Welcome to the thirty-fourth issue of the newly-renamed ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our e-journal offers a PDF collection of articles that explore the subject of transitions in care for children, adolescents, and family members who are coping with life-threatening or life-limiting conditions. We take the term "transitions" very broadly, to include among other things: transitions from pediatric to adult care systems; transitions from home to hospital to hospice or vice versa; transitions from one set of care providers to another; and transitions experienced by professionals. We hope that the articles in this issue and the comments they make about many types of transitions in pediatric palliative and hospice care will increase sensitivity to the challenges posed in these transitions for all who are involved.

This newsletter 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, co-chaired by Christy Torkildson and Maureen Horgan. 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 at christytork@gmail.com or Maureen at horgan.maureen@gmail.com.

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Issue #34:
Transitions in Pediatric Palliative and Hospice Care

Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.

**Some Ways the Illness and Death of His Brother Affected an Older Sibling’s Life**  p. 4
Scott Newport
We have long known and appreciated Scott as our "resident" poet. In this issue he offers not a poem but an essay on some ways in which his son Evan's life and death affected Evan's older brother Noah, resulting in changes and transitions in the older sibling's life.

**Moving from Point A to Point B: Easing Patient/Family Transitions along the Pediatric Palliative and Hospice Care Continuum**  p. 6
Ann Fitzsimons, BS, MBA
Ann is a bereaved aunt who often helps us include family perspectives in this journal, sometimes by locating family contributors, sometimes by offering her own contributions, and sometimes by focusing on resources for family members. In this article, she gives us several examples of the many transitions that families often face in pediatric palliative and hospice care, offers suggestions to ease those transitions, and calls for collaboration among providers to make families feel "safe, secure, and looked after."

**Improving Transitions of Care for Youth and Young Adults**  p. 10
W. Carl Cooley, MD
This article provides a general overview of the state-of-the-art and the challenges posed in ensuring safe and seamless transitions from pediatric care to adult care. Included is a Table that identifies Six Core Elements in a six-step model for a planned health care transition process.

**Transitions in Care for Children with Medical Complexity: An Overview**  p. 14
Suzanne S. Toce, MD
Organized around a case example, this article identifies barriers and facilitators to successful transitions in care, describes an existing model for transitions, offers tools to aid transition, coordination, and consistency, and lists relevant publications, websites, and other resources.

**I'm Transitioning from Childhood to Adulthood, Isn't that Enough?**  p. 19
Jennifer S. Linebarger, MD
Based on a sketch of the fluid developmental processes that characterize adolescence, this article offers a shared management model in which patients progress from being the recipients of health care to being the CEO of their healthcare.

**Transitions: Children with Special Healthcare Needs**  p. 22
Hilary Flint, DO
The focus of this article is on what a palliative care team can contribute to facilitating and improving care for children with special healthcare needs.

**The UK Transition Taskforce**  p. 24
Lizzie Chambers
This article describes the establishment of “a UK-wide Transition Taskforce to develop a coordinated approach to providing integrated local support for the planning and delivery of care and support for young people with life-limiting or life-threatening conditions as they make the transition from children’s to adult services.” Also described are the first year's efforts under a three-year grant to get underway six “workstreams” to serve the goals of the Taskforce.
Transitioning Terminally-Ill Pediatric Patients  
Rebecca Brown, MDiv, C.T.
This article focuses on adolescents who are hospitalized with cystic fibrosis and the transition dilemma that arises when, after they have built a trusting relationship with their pediatric providers, they are turned over to adult health care providers who may not have expertise in this pediatric disease. Things become especially difficult when the adolescents view the transition to adult care as a transition to "where you go to die." Rebecca asks "how do we in good conscience transition patients in fragile health and ask them to deal with the stress of transition and end of life at the same time."

Noah’s Children: Transitions in Life and Lives  
Bob A. Archuleta, MD, FAAP
The founder and Medical Director of Noah’s Children Hospice and Palliative Care describes some of the many transitions that have emerged for children, families, professional staff, and the organization itself over its 16-year history. Many of these transitions were unexpected; most were dynamic, complex, and multidimensional.

A Rocky Foundation or the Human Factor?  
Prudence Mbu, MD, MPH
Using a case example, this article explores a transition from the acute aggressive care model to the hospice model and eventually to the withdrawal of certain interventions before end of life. Throughout, the stress is on the importance of interdisciplinary teamwork and good communication in providing pediatric palliative/hospice care.

Reflections from a Pediatric Hospice Nurse  
Kellye Byrn, RN, CHPPN
In this brief article, the author reflects on her experiences with a child who, against all predictions, lived 2½ years before her death. Kellye also comments on the transitions she experiences in providing hospice care for children and families.

Items of Interest
In each issue of our ChiPPS E-Journal, we offer additional items of interest.
SOME WAYS THE ILLNESS AND DEATH OF HIS BROTHER AFFECTED AN OLDER SIBLING’S LIFE

Scott Newport
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I started to realize Noah’s unique gifts when he was just five years old. That was when Noah’s newborn brother, Evan, was hospitalized for almost a year at C.S. Mott Children’s Hospital. Even though he was only five, Noah’s gift of sharing life with others was apparent. I can still remember how he befriended Mike, a boy who had been burned by his mother. This boy—who had no family except for his mother (who was in jail)—was bandaged on one whole side of his body. Noah would take Mike for a wheelchair ride around the fifth floor just about every day.

Eleven or so years later, I still see Noah taking in life and sharing it with others. These days I don’t always get to see the "Mikes" in his life, but I do see the results. Just last year, Noah received two unexpected awards, the Caring Award from his middle school and the Rising Star Award from our community. On the way home from one of the award ceremonies, Noah spoke up from the back seat and said, “I guess I got that because of Evan?” My wife, Penni, and I nodded, both of us trying to hold back the tears. You see, Evan died four years ago at the age of seven.

Even though I only made it through high school and I now work with my hands to make a living, I see so much more for Noah. At such a young age, he had to grow up so fast. Maybe because of all he’s been through with the illness and loss of his brother, Noah’s most dominant characteristic is that he cares for others. But he has also grown up to be a great student academically and a leader when it comes to sports. As a freshman in this past marking period, Noah received all A’s on his report card. This past fall, he was the captain of his team and played offensive center, inside linebacker, and kicker. He has proven his ability to protect the team; defensive positions are his favorite.

In one game, the opposing coaches called a conference in the center of the field at the end of the third quarter. Noah's coach and the official were there as well. The other coach was pleading to have #55 (my Noah!) stopped. The official threw his hands up and Noah’s coach said, “I can’t stop him. He does this all week in practice. What am I supposed to do?” One of our family mottos is: “Every Play Matters.” Noah lives that out—on the field, in the classroom, and in his relationships.

I’ll end with one story about how Noah practices caring in everyday life. Two years ago, after arriving home from being out of town, my wife told me that one of Noah’s teachers had called. Immediately I feared that Noah had done something wrong and prepared myself for disappointing news. With all the stress in our family that comes along with having a sick child and then a death, there are plenty of
underlying issues in play. I feared that something had erupted in Noah.

But Penni said, "Noah's English teacher called and said that Noah had offered to give a dresser away to a family at the school that is in need." I didn't get it at first, but then I realized Noah had offered up Evan's bedroom dresser. Noah did something I could never have done. You see, Evan’s room had looked the same since the day he'd died. But Noah saw a need and responded with caring. That's just who he is.
Changes, even little ones, are hard. Our human nature is to resist and stay with the status quo—with that which is known and comfortable, and, therefore, perceived to be a bit “safer.” If your favorite brand of shampoo is out when you go shopping and you have to switch brands, this may give you pause, but you’ll get over it (and you can always go back to your favorite brand on your next shop). However, imagine, for a moment, what it’s like for the family of a child whose curative care treatment options have been exhausted without “success” and they must now contemplate “transitioning” to hospice care. We all know these decisions, or “transitions,” can be painful, difficult, defeatist, and guilt-ridden for our pediatric patients and their families, and perhaps even for ourselves, as the professionals caring for them. C.S. Lewis once wrote, “Getting over a painful experience is much like crossing monkey bars. You have to let go at some point in order to move forward.” This journey of “letting go” and moving forward through the many transitions families face along the pediatric palliative and hospice care continuum seems to deserve more of our attention, time and effort, so that these children and their families, can make it across to whatever is waiting for them on the other side of those painful monkey bars, one rung at a time, with our help, guidance, and support.

