of Hope Pediatric Hospice and Palliative Care in South Carolina are one such organization. Hands of Hope is a comprehensive in-home pediatric support service organization that values the importance of Child Life Specialists when it comes to serving pediatric patients in the home. Hands of Hope utilizes a comprehensive model of care to be the sole provider of in-home hospice and/or palliative care services for any child, birth to age twenty-one, living in or visiting the state of South Carolina. This nationally board-certified interdisciplinary team implements a unique model of care that seeks to prevent and relieve suffering for patients, and ensure the highest possible quality of life. The Hands of Hope team not only includes Child Life Specialists, but also the only board certified Hospice and Palliative Care physician in South Carolina, Certified Hospice and Palliative Pediatric Nurses and Nurse Practitioners, Licensed Medical Social Workers, and Chaplains. By bringing all of these professionals together, Hands of Hope is able to provide child-centered and family-focused compassionate care that not only addresses the physical needs of pediatric patients, but also the emotional, psychological, social, and spiritual needs of both the child and family.

April M., Pediatric Resource Nurse for Hands of Hope, reflects on the work of a Child Life Specialist with an eight-year-old patient: “Many times the only person that can make a connection with the patient is child life. Through expressive play, they are able to help the child have a voice. Many times this changes the course of treatment for the child. A great example is when I was able to sit in with one of our Child Life Specialists while doing ‘My Wishes’ with a patient in end stage mitochondrial disease. During the process of completing My Wishes, the child was able to express that she hated the hospital and never wanted to go back, even if she got really sick. The patient’s mother, while in the other room, overheard her child say this and decided that day to change her code status to an AND (Allow Natural Death) and refuse any more hospitalizations. The mother said ‘How can I continue to bring her to the hospital when she doesn’t...
want to be there? I feel so selfish for all the time spent in the hospital—it was because I wanted her to be there, she didn't. Without child life, this patient could have suffered through more hospitalizations or irrelevant treatments. Child life is vital to the hospice team to allow the children to have a voice."

Child Life Specialists not only serve as valued members of the interdisciplinary team, they are also integral when it comes to the care that the family is receiving in the home. Edith S., whose teenaged grandson is a patient with Hands of Hope, says that having a Child Life Specialist involved is “definitely the bright part of his day. Having those visits gives him companionship, something to do to help keep his mind off of himself and the negative things going on in his life, and helps him to have a more positive spirit. Child Life also helps the family to have and to hold things he has helped to make.” Jennifer M. is the mother of an infant who came home from the NICU on hospice services with Hands of Hope. In regards to having a Child Life Specialist work with her family, she says that “when you are here, I get to enjoy being his mother. I get to enjoy my baby, not just manage his medical needs.”

The uniqueness of having these trained professionals on a hospice team is that they are not just specific to pediatric patients, but can also provide services for children of adult patients as well. Many children experience the loss of a loved one on adult hospice services. While sadness is a common response for children losing a loved one, there are certain triggers that can indicate the need for a child life referral. These triggers can include, but are not limited to: excessive attachment to the patient, withdrawal, aggression, fear of staff members, refusal to talk or interact with the patient, increased anxiety, and lack of adequate support from the family. Catrina D., whose seven-year-old son and cousins were seen by a Child Life Specialist before and after the death of their grandfather, writes, “There is really no way to put into words the experience that we have had for most to understand. There is an unbreakable bond that has put a lasting impression that will forever leave an imprint on our lives and hearts. Hospice and our Child Life Specialist have become a part of our forever family. They have helped us, never judged or criticized. They listened, hugged, laughed, cried, but most importantly, loved.”