Spanning the pediatric palliative and hospice care continuum is a myriad of different transitions. A few examples:

- The baby being born with a lethal pre-natal diagnosis which is incompatible with life, who may not even survive childbirth, where the family has to transition from a mindset of welcoming a new life, to preparing for a prenatal or neonatal death;
- The pre-teen with cancer who was in remission but whose cancer has come back and he must now transition from a “normal, healthy life” back to active treatment and hospital stays;
- The young adult with cystic fibrosis who has “outlived” (and therefore “outgrown”) her pediatric hospital and care team and who must now transition to a new adult care provider, care team, and healthcare facility.

While each continuum of care transition that our pediatric patients and their families face is uniquely different based on the age of the child, the illness/medical condition/diagnosis/prognosis, the child’s/parents’ level of care plan involvement and advocacy, their religious beliefs/culture, and so many other factors, there are some shared characteristics which seem to run through all of these transitional decisions, contributing to why they’re so difficult and painful for the families to make. These might include:

- The decisions are “heavy” ones with serious implications and ramifications that the child/family have to live with for a lifetime; they need to be sure that what they decide in this transition is “right” for their child, the rest of the family, for themselves
- The decisions often need to be made with incomplete information and facts or with differing opinions and points of view (or no recommendations or guidance) being offered by the healthcare team, further adding to the family’s indecision about making the transitional care decision
- Depending on the event(s) precipitating the transition, the family may just not be “there” yet and therefore, need more time (which may or may not be possible) to make an informed decision about what to do; sadly, some families may never get to where they can make a necessary transitional care decision and the child’s care plan, therefore, remains sub-optimal
- The family hasn’t had the “other side” of the transitional decision explained or introduced to them as the players may not yet be involved with the family if it’s a transition to another facility or healthcare team, for example.
So what can healthcare professionals do to help make these transitions of care easier for pediatric patients and their families? I was struck by a comment made by Myra Bluebond-Langer, PhD and Professor and True Colours Chair in Palliative Care for Children and Young People at the Louis Dundas Center for Children’s Palliative Care UCL-Institute of Child Health and author of *The Private Worlds of Dying Children*. She was a presenter at the Children’s Mercy Bioethics Center Webinar Series and in a recent webinar, she commented that the “holy grail,” if you will, “would be the achievement of death in a particular place where they (the child and/or family) feel most secure and looked after with and by those they know.” Now while not all pediatric transitions of care end in death, there’s something to this notion of making the child and family feel secure and looked after…to create a “safe” space for them as they make the transition, and that they also feel secure on the other side of the transition…wherever that has taken them.

In looking to information on other types of transitions—whether it be for a young child leaving mom and home to enter pre-school or kindergarten to aged adults transitioning to end-of-life care—there are several suggestions offered which could have some applicability for easing the fear and uncertainty that surrounds pediatric palliative and/or hospice transitions for our patients and their families. This might begin with broadening the definition of a “transition of care.” While the Joint Commission has defined “transition of care” as “the movement of a patient from one health care provider or setting to another,” and the American Medical Director Association talks about “the movement of patients between health care locations, providers, or different levels of care within the same location,” I offer for consideration that our pediatric palliative care “transition” definition should be broader, to include “the movement of a pediatric patient and his/her family from any point on the continuum of care to another in body, mind, and/or spirit.” This could include transitions from one provider or facility to another, as well as just a transition of mindset from the kind of care to pursue for their child, say from “Curative/Do everything” to “Palliative/Hospice—Stop everything but comfort care measures.”

Some practical considerations and interventions to consider in making these transitions of care (body, mind, and/or spirit) easier for these pediatric patients and their families include the following:

- Set an open and positive tone when having the conversation about whatever the transition might be. Let the patient/family voice their fears and grieve the loss of leaving something/someone known/comfortable/familiar and answer their questions honestly about how this will all work.
- Be positive and confident about the transition of care with the family; make them feel that you believe they are in good hands and that this is/will be a good decision for their child; they will take their cues from you, as the provider, so lead the way and instill confidence in them.
- Have the current care provider/care team personally come to say good-bye to the patient/family when they’re leaving a particular institution for another, or to return home in another city; this validates that they mattered and that they will be missed, which is important given the patient/family often considers the healthcare team an extension of their family. This might include the provider and healthcare team signing a good-bye card for the child and his/her family to take with them as a tangible reminder.
- Consider how to arrange a positive introduction if the transition is to a new provider or facility; look into the use of electronic communications (Facetime, Skype, etc.) to make a personal introduction to the new provider/team.
- Follow up with the patient’s parents after the transition to see how things are going and to see if they need anything further—provide that safety net during the transition and assurance that they won’t fall between the cracks/
- If amenable, make yourself available for questions by the family as they make the transition to a new provider, team, facility; let them know they are not alone.
- Empower the patient/family with being the best keeper of their medical health record and experiences and reinforce what great advocates they have been, and will continue to be, through this transition.
• Establish an “Ambassador” program whereby someone is assigned as an “Ambassador” to help meet each new patient/family and help them get settled in during the transition from one unit to another, one provider to another, one facility to another. This could be a peer, family member, volunteer, or staff person.
• Develop a collaborative cross-continuum interdisciplinary team that will facilitate within or outside a healthcare system transitions, much like a transport team might work with another facility to retrieve or deliver a patient to them.
• Invite the palliative care team in for a consult to help with the various transitions of care that may be anticipated for a particular pediatric patient and his/her family.
• Get to know and develop relationships with your local community-based pediatric palliative and hospice providers, to whom you may need to have children transitioned to given a particular child’s prognosis; invite them in to consult and partner on cases which will likely require a transition of care down the road so they’re known to the child and the family.

The Joint Commission’s Hot Topics in Health Care, Issue #2: Transitions of Care: The need for collaboration across entire care continuum also identifies the following activities as having a very positive effect on transitions of care:

• “Strong leadership support for new transition processes;
• Positive relationships between the sending and receiving providers;
• Involvement by the interdisciplinary team;
• Handoffs that involve interpersonal communication (instead of only written or electronic communication);
• Medication reconciliation, with the involvement of pharmacists;
• Two-way patient and family education – teaching the patient and family about their role and responsibility in managing a condition while gaining an understanding of psychosocial issues affecting the patient and family
• Electronic health records (EHRs), as long as they are not relied upon as the sole method of communication;
• Assigned accountability for transition-related tasks and outcomes.”

Important to note is that to pediatric patients and their families, it’s oftentimes the little things that can pay huge dividends during these times of transition in the care of their child. A few examples:

• When my infant niece was being transported from a suburban hospital to a specialized children’s hospital, being born with a life-threatening brain tumor, the transport team came to my sister’s room to get her and happened in on us baptizing her and praying over her before she was taken from my sister (who was not going to be able to travel with her due to her own post-surgical issues). The transport team stopped, waited, and even prayed with us, honoring a ritual that was important to us. This gave my sister great confidence in handing off her one-day-old daughter to a complete stranger who was going to transport her down to an urban children’s hospital. A few days later, when my sister was released and able to join her daughter at the children’s hospital, this same transport team saw that we were having some issues and asked how they could help us. They then proceeded to work some magic to get a room for my sister and her husband (when there hadn’t been one) at the local Ronald McDonald House so they could be near their dying baby. Another small thing that meant the world during the transition from life to death of my infant niece.
• There was a young adolescent who was being discharged and transitioned to care at his local children’s hospital in Detroit from a prestigious East Coast children’s hospital where he’d received care for a significant amount of time. Much to the dismay of the young man and his mom, not one of the staff came to say good-bye to them when they were leaving. This young man was not coming back to this facility again, and in fact, likely wasn’t going to win his cancer battle (which he did not), yet the healthcare team didn’t take the time to stop by and say so much as a good-bye upon their departure. Out of all that happened during her son’s care there (much of it good), this is the one thing that the mom most remembers.
My sister was dying after a 15-month battle with cancer. After the decision had been made to return home under hospice care, her oncologist came to see her at bedside and spent what seemed like an eternity (but was maybe an hour) saying good-bye to her and asking her what else he could do to help her at this point. While she was scared going home to face her death and to leave her provider/team behind, she felt better knowing that she had mattered enough to him for him to make the time to come say good-bye and to offer any further assistance during this difficult transition of care.

While these certainly aren’t complete lists of interventions or types of transitions our pediatric patients and their families face, it’s my hope that they do provide some food for thought. However and maybe most importantly, underlying all of this is the call-out for collaboration among providers all along the pediatric care continuum. While being in different healthcare systems, insurance reimbursement, questions of “who owns the patient,” etc., continue to pose challenges in how to make this collaboration happen more easily and frequently, this seems to be the crux of what will make the care transitions smoother and more successful for the child and his/her family. To go back to Myra Bluebond-Langer’s premise, it’s all about making the child and family feel safe, secure, and looked after. For our pediatric patients and their families, this means that they ultimately know that no matter what happens on this journey with their child, and no matter where they are or who they are being cared for, that their extended family (i.e., the provider/healthcare team/facility) has their back. As providers for these children and their families, you need to now ask yourself whether you’re doing this well during their times of transitions of care or mindsets, when they may need you the most. If you make them feel “safe, secure and looked after,” it’s a great start; if not, it’s time to get to make some positive transitions of your own to improve this for the families.

References


The Joint Commission. Transitions of care: the need for collaboration across entire care continuum. (February, 2013). Hot topics in health care, Issue #2
All transitions of care involve transfers of information and responsibility that put patients at risk. Relationships on one side of the transition bridge are disrupted while those on the other side must develop or reform quickly to fill the void. Without appropriate preparation, planning, communication, and coordination, any transition of care may result in poor health outcomes and increased costs. 1 While the transitions from hospital care to home or community care occur more frequently, for pediatric patients, the transition from pediatric care and services to the adult health care system may have more far-reaching impact. The topic of this journal explores the issue of transition from the perspective of patients, families, and providers involved in palliative and hospice care services. This article provides a general overview of the state-of-the-art and the challenges posed in ensuring safe and seamless transitions from pediatric care to adult care. While not written from the perspective of a palliative care expert, the article includes principles applicable to any specific population and concludes with a discussion of palliative/hospice care as a special case.

Adolescents and young adults find themselves in the biopsychosocial grip of an important life course transition involving the assumption of greater independence and attendant responsibilities in which the transition to adult health care assumes variable importance.2 Youth receiving palliative or hospice care may also be on the threshold of the largest of life course transitions against which leaving familiar relationships with pediatric care providers and forming new ones in adult health care settings may appear impossibly harsh and disruptive. With these ideas in mind, what is the current national context for pediatric to adult care transitions and what are the emerging best practices?

Unfortunately, most youth in the United States experience no preparation, minimal planning, and generally poor or absent coordination when their care is transferred from pediatric to adult providers.3 Pediatricians tend to postpone transition planning to age 18 offering little direct assistance with the transfer to a new adult care provider.4 While pediatricians experience difficulty finding adult providers for their patients, the adult providers find young adults poorly informed about their health conditions and medications, unready to ask questions, and unable to self-manage their care.5 The adult providers worry about their limited training or experience in the management of conditions of childhood onset.6

In 2011, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians published a clinical report titled “Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home.”9 In a granular, algorithmic format, the report guides both primary and specialty practitioners towards the incorporation of transition support into encounters with patients throughout adolescence and young adulthood. This clinical report provides the framework for a growing list of health care transition developments in quality improvement, research, education, and policy. Quality improvement offers evidence-based methodologies for the rapid incorporation and evaluation of new structures and processes of care into existing systems. Since 2010, the National Health Care Transition Center, GotTransition, funded by the US Maternal and Child Health Bureau successfully supported the implementation of its Six Core Elements of Health Care Transition into practice settings in six states and the District of Columbia using a learning collaborative model (See Table).
Transitioning Youth to an Adult Health Care Provider
Six Core Elements of Health Care Transition 2.0

1. Transition Policy
   - Develop a transition policy/statement with input from youth and families that describes the practice’s approach to transition, including privacy and consent information.
   - Educate all staff about the practice’s approach to transition, the policy/statement, the “Six Core Elements,” and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
   - Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. Transition Tracking and Monitoring
   - Establish criteria and process for identifying transitioning youth and enter their data into a registry.
   - Utilize individual flow sheet or registry to track youth’s transition progress with the “Six Core Elements.”
   - Incorporate “Six Core Elements” into clinical care process, using EHR if possible.

3. Transition Readiness
   - Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care.
   - Jointly develop goals and prioritized actions with youth and parent/caregiver and document regularly in a plan of care.

4. Transition Planning
   - Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.
   - Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
   - Determine need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
   - Plan with youth and parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.
   - Obtain consent from youth/guardian for release of medical information.
   - Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.
   - Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

5. Transfer of Care
   - Confirm date of first adult provider appointment.
   - Transfer young adult when his/her condition is stable.
   - Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.
   - Prepare letter with transfer package, send to adult practice, and confirm adult practice’s receipt of transfer package.
   - Confirm with adult provider the pediatric provider’s responsibility for care until young adult is seen in adult setting.

6. Transfer Completion
   - Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process.
   - Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.
   - Build ongoing and collaborative partnerships with adult primary and specialty care providers.
Proceeding directly from the clinical report’s health care transition algorithm, the Six Core Elements provide a six-step model for a planned health care transition process. Funding for GotTransition was renewed for five more years in July 2013, and all of the GotTransition tools and guidance are available at www.gottransition.org.

Over the past decade, the health care transition research literature has expanded, reflecting a growing interest and a better-developed network of communication among researchers. While the validation of tools and measures occupies much of this research, more work is beginning to focus on the outcomes of health care transition. This will be particularly important in order to evaluate the effectiveness of new health care transition practices in producing safer, more effective, and lower cost transitions to adult health care. The Health Care Transition Research Consortium and the recent formation of a health care transition special interest group within the Pediatric Academic Societies are further evidence of an expanding field of research.

The American Academy of Pediatrics and many pediatric subspecialty societies now incorporate health care transition topics into continuing education curricula and conference agendas. More work is needed to build health care transition content into medical school and residency education as well as involving physicians in training with care models of transition. The training and continuing education of adult health care providers presents an even greater challenge in the context of the adult health care system’s focus on an older, aging population.

In the area of policy, the access of health care insurance to young adults was greatly improved by the Affordable Care Act of 2010 through Medicaid expansion and the extension of dependent eligibility to age 26 in private insurance plans as well as the elimination of lifetime caps on insurance benefits and of pre-existing conditions as obstacles to coverage. Payment reforms are needed to incentivize both pediatric and adult providers to deliver high quality transition care. The transition process may extend over a period in which both pediatric and adult providers should be involved, requiring a mechanism for payment on both sides of the transition bridge. Currently, the US MCHB and its Office of Children and Youth with Special Health Care Needs have no public health policy responsibility beyond age 21, and no counterpart agency exists with a public health interest in young adults. Either the USMCHB mandate should be extended to age 26 or an agency for young adult health should be established so that members of this population have the benefit of being regarded as vulnerable and the opportunity for the healthiest possible life course.

Many patients in hospice or palliative care need special considerations regarding the timing or even the advisability of a transition from pediatric to adult care. In some instances institutional policies of children’s hospitals may dictate arbitrarily that care after a certain age must take place in the adult setting across the street or across town. Without preparation and planning, these sudden transitions can be emotionally wrenching, traumatic, and even dangerous for some young adult patients and their families. The special circumstances of youth receiving palliative care make the Six Core Elements of Healthcare Transition even more critical. Palliative/hospice care clinics and programs should all have a written policy or approach to transition that is familiar to and shared with all patients and staff. Young adult patients and families should be engaged in the development of such policies to ensure that their perspectives have priority. Planning and preparation for health care transition, even when that transition may be postponed indefinitely, should begin early with a mindful, explicit, and transparent process. Issues of the privacy of health information and the possible need for shared decision making or guardianship require consideration well before age 18. Finally, all young adult patients regardless of their prognosis, or current needs, should receive an adult model of care delivered with dignity and respect.