When it comes to community education and support, the Child Life Specialists for Hands of Hope also assist in creating curriculum and serving as leaders at Camp Hands of Hope, a bereavement camp for children, ages five through eighteen, and their families who are grieving the loss of a loved one. Whitney Rogers, Associate Director for the Hospice and Palliative Care Foundation, states “Child Life Specialists are instrumental in assisting with the development and growth of our semi-annual weekend long bereavement camp. Their knowledge and expertise are essential in developing curriculum and activities that are appropriate for each of the age groups we work with. Their talent and skills are a necessity when it comes to developing a well-planned bereavement camp for youth of all ages. Having Child Life Specialists as part of our camp development team has allowed us to become the leader in the state when it comes to child-centered, family-focused bereavement camps.” When discussing the benefit of Child Life Specialists in the bereavement camp setting and being around peers who are also grieving, Catrina D. states, “It opened them up and they were able to talk about their feelings that us parents weren’t able to get them to do. They were able to see that they too had other kids their age that had been through something similar to them and that they weren’t the only one’s out in this big ol’ world going through something so hard. They had someone they could confide in.”

The presence of Child Life Specialists in the field of hospice is uncommon, but the need is crucial. When looking to enhance your interdisciplinary team and improve the quality of life for pediatric or adult hospice patients and families, consider child life.
HELPING PARENTS TALK TO CRITICALLY-ILL CHILDREN ABOUT END OF LIFE

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At its core, The Conversation Project is a national public engagement campaign to make sure that everyone’s wishes for end-of-life care are both expressed and respected. The initiative, co-founded by Pulitzer Prize-winner Ellen Goodman and launched in collaboration with the Institute for Healthcare Improvement (IHI), believes this mission is both simple and transformative. Too many people die in a manner they would not choose, and too many of their loved ones are left feeling bereaved, guilty, and uncertain. The Conversation Project offers people the tools, guidance, and resources they need to begin talking with their loved ones about their wishes and preferences, before a medical crisis – “at the kitchen table,” not in the intensive care unit.

Helping families overcome the communication barrier is the goal of The Conversation Project, a public engagement campaign with the mission to have everyone’s end-of-life care wishes expressed and respected. At the heart of the project is the Conversation Starter Kit, a free, downloadable (see http://theconversationproject.org/starter-kit/intro/), step-by-step guide that helps adults have “the conversation” about their preferences for end-of-life care. The kit focuses on values and goals of care. It asks the question, “what matters to you?” not “what’s the matter with you.”

Once the Starter Kit became widely used by adults, parents and pediatricians began contacting The Conversation Project to express the need for a guide specifically designed to help parents have the conversation with their seriously-ill children, often not just once, but over time as the disease progresses. Parents and medical professionals alike agreed that this kind of resource was missing from the current discourse. There are tools out there that help children think about death and dying, but nothing that specifically supports parents as they navigate these extremely difficult conversations with their children.

Research has shown that parents who talk about death with their children do not regret it (see http://www.ncbi.nlm.nih.gov/pubmed/15371575). In fact, many of those who do not have these conversations with their children regret not having done so. In fact, Kreicbergs and colleagues highlight this point exactly in an article published in the New England Journal of Medicine. They state that, “Parents who sense that their child is aware of his or her imminent death more often later regret not having talked with their child than do parents who do not sense this awareness in their child; overall, no parent in this cohort later regretted having talked with his or her child about death” (Kreicbergs et al., 2004). Medical literature and stories from the field show that children often sense that they are dying well before their care teams and families. Children don’t talk about it because they don’t want to upset, and feel an urge to protect, their parents.

“For most adults, planning their own end-of-life care is difficult enough, let alone planning for the loss of a child. It’s never easy, but we know how important this conversation is,” says Ellen Goodman, founder of The Conversation Project. “We collaborated with parents, palliative care experts, and nurses to bring forth a guide to help ease parents into this delicate topic. There is no prescriptive, one-size-fits-all methodology, but rather multiple ways to begin and continue this conversation.”

It is with a lot of modesty that The Conversation Project released the new Pediatric Starter Kit: Having the Conversation with Your Seriously Ill Child (see http://theconversationproject.org/wp-content/uploads/2014/10/TCP_PediatricSK_Forms_rev7.pdf). This kit offers advice and provides stories from parents and palliative care specialists who have been there. It provides questions that can help parents navigate the approach to the conversation based on the personality and cognitive level of the child.
“No one wants children to die, but they still do,” says Dianne Gray, president of Elisabeth Kübler-Ross Foundation and a contributor of the Pediatric Starter Kit. “I understand it can seem unkind or cruel to talk to children about their own death, but it is not.” In 2005 Dianne experienced the loss of her son, Austin, age 14, as a result of a neurodegenerative disorder.