References


Despite the known benefits of coordinated, consistent care, many adolescents and young adults (referred to as “youth”) with medical complexity and their families suffer with fragmented, inconsistent, poorly coordinated care as they interact with multiple providers and sites of care. Poorly managed transitions of care are particularly challenging for those youth with significant palliative care needs. The focus of this article is to clarify strategies and tools that can be used to improve transitions of care as the youth moves between providers, sites of care, organizations, disciplines, and, especially, between pediatric and adult focused management.

**Scope of the problem:** There are over 400,000 children with medical complexity (CMC) who have functional limitations in the US. 2-3% of CMC have severe disability and 8,600 children might benefit from palliative care on any day. Medical complexity is characterized by a high symptom burden, multiple diagnoses and co-morbidities, frequent technology dependency, high resource use, and high family stress. They interact with multiple providers, organizations, and sites of care. These children/adolescents deserve special consideration as they are at highest risk for adverse outcomes, they are the most challenging (and possibly the most satisfying), and intervention improves outcomes. As 10% of children on Medicaid consume 72% of the costs, improving outcomes is not only a lofty goal but a practical one as well. Care and quality should not be site or provider specific.

**Case:** Damien is a 14 year old with moderate to severe cerebral palsy and moderate mental retardation. Over the last year, he has had 4 ER visits, 8 office visits in his home community and 5 at the children’s hospital, and 3 hospitalizations of respiratory deterioration, 2 of which required intensive care. He has seen his pediatrician, 4 pediatric neurologists, 5 intensivists, 2 pulmonologists, 3 social workers, 2 physical therapists, 2 home nurses, 3 ER physicians… His parents are getting mixed messages and are confused about what the future will bring.

Does improving collaboration, coordination, and consistency with successful transitions really help? Everyone has heard the phrase “quality happens in the hand off.” It is true! With this approach, the focus is on living, care is youth/family centered, suffering is minimized, and resources are used efficiently. Both provider and youth/family satisfaction are improved. Goals are identified so that there is a shared perception and higher chance that the treatment plan and goals are concordant. Practice models that reflect this approach include the medical home model and, not surprisingly, the palliative care model.
Barriers and facilitators to successful transitions: Fragmentation and poor coordination, lack of preparation/planning, inadequate models, youth/family/provider reluctance, lack of trained adult providers, and lack of funding for adult services all impede successful transitions. Models that focus on the organization rather than the youth/family are rarely successful. “Silos” are bad. Poor transition planning is associated with increased rate of drop out from medical care. When successful outcome of transition planning is defined by the youth taking responsibility for his or her health care, and completed discussions about future adult providers, adult health care needs, and/or change in insurance, transition outcomes in the US are poor and not improving (McManus 2013). Hispanic or African-American ethnicity, more severe conditions, lower income, public insurance, and absence of a medical home were associated with a poorer outcome of transition (McManus 2013; Lotstein 2009).

Successful transition planning starts prior to adolescence, is youth/family focused, and is based on the individual needs of the youth (Reiss 2002; Doug 2011). The primary decision maker is clearly identified and the youth/family are considered partners in care. Care should emphasize personal and medical independence and problem solving. There is advance planning and a designated transition coordinator. One such model, using coordinated pediatric/adult care and patient navigators to facilitate transition to adult providers for youth with type 1 diabetes, reduced the rate of youth dropping out of medical care by 1/3 (Van Walleghem, 2012). The documentation system supports shared information and communication. There is access to and reimbursement for needed services, hopefully within the same site. Implementation of the Affordable Care Act is expected to improve insurance coverage, including concurrent life-prolonging and hospice care, for these CMC.

Multiple perspectives: What are youth and family saying? (The Center for Health Care Transition Improvement)

- “It is normal to move to an adult system of care, even though at first I felt like the doctor was kicking us out of the practice”
- “It is hard for me to let go of my child’s care, but this helped me to promote my child’s independence”
- “It was time for my child to be comfortable and knowledgeable about their health and health care needs”

Youth: For children and adolescents, transition timing should be individualized and based on maturity, development, and understanding of the disease/condition. Age 12 is one frequently mentioned time to institute discussions. Discussions should be oriented toward the youth and time should be available to privately review quality of life issues, fears, and concerns for the future. Self-care and management is emphasized. A transition plan including goals of care should be developed.

Parents: Both pediatric and adult providers should view the parents as partners and experts in their child’s condition. They should assess parental understanding of the disease/condition, prognosis, potential complications, quality of life, and goals of care. Parental fears should be addressed.

Providers: The youth, family, and pediatric providers must overcome “separation anxiety.” Adult providers should develop appropriate palliative care skills as well as skills needed to care for youth with disability and medical complexity. They should clarify the primary decision maker and have clear consent and privacy policies. Clear information concerning access, and the function and culture of the practice should be available. Adult providers should facilitate not sever prior pediatric provider relationships (Sable, 2011).

Existing models of transitional care: There are many successful condition-specific models of transfer from pediatric to adult providers such as those for cancer, cystic fibrosis, congenital heart disease, and type 1 and 2 diabetes mellitus. While there is consensus about attributes of successful transition, there are few data on effectiveness or cost effectiveness. For some conditions, such as congenital heart disease and diabetes mellitus, there is emerging evidence that medical outcomes following successful transition to adult care are improved. Unfortunately, there is no evidence-based literature concerning transitions in palliative care. Many of the successful generic and condition-specific models are based on
blended and/or coordinated pediatric and adult interdisciplinary providers, especially in a single health care system. The pediatric partners can provide education in palliative care principles and conditions previously only seen in the pediatric population to support the adult provider caring for young adults. Some young adults prefer to see a pediatric provider at an adult site (or, alternatively, an adult provider at a pediatric site). Policies supportive of pediatric providers and hospitals caring for young adults may be helpful during transition. Direct transfer from a pediatric to an adult care provider is possible, but there may be limited access to skilled adult providers. Access to adult providers who are also skilled in palliative care is even more challenging. A less frequently mentioned model is that of an adolescent or transitional clinic. Co-management where the youth/family partners with multiple health care professionals in the medical home to provide consistent care is ideal.

Next steps for Damien: His pediatric neurologist, Dr. Winters, assumed the role of his primary physician and her nurse practitioner, Jim, became his key coordinator. Jim convened an interdisciplinary care conference including Damien, his family, and his community pediatrician. The topic was primarily to discuss the likely course of his condition, possible complications, upcoming transitions, and what the future might bring. Dr. Winters mentioned that, when the appropriate time came, she would collaborate with Dr. Turner, an adult neurologist who coordinated the adult cerebral palsy clinic. During the meeting, the parents’ goals were identified: to keep him home as long as possible, to keep him comfortable, and to facilitate attendance at his weekly playgroup that he enjoys. They developed an advance care plan consistent with these goals. The parents are concerned that, with so many transitions, uncertainties, and providers, their wishes won’t be followed.

Tools to aid transition, coordination, and consistency: There are many types of documentation both within and external to the organization-specific medical record that have shown to be helpful. The Center for Health Care Transition Improvement, [www.GotTransition.org](http://www.GotTransition.org), is a useful resource and contains several sample tools and policies.

- Physician (or Medical) Orders for Life Sustaining Treatment: These are usually state-based. Many states specify that minors and their guardians can complete this form describing preferred treatment in case of an out-of-hospital emergency (Sabitino, 2011)
- “My Wishes”: Pediatric version of “Five Wishes” from Aging with Dignity. The youth can document treatment preferences and goals of care
- “My Choices”: Advance care planning for children with life-limiting conditions (Noyes, 2013)
- Portable record or “healthcare passport”: This contains primarily medical information and is kept with the individual not the organization providing care
- Emergency information form: The American Academy of Pediatrics has an excellent example focusing on the medical issues of special needs children
- Transition plan/Action plan: Shriners Hospital and GotTransition.org, as well as others listed in the resources, have examples
- A written Advance Directive/Durable Power of Health Care Attorney or Advance Care Plan

Transition planning should be integrated into the Advance Care Plan. The advance care planning process provides anticipatory guidance, decisional support, goal identification, and a treatment plan. Physical, emotional/psychosocial, and spiritual suffering are identified and addressed. The interdisciplinary team, including both pediatric and potential adult providers, as well as the youth/family, is identified. How to and when to access providers is clarified. The plans developed are consistent with the goals. The team identifies community resources and available logistical support. The plan also addresses potential emergencies, complications, and indications for review of the goals and plan of care. A written or electronic Advance Care Plan is optimal, with copies available to the youth/family, and all current and potential care providers.

Damien’s transitions: The initial plan for Damien focused on life-sustaining treatment. This advance care plan was documented in the electronic medical record. The improved care coordination resulted in fewer hospitalizations, PICU days, and ER visits. At age 18, consistent with the transition plan, he began seeing both Drs. Winters and Turner in the Adult CP clinic. As his respiratory condition deteriorated, the plan soon transitioned to primarily palliative care. A written advance care plan, POLST, & communication
with community peds & home RN minimized ER visits & hospitalization. With the support of the palliative/hospice program, the community providers were able to ensure a peaceful death at home.

Summary: There is consensus that transition planning including coordination of multiple providers and services, consistency, and a designated coordinator improves outcome in youth with medical complexity. It is anticipated that the same strategies will improve care for youth with palliative care needs. Education of adult providers will enhance access to appropriate medical and palliative care services. Fostering self-care and problem solving of young adults will enhance their independence, as they are capable. Written and/or electronic documentation of the transition plan, treatment plan, and advance care plan will facilitate implementation regardless of provider or site of care.

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• East Midlands Development Centre. Principles For Transition: Guidance materials to improve transition into adult life for young people with additional needs. www.act.org.uk/core/core_picker/download.asp?id=389
• Center for Health Care Transition Improvement www.gottransition.org_Resources and tools for youth, families, and providers.
  o http://www.gottransition.org/UploadedFiles/Files/Six_Core_Elements_PDF_Package3.pdf
• Wisconsin Community of Practice on Transition 2009 www.waisman.wisc.edu/wrc/pdf/pubs/TAHC_2.pdf
• Sick Kids www.sickkids.ca/good2go

Medical record passports/transition tools
• Center for Children with Special Needs. Seattle Children’s Hospital http://cshcn.org/planning-record-keeping
• Shriners Hospital for Children
  o http://www.shrinershospitalsforchildren.org/en/CareAndTreatment/Orthopaedics/TransitionPrograms
  o http://www.syntiro.org/hrtw/tools/check_care.html
• Texas Children’s Hospital Transition Template Handouts. http://www.texaschildrens.org/Locate/Departments-and-Services/Adolescent-Medicine/TRACS-Medical-Topics/
• Tools from SSM Cardinal Glennon Children’s Hospital (FOOTPRINTS) and Seattle Children’s http://www.promotingexcellence.org/glennon/ http://www.promotingexcellence.org/childrens/
• Florida Health Care Transition Planning Guides (also in Spanish) http://hctransitions.ichp.ufl.edu/products_planning_guides.php
I'M TRANSITIONING FROM CHILDHOOD TO ADULTHOOD, ISN'T THAT ENOUGH?

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Adolescents are busy, and I’m not just talking about their social calendars. They are changing physically, forming their identity, becoming more autonomous, and evolving their cognitive skills. Each of these four developmental tasks of adolescence influences how they face challenges, make decisions, and cope with an illness. Each also needs to be incorporated into how health care providers facilitate a transition from pediatric health care to adult health care.

**Physical development**
Physical changes of puberty may start even before the “traditional” beginning of adolescence at age 10. Not only does each person go through puberty at different times, but parts of the body change at different rates. Outward appearance impacts how adolescents feel about themselves and how providers treat them (just think about the phrase, “appears older than stated age”). Both the pace of puberty and physical appearance/function can be greatly impacted by an illness and the medicines used to manage/treat it.

**Identity development**
Identity (“ego identity” in Erik Erikson terms) is the sense of self that develops through social interactions. That self-concept is a set of attitudes, ideals, and values that defines a person and shapes/guides behavior. The early adolescent may start to think about identity by asking, “Am I normal?” and comparing her/himself to others. Overtime, the adolescent may have more introspection and start to wonder “Who am I?” and eventually “Who am I in relation to others?”

The timing of illness diagnosis or illness flares within the process of identity development and can greatly impact how an adolescent views her/himself. Some adolescents become defined by their disease, while others may not want to acknowledge the impact having a disease has on their view of self (may deny that it changes them in any way). Some adolescents with life-threatening illness may not have access to the same peer groups and activities as they might otherwise (especially if they are frequently in the hospital or home-bound), thus limiting their ability to figure out who they are in relation to others or to establish functional roles (“I am a loving sister” or “I am a junior in high school”).

**Development of autonomy**
At the beginning of adolescence, most children are dependent on their caregivers. Over time, the adolescent may test the limits and take risks in effort to gain greater independence. Eventually, the adolescent may recognize the impact of risk-taking on their relationships with loved ones, and at that stage, they’ve developed interdependence. Adolescents with a chronic illness often have increased dependence on their family (compared with healthy peers). Some will exert themselves to regain a sense of control (often through treatment non-adherence), while others with long-standing illness may have a degree of “learned passivity.”

**Cognitive development**
Throughout adolescence, cognition advances from concrete operational thought (black and white thinking) to formal operational thought (abstract thinking, future-oriented “what ifs”). It’s estimated that only about 75% of all adults truly have the ability for abstract thinking, and the capability for abstract thinking is strongly impacted by health status.

**Development is fluid and fluctuates**
With development happening in a fluid process, it may be hard to know where an individual adolescent is at any one time. I like to picture a teeter-totter or a tug-of-war as an adolescent fluctuates between...
sometimes opposing thoughts. Take the adolescent who wants desperately to be normal, but at the exact same time wants someone to see them as special. Or the ones who get mad when others judge them, but then check in with their peers on whether what they are wearing, doing, or saying is “okay.” And that same teen who does something brave, may be viewed by peers as “attention seeking.” This ongoing internal conflict can play out with an illness as well. Some teens may say that a provider is giving them too much information, but in the next visit is upset because the provider is “keeping things from them.” Or the teen in one moment may recognize that death is near, and in the next continues acting like “it won’t happen to me.” Within the frame of transition from the pediatric health model to the adult health model, these same ups/downs and push/pulls may occur: “You’re kicking me out,” sentiments followed by “Stop treating me like a child.”

**Shared management**

Just as the adolescent is changing physically, forming their identity, becoming more autonomous, and evolving their cognitive skills, the health care system is asking them to develop their management skills. The Shared Management Model was developed within the world of physical disabilities, and can be applied to anyone with a complex medical condition (1). Within this model, patients progress from being the recipients of health care to being the CEO of their healthcare.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Parent/Family</th>
<th>Young Person</th>
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<tbody>
<tr>
<td>Major responsibility</td>
<td>Provides care</td>
<td>Receives care</td>
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<td>Support to parent/family</td>
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<td>and young person</td>
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<td>Resource to young person</td>
<td>Consultant for the young person</td>
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<td>and parent/family</td>
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Many “transition readiness” checklists apply the Shared Management Model. In the earliest stage, around 12-14 years of age, providers spend time “planting the seeds” about future healthcare responsibilities and the eventual transition to adult healthcare providers. By 15-17 years of age, adolescents should become independent in the daily disease management needed for their condition. Providers and parents can coach them to explain their disease and past medical history as well as their current medication and management. The hope is that through practice, the adolescent patient will become the expert on his or her health care. The actual age of transfer is highly variable, but it is most often between 18-21 years of age. Young people will still need guidance from their family and healthcare providers regarding their condition, when to seek medical attention, and medical decision-making.

**You’re not alone**

Some parents and pediatric providers have this idea that when a young person enters the adult healthcare system, the young person has to “do it alone.” However, such an image of the “big, bad adult hospital” is not in line with the framework of a patient-centered medical home (2, 3). In a survey study of internists, many of them wanted parents and families to stay involved, but also feared families would have high expectations for the internists’ time (4). Identifying the hopes and fears related to transition for both the young person and for the parent/family may help the provider (on the pediatric or the adult side) understand the meaning given to the transition process (5).