During the creation of the Pediatric Starter Kit, Dianne often reflected on the final years of Austin’s life. During one of the design meetings she said, “Though he was nonverbal the last five years of his life, we had developed a method of communication that worked for us,” says Gray. “Having those conversations with him was one of the most difficult, yet grandest acts of love that I could do for him. Knowing that he was a part of the decision making helps me feel such peace.” She now shares this message globally, as an advocate for pediatric palliative care via the International Children's Palliative Care Network and the American Academy of Pediatrics Section of Hospice and Palliative Medicine.

The Pediatric Starter Kit provides suggestions and ways to navigate the conversation if a child or baby cannot speak.

“How parents and loved ones handle the end-of-life of a child can truly define that family going forward. Talking it through makes the impossible slightly less impossible,” says Blyth Lord, founder of the Courageous Parents Network and contributor to the Pediatric Starter Kit. “When your child has a terminal illness it becomes a part of the family’s narrative. Being prepared and having a plan can write the story of their child’s life so they can be at peace with the way it ended.”

Blyth never got to have that conversation with her two-year-old daughter, Cameron, who died from Tay-Sachs, a degenerative disease. However, she credits her palliative care team for guiding her family through some of the most difficult decisions they’ve ever made.

“My husband and I had these conversations, practiced them with each other, and thought through every option with our pediatrician,” Lord says. “We would hear of families making these emergency decisions in the hospital, without time to think, and felt horrible for them. It’s hard to make a thoughtful decision in a crisis when you haven’t done the work.”

At The Conversation Project, we are dedicated to making sure that everyone’s wishes for end-of-life care are both expressed and respected. We are not experts in this area, but we are parents; we are aunts and uncles; and we are brothers and sisters; and it is with a lot of humility that we offer this new Pediatric Starter Kit as a resource to help parents and loved ones begin a conversation with seriously-ill children.
ITEMS OF INTEREST
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. REGISTER NOW for NHPCO’s 16th Annual Clinical Team Conference and Pediatric Intensive!
The conference will be held October 15-17, 2015 at the Gaylord Texan Resort and Convention Center, just outside of Dallas. Special pediatric features at the conference include:
   - A two day preconference pediatric palliative care training (for new and developing pediatric hospice and palliative care professionals) held before the main conference, October 13-14;
   - Special clinical practice pediatric plenary session, Care Coordination in Palliative Care for the Medically Complex Child - Palliative Care to the Rescue!, with Sarah Friebert, MD and Stephanie Allen, MSN, RN, CPN, both of the Haslinger Family Pediatric Palliative Care Center in Akron, Ohio;
   - Six concurrent sessions for the Pediatric Intensive designed for more seasoned pediatric palliative care practitioners; and
   - A Pediatric Networking Meeting supported by the Hospice and Palliative Nurses Association Advance registration with discounted rates is available until September 20, 2015. To learn more and register, visit www.nhpco.org/CTC2015.

2. NEW NHPCO Pediatric Palliative & Hospice Care Facts and Figures Available. The 2015 version provides an overview of pediatric hospice and palliative care for providers, policy makers, funders and the media. The purpose of this report to:
   - Describe the current known state of pediatric palliative and hospice care in the United States;
   - Identify children who may be in need of palliative and hospice support; and
   - Identify gaps in service.
   Read NHPCO’s press release for more information.

3. Wear a Hat on Friday October 2 for ICPCN’s Hatson4CPC day. International Children’s Palliative Care Network has declared the first Friday in October as a special awareness campaign day for children’s palliative care. Wear a hat to work on that day and donate to any children’s palliative care programs or services. Learn more and participate.

4. Honor Children on World Hospice and Palliative Care Day, Saturday, October 10. World Hospice and Palliative Care Day is a unified day of action to celebrate and support hospice and palliative care around the world. This year's theme, "Hidden Lives / Hidden Patients," will focus on the patients living in unique conditions that often struggle with access to palliative care including children, LGBT individuals, HIV prisoners, soldiers and those living in rural settings. Learn more and get involved!