Palliative care providers are familiar with meaning-making and care collaboration, so are uniquely qualified to meet the patient “where they are” in the healthcare transition process (not just the transition from a state of health to disease or end of life!). My hope is that the developmental framework outlined here offers guidance for the patient “passing” from childhood to adulthood (pun intended!).

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Palliative care continues to gain acceptance within the field of pediatrics and referrals to our subspecialty are increasing. This may be due to a variety of reasons including the growing experience with and understanding of the benefits of palliative care involvement in the care of a pediatric patient. One often overlooked population that can benefit from involvement of a palliative care team is children with special healthcare needs (CSHN). This patient base is increasing with an estimated 10.2 million children that currently have special health care needs with 3% of them suffering from severe physical disabilities. It is also estimated that 15,000 infants, children, adolescents, and young adults die yearly from complex care conditions that would likely benefit from supportive care services such as palliative care. The expanding number of CSHN is, in part, due to modern technologic and pharmacologic advances for children with multisystem conditions. These medical advances can be life sustaining that can lead to prolongation of life while simultaneously causing a decline in overall quality of life. Many CSHN are cared for by a general pediatric practitioner as well as multiple subspecialists. They often require frequent and prolonged hospital stays as well as increased use of medical resources. Care coordination is important as many families of CSHN often feel overwhelmed and lost in the medical care shuffle as they try to access the best care possible for their child. Palliative care has great potential to help such patients and families navigate the medical system and consider their goals for their child’s care.

When first meeting a patient with complex health care needs and their family, I always try to determine the overall goals for the child’s care. I am often surprised to hear from my patients and families that they have never been asked questions about their hopes and wishes for their child and sometimes I find that I bring parents to tears for discussing such issues. The tears are not due to anger but they are due to the fact that no one has ever asked them questions about their goals for their child. They sometimes tell me that they have often thought of such topics but never felt comfortable bringing their thoughts to their child’s physician. It is our responsibility as pediatric medical practitioners to explore these issues with our patients and families. Many parents have considered their child’s poor quality of life and have wondered if they were doing the “right thing” by aggressively treating their child and advancing the technology required to care for them. As a palliative physician who specializes in CSHN I am fortunate to be available to discuss these sensitive issues with families at a time when they are open to discussion and comfortable talking with me. Allowing parents to consider and discuss whether they wish to transition their goals to a palliative focus can be very helpful. It must be emphasized that often these conversations are very difficult for patients and families and we must provide them with the space and time to consider their options carefully.

The inclusion of palliative care into the medical management of CSHN allows patients and families to focus on quality of life. The introduction of palliative medicine into the care of a child with a complex, life-limiting disease has improved in the last few years but there continue to be many barriers. One major barrier is the idea that palliative care can only be introduced when all hope for a cure is lost and life-sustaining therapies are not effective or stopped. This is very inaccurate. Palliative care can be provided in conjunction with cure-directed and life-prolonging treatment. The role of the palliative care physician and/or team should be explained as one that can improve care coordination and the child’s quality of life and not to simply help the family make the decision to sign a DNR order or withdraw care. When examining the goals and wishes of the patient and family, it is important to understand that every child and family is unique in their perception of quality of life. At times medical practitioners can see patients with severe developmental delays or other complex medical needs as having poor quality of life while their families see a happy child that has a good quality of life. It can be difficult to separate our own
feelings of what quality of life means as it has different meanings for everyone. A palliative care team can assist with these perceptions of the medical staff as well as work with the family to assess the patient’s quality of life along with the family’s wishes if medical decline occurs.

Transitioning from a life that does not include a CSHN to one that does can be extremely difficult for families. Parents have described this process as involving a type of grieving that can affect every aspect of their lives. The lives of CSHN and their families can rapidly become “medicalized” which can create a situation where the family is, in many ways, dependent on their child for their identity just as the child is dependent on their family for their medical care. When this occurs it may be challenging for the family to engage in discussions about limiting care or considering their child’s quality of life as they have great difficulty considering their life without their child. Palliative care teams have experience with such situations and can guide families as needed through the many transitions that occur in the life of a medically fragile child. One family described the “roller coaster” ride of emotions to me that occurred each time their daughter faced a significant medical illness that they were sure would end her life but then she would recover. The family chose to continue to support her with medical therapies such as ventilator support and antibiotics with each illness she faced, but she did ultimately die when they chose to limit aggressive medical therapies. Thankfully, I was able to become involved with this family early on which allowed me, and additional members of the palliative care team, to become a part of the patient’s medical team and not just a consultant whose purpose was only to discuss the child’s worsening prognosis.

Due to advances in technology and pharmacology, CSHN are surviving much longer than they would in past years. With each illness a CSHN faces, families may become less and less concerned for their child’s survival despite being told that their child is very ill and may not survive. This is an understandable position as their child may have “pulled through” each serious illness and families believe the child will do so again. One concern often voiced by medical providers is that parents of CSHN may not understand the importance of discussing and planning for their child’s decline and eventual death. Palliative care teams have unique experience with such circumstances and can assist the family throughout their medical journey with planning and preparation for future medical decline of their child’s illness. It is ideal that these discussions occur prior to an acute deterioration of the health of the child.2

Early integration of palliative care in the medical management of CSHN is essential. The relationship between the palliative care team and the patient and family evolves over time. Therefore, the earlier this partnership is created, the better. Palliative care can assist with symptom management and care coordination as well as ensuring that the family has all of the information required to make well-informed decisions for their child that are in line with their overall goals. Palliative care is not just about hospice and planning for end of life. Palliative care is about supporting families through difficult decisions as their child’s care requirements change over time and they consider their goals for their child.

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What do we mean by transition?

Transition can be described as the transfer of young people’s care from children’s to adult services. Transition is the name given to the planned and managed process of handover to adult care, including health, social care, housing, transport, education, and employment.

“...a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.” (Blum RW et al., 1993)

Why do we need a Taskforce focussed on transition for young people with life-limiting or life-threatening conditions?

In the UK, there is a big programme of reform underway for services for disabled young people. Most young people will have the same needs, whether they are deemed to have a disability or a life-limiting condition. We recognised that if we work with partners to improve the support available for disabled young people, we will improve much of the support that is needed for young people with life-limiting conditions too. So why have we established a separate programme to address the needs of young people with life-limiting or life-threatening conditions?

There is one principal difference, which is the unpredictable and degenerative nature of life-limiting or life-threatening health conditions. This means that health care and/or local hospice and other palliative care services need to be part of the planning and be available to provide 24/7 symptom control and end-of-life care as and when required.

The fact that young people with life-limiting conditions have deteriorating physical health and cognitive faculties may make transition planning a challenging prospect. It can get in the way of planning for a future in adult services and make it difficult for children’s services to “let go”.

We also have emerging evidence that the numbers of young people in the UK with life-limiting conditions is increasing year on year (Fraser et al., 2011). The prevalence (per 10,000 population) of young people aged 16-19 years old had risen from 16.3 to 23.6 between 2000 and 2010.

The Transition Taskforce

Together for Short Lives has established a UK-wide Transition Taskforce to develop a coordinated approach to providing integrated local support for the planning and delivery of care and support for young people with life-limiting or life-threatening conditions as they make the transition from children’s to adult services.

The Transition Taskforce wants to reduce these barriers to good transition for young adults with life-limiting conditions, by building bridges between adults and children’s services. With the right partnerships in place and the right training and support, these young people can be supported in a wide variety of settings by a wide variety of agencies.
Our vision is that all young people with life-limiting or life-threatening conditions will make the transition to adult services and live their lives as independently as possible according to their wishes, while receiving the care and support they and their families/carers need.

The Taskforce has an inclusive approach, working with everyone who has an interest in resolving the question of transition for young adults with life-limiting or life-threatening conditions, in particular those from adult services. The Taskforce proactively fosters engagement at local level with young people themselves and their parents as well as a variety of different professionals.

**What are the principles of the Taskforce approach to transition?**

The Taskforce approach is based on the model set out in the ACT Transition Care Pathway. It is a young-person centred approach which also takes account of the needs of families. The Pathway approach is about meeting the whole range of needs of a young person and their family, from recognition of the need to plan for transition, providing support within adult services, through to end-of-life care and ongoing support for the family. The approach advocates that planning for transition needs to start early, by age 14, and that parallel plans are in place both to maximise life opportunities and to ensure that they have the best possible end-of-life care, should this be needed.

“A journey is what the family take… A pathway includes all the resources required to make that journey...” (McDonagh et al., 2006)

The young person’s health care needs are an essential part of this support. We are working to support medical and nursing colleagues in the adult sector and to foster stronger integration between children’s and adult hospice services and to engage with specialist young adult hospice units where these exist. However it is not just a ‘health’ problem and we will be working with a wide variety of individuals, organisations, and alliances to help them to understand the needs of young adults with life-limiting conditions and what adaptations or changes to practice they can make to ensure that their service is accessible to young people with these conditions. We will be developing links with a range of adult providers and encouraging them not just to be part of transition planning in their region, but to lead the development of services and smoother transition for young people.

We are seeking to balance the ‘push’ from children’s services with a ‘pull’ from adult services.

The approach is about adding value to existing initiatives, whether these are services or networks, to make them fit for purpose for young adults with life-limiting or life-threatening conditions.

“Transitional care must involve young people, their families and /or carers as well as pediatric and adult care providers in health, education, social services and the voluntary sector.” (McDonagh et al., 2006)

**The six workstreams**

The Transition Taskforce has six workstreams:

1. Establishing Regional Action Groups across the UK to support service development
2. Developing and promoting reach and best practice resources
3. Ensuring the engagement and involvement of young people, parents, and key partners
4. Raising awareness and providing an information hub
5. Influencing policy agendas
6. Exploring sustainable funding models for the development of services
Progress to date

The Transition Taskforce had a real boost with a 3-year grant from the Department of Health in England to support its activity in England from April 2013 to March 2016.

The first year of the Taskforce has been a ‘forming’ phase with the focus on the establishment of the structure to support the ongoing development of the Taskforce strategy and delivery mechanisms to enable us to reach all parts of the UK. This included the development of the six workstreams described above.

The activity has expanded very quickly and the team now consists of an Executive Chairman, Executive Director, Head of Service Development, and Project Manager who has responsibility for young people’s and parents involvement in the Taskforce.

Workstream 1: Regional Action Groups (RAGs)

We set about establishing RAGs and National Transition Forums in the devolved nations and are now seeing these take shape and provide the impetus regionally to ensure that the needs of young people with life-limiting conditions are addressed in a coordinated and collaborative way. We have established a new forum for the chairs of these national and regional action groups to share their learning.

Workstream 2: Research & Professional Resources

In 2010 the Transition Partnership (a collaboration between Together for Short Lives, Help the Hospices, and the National Council for Palliative Care) working alongside a team of academic researchers at the University of York, was awarded funding by the Big Lottery Research Programme to conduct the STEPP Project (Supporting health transitions for young people with life-limiting conditions: researching evidence positive practice).

Key findings from this research related to:

- Who is a young adult and how are young adults with life-limiting conditions different from their peers?
- Young adults and their parents involvement
- Early days in the adult clinic & staying on an adult ward
- Helping young adults deal with uncertainty & conversations around end of life
- Developing partnerships with palliative care services
- When a young adult dies – bereavement support for parents

Two resources to support best practice were developed from the findings of the Study: a research briefing and a set of practice prompts. These are available as free downloads from the Together for Short Lives website: [http://www.togetherforshortlives.org.uk/professionals/projects/project_two](http://www.togetherforshortlives.org.uk/professionals/projects/project_two).

A key part of the Taskforce role will be to support colleagues working in adult services to implement the practice recommendations from this research as well as to develop and promote further good practice resources.

Workstream 3: Getting involved

To ensure the Taskforce is informed by what really matters for young people, we have set up a national Young Avengers Group (YAG). The YAG will be vital to enable us to raise awareness and influence service development directly based on the expressed needs of young people.

A Parent/Carer’s group is also established and we hope that in time this too will be an active group with a range of members with whom we can share ideas and who can act as our critical friends.
Workstream 4: Information and Awareness

The first phase of a Transition Taskforce web hub was developed in 2013 and this is now being refined to become a real ‘hub’ to showcase research, resources, and examples of innovation and new models of service delivery. The Taskforce also produces bi-monthly newsletters to share news, examples of services developments and good practice.

Workstream 5: Influencing

To ensure that the needs of young adults with life-limiting conditions were reflected in government policy across the UK we have established a separate, virtual, influencing group to ensure that we work with key policy partners with a collective voice when needed.

Workstream 6: Funding

The sustainable development of services is a critical success factor for the Taskforce and a key output in 2014 will be a publication called the ‘Framework for Service Development and Funding’ which will set out how services can be commissioned and funded through a range of mechanisms.

Conclusion

Whilst only a year in to the Transition Taskforce strategy, we have been delighted to see such fast progress and high levels of engagement, not only across the children’s and adults hospice and palliative care sector, but also within the wider sectors of health, social care, further and higher education, employment, and housing. With such great enthusiasm and commitment from our many partners in this project, we are optimistic that we will be able to bring about the change that we want to see - that everywhere in the UK young people with life-limiting and life-threatening conditions are receiving the care and support that they need to live their lives as independently as possible.

References

TRANSITIONING TERMINALLY-ILL PEDIATRIC PATIENTS

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Where would you want to die? With whom would you want to have that discussion? Pediatric patients approaching 21 do not always get a choice.

First, let me back up…. I direct an adolescent inpatient psychosocial palliative care program called Streetlight where college-age students partner with chronic and terminally ill adolescents. Our primary disease populations are Cystic Fibrosis (CF), Cancer, and Sickle Cell. For the purpose of this article, I will use the transition dilemma that has emerged with our hospitalized CF youth. After building a trusted relationship with them through their adolescent years, we hear this comment as they approach the transition to adult care: “Adult care is where you go to die.”

Nearly all parents of the CF patients we see were told their children would die before 21, if not earlier…and some did. However, due to medical advances in the past three decades many are living into their twenties and beyond. A pleasant surprise for the patient and family? Yes and no. The CF battle has not yet been won. In fact, the psychosocial stress of dying as an adolescent or young adult has presented a new and different challenge for the patient and family living with cystic fibrosis. (See, http://www.youtube.com/watch?v=mXe0bCceXqw) So, transition has become a palliative care matter for us. The patients’ fear is palpable. Reaching 21 is not seen as a happy achievement for some, but instead an acceleration of anxiety. It means the finish-line for comfort, familiarity, and trust.

During the election year of 2008, I was watching the many spin room discussions on cable TV. As I sat and listened, I was struck with how the very same speech could take on different meanings in the hands of a clever political analyst. Could it be that the idea of moving to adult care had received a really poor “spin” for CF patients? If so, could that be undone? Could we put a different spin on it? This was also the year of my daughter’s graduation from high school, and as I thought more about the power of the “spin,” it occurred to me that matriculating from high school to college had been given a pretty “cool” spin. Otherwise, why would she be so anxious to move from a bedroom of her own to one she would share with three other girls in a smaller space, and a bathroom she’d share with twelve others? Why would she look forward to being only one of two hundred in a classroom when in high school she had twenty classmates, and knew all her teachers well? In her case the questions seem laughable. She was leaving a rural high school to attend college at Cornell. The unspoken spin? This was an honor. It was an achievement. It promised independence, greater learning, and a host of new experiences. So, I wondered, could we “spin” the CF transition to adult care as an honor, an achievement, a promise for more independence, greater learning, and new experiences? We did just that.

With three of our Streetlight members (all in medical school or residency now), we started a four point program to give transition a better “spin.” We created: (1) a CF Yearbook; (2) a Graduation Dinner at a local restaurant; (3) a transition video created by the students and modeled after the TV show “The Office”; and (4) a Streetlight companion to go with them the day of transition. Central to our project was the development of a CF Yearbook. We requested photos from all of the pediatric staff they would have known: doctors, nurses, RTs, clinic receptionist, etc. We asked each one to submit a quote or words of encouragement to the graduate. In the center of the yearbook, we had two full pages devoted to each graduate, which included their own personal bio and the pictures they wanted to share. We usually had two to three grads per year. This was followed by a pictorial introduction to each adult team member doing something outside the hospital (e.g., fishing, playing an instrument, or spending time with their
family). We wanted them to meet the adult team first as real people, not simply as professionals. There was room in the yearbook for autographs. It also included a group picture of the Streetlight team (many of whom they knew already) with this caption beneath it: “We’re still here for you.”