5. Get Certified in Pediatric Hospice and Palliative Care and/or Perinatal Loss Care. The Hospice and Palliative Credentialing Center offers two specialized pediatric certifications, CHPPN® - Certified Hospice and Palliative Pediatric Nurse and CPLC® – Certified in Perinatal Loss Care. The CHPPN® credential is for experienced hospice and palliative pediatric registered nurses, while the CPLC® credential is appropriate for nurses and other professionals in either perinatal loss care or bereavement support. Remaining testing windows in 2015 for both certifications are in September and December. For more specific information on each certification, including candidate handbooks and testing information, please follow the links below:
   - CHPPN®
   - CPLC®
   To register for either certification, visit the Hospice and Palliative Credentialing Center online site.

6. Pediatric Education Conference in PA. The Pediatric Palliative Care Coalition will present a full day educational conference: The Unique Role of Pediatric Palliative Care in the Life a Medically Complex Child on Thursday, November 5, 2015 in Harrisburg, PA. The program includes a special presentation of The Magic Bracelet, as well as sessions on providing palliative and hospice care to
children and their families. Registration available online.

7. **TJC New Standards for Palliative Care Certification.** The Joint Commission published New and Revised Standards and Elements of Performance (EPs) for Palliative Care Certification effective for Palliative Care Centers, July 1, 2015.

8. **NIH announces available end-of-life and palliative care grants.** The National Institutes of Health (NIH) will be awarding grants toward research on the perspectives, needs, wishes, and decision-making processes of adolescents and young adults ages 12–24 with serious, advanced illnesses. The grants will also be supporting research on end-of-life/palliative care models that support the physical, psychological, spiritual, and social needs of 12–24-year-olds with serious illness, their families, and caregivers. Learn more.

9. **The International Children's Palliative Care Network (ICPCN) Issues Call for Abstracts.** The 2nd ICPCN conference will take place in the vibrant city of Buenos Aires from 18 to 21 May 18 – 21, 2016. A “call for abstracts” has been issued, with a closing deadline of October 26, 2015. The conference theme is “Children's Palliative Care - NOW!” and provides for abstracts for presentations and/or posters on a wide range of thematic areas. Visit the ICPCN Conference website for more details and to submit abstracts online.

10. **Pediatric Hospice and Palliative Care Resources Available:**
   - **National Institute of Nursing Research (NINR) new brochure,** “Palliative Care for Children: Support for the Whole Family When Your Child Is Living with a Serious Illness” provides an overview of pediatric palliative care and answers questions that parents and families may have in easy-to-understand language. The brochure is part of NINR’s Palliative Care: Conversations Matter® campaign. Order or download a free copy of the brochure and learn more about the Palliative Care: Conversations Matter® campaign online.
   - **New from the American Cancer Society:** Putting Quality of Life in Prime Time: Palliative Care Resource Guide.
   - **Free Online Course from the National Center for Disaster Medicine & Public Health,** Psychosocial Impacts of Disasters on Children, addresses the unique mental and behavioral health needs of children in disasters.

11. **News Articles**
   - **A Better Way To Care For Seriously Ill Children And Their Families,** WBUR, by Joanne Wolfe, MD.
   - **Talbot Hospice's New Program for Children,** the Talbot Spy.
   - **Play garden at Ames Family Hospice House in Westlake helps kids with sick relatives,** Cleveland Plain Dealer.

12. **SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL.** For the upcoming E-Journal issues, Issue #41 will be Part Two of the topics in Issue #40; while Issue #42 will address the different types of bereavement. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

13. **READER’S CORNER.** Our Reader's Corner columns provide brief summaries and bibliographical
information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric hospice and palliative care, but that may not be known to readers. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles. Please send suggestions to Christy Torkildson at christytork@gmail.com.

14. Calendar of Events As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at christytork@gmail.com to have your pediatric palliative care educational offering listed.
Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpc.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.