The Graduation Dinner took place at BJ’s restaurant, which as you may know supports CF. They have provided free graduation dinners for our graduates and their families for years now. Ideally, these dinners were intended to include the patient and a family member, someone from pediatrics, someone from adult care, and their Streetlight friend. We were less successful getting clinicians to these dinners, so it was usually just the patient, family member, and Streetlight. The video we created was light and humorous and had some of the typical breakaway monologues made popular in “The Office.” There was humor, but also some straight talk and some sincere “spin” on the achievement of making it to adult care. However, with staffing changes the video quickly became obsolete. As the final piece of the project, they had their Streetlight friend who had either been assigned to them or had naturally become their friend during hospitalizations.

It seemed like a truly creative solution, and one we took on for four years, but I am seeing now that the difficulties in CF transition require so much more than “spin.” Looking back on those yearbooks (from 2009 through 2012), at least one graduate died each year within the first year of transition. Spin can only go so far. We have stopped making the yearbook because I now fear it masks a problem which must be addressed. Should CF patients be transitioned if their health trajectory is imminently and irrevocably fatal? My palliative perspective says, “No, they should not. They should remain with the treatment team that knows them best and on the hospital floor with familiar nurses and staff.” In our hospital, Streetlight had been the only crossover they had, and I do believe we provided comfort and a familiar face. We had been there at death and had sat in on hospice discussions, but pediatrics was missing from this picture. And that loss was painful.

There is a time for everything, and I do believe there is a time for transition. There is a time to grow up, a time to go off to college, and a time to move on to adult care and learn the independence and life skills needed to live with a life-limiting illness. But that time does not make sense for every patient living with a life-limiting illness at age 21. Some of our CF patients cannot (by all medical evaluations) turn their health around, no matter how compliant they are. They are on a certain decline to death. Some are socially and developmentally delayed because of poor family support or poverty or lack of education. If they cannot advocate for themselves when left alone, how will they navigate the adult floor of a hospital?

There is then, the other piece to this problem that needs addressing. Some of our adult floor nurses have not been trained in CF because it has historically been a pediatric disease. So, when even healthier CF young adults arrive ready for transition, they lose that trust and optimism when (for example) an adult floor nurse restricts their enzyme intake to three times a day or asks them why they would want double portions for their meals. One of our transitioned patients said, “They should be paying me for teaching these nurses about CF!” Another remained on the floor for months and was told she was not sick enough to be considered for a lung transplant. She later died on that admission. Once we lost a beautiful young man on his first admission to the adult floor. While I realize this can happen, what that young man’s father needed (more than antibiotics or advice) was to see a familiar pediatric face when he had to remove him from life support.

I realize that that there are insurance issues to consider and that exceptions get complicated, but death is a difficult thing to endure in a foreign environment—for the family and for the patient. I fear that there are egos involved and territorial claim-staking, but if we have promised to “do no harm,” how do we in good conscience transition patients in fragile health and ask them to deal with the stress of transition and end of life at the same time. We can do better—and we must.
Life in palliative care is a life in transition, whether as a patient, a palliative care physician, or a palliative care program. I started Noah’s Children Hospice and Palliative Care sixteen years ago. Needless to say, my professional life has been in transition ever since. The lives of our children and families are, likewise, in transition. The Noah’s Children program has been, and likely will always be, in transition. My intention with this narrative is to share some of what I have learned through my evolution as a palliative care physician, and also founder and medical director of a pediatric palliative care program.

Transitions are ongoing processes characterized by change and experienced by individuals, families, and organizations. Transitions are complex and multidimensional. They are experiences that are both a result of and result in change in lives, health, families, relationships, and organizations.

It was a typical hectic afternoon in the spring of 1999 in my medical office. I had patients to see, phone calls to return, and charts to dictate. For the previous two years, I had been juggling the challenges of managing Noah’s Children Hospice and Palliative Care Program, the only organization of its kind in Central Virginia, with the daily demands of a busy general pediatric practice. I was searching for ways to squeeze more hours than 24 out of a given day, when I met a family that convinced me to keep trying.

The thin, 16-year-old girl with a mass of glossy, black curls led her blind mother to a chair in my consultation room. When her father took the other seat, she sat on the arm of his chair and rested her hand gently on his shoulder. I noticed her fingers were red and swollen, the nail beds raw. The parents had come to me in a last-ditch attempt to seek help in caring for their daughter. The girl’s father, who struggled himself with the limitations of cerebral palsy and his wife’s blindness, poignantly related his daughter’s medical history. A happy and active child, she had been mildly developmentally delayed through her early childhood. She then began experiencing increasing muscular weakness, mental deterioration, and feeding problems. She had lost weight. She had become less communicative and more aggressive, with frequent outbursts. She began mutilating herself by pulling out her fingernails. The parents had consulted many specialists, including neurologists, endocrinologists, metabolic specialists, developmental experts, and gastroenterologists. Their daughter had been hospitalized many times. Most recently she had been in an intensive care unit at a local hospital, where the staff physician insisted the parents comply with an order for endotracheal tube placement to improve their daughter’s breathing. Not wishing to put her through another frightening procedure, they refused. Their daughter “wouldn’t survive until Christmas,” they were sternly told, and it would be “all their fault.” No physician had suggested why a tracheostomy was the better option, nor asked them how they were coping as a family with their terrible ordeal.

The parents inquired about Noah’s Children Hospice and Palliative Care for their daughter. After a thorough review of the child’s illness, and a discussion of the family’s fears, needs, wishes and hopes, I enrolled the child into the program. From that moment until she died two years later, their lives changed dramatically. With each passing day the family was visibly less anxious and distressed. A team of professionals including nurse, social worker, chaplain, and myself as their physician visited the family in their home on a regular basis. Their daughter never spent another day in the hospital. Her last hours were at home in her own bed, surrounded by family and friends. Later, the father described that difficult time this way: “Pediatric hospice is not about dying. It is about living life with dignity.”

A Richmond pediatrician for 33 years, I have been interested in how best to maintain a child’s good health and quality of life. I believe that I have a responsibility to advocate for and promote healthy lifestyles for
children. I have also learned that children and adolescents are likely to enjoy the highest quality of life when they also enjoy good health. Children have taught me that good health is directly dependent on key dimensions that include more than physical or emotional concerns. Good health is also determined by behavioral, social, family, cultural, academic, and spiritual health, and community connectedness. When all nine components of good health are in proper balance, a child or adolescent is likely to feel "whole" and enjoy a happy, healthy, and well-adjusted childhood. These nine dimensions of good health are important for all children, whether they are considered physically healthy or whether they are challenged with a life-threatening illness. When any of the nine dimensions is dysfunctional, the child is not whole and he or she and the family suffer. Restoring the wholeness helps to heal the child and family of their suffering.

In March of 1997, I attended a fundraising auction at my daughter’s school and was fortunate to place the winning bid for her kindergarten class art project, a large torn paper collage of Noah's Ark. It was charming, and I had it framed and placed in my waiting room. So many patients commented on the piece that it seemed to me something more should be done with it. This same class had constructed a giant cardboard castle for the playroom at the hospital adjacent to my practice. As part of the field trip to donate the castle, an "artists' reception" was planned at my office to celebrate the students' creativity. I made a print of the Noah’s Ark collage for each child artist. I suggested to the children that we might actually consider selling more prints and asked them what they would like to do with any profits. Fresh from the pediatric ward, they quickly responded "help sick children," and then suggested using the money to help "dying children."

Inspired by this group of fledgling artists, I began to envision an organization dedicated to raising awareness in our community of our seriously ill children and their families. Through the years in my practice, I had shared the frustration of such families because of the paucity of local services designed for their specific needs. Noah’s Children was officially incorporated on April 29, 1997. (The name of the organization was suggested by my daughter’s tireless kindergarten teacher!) My hope was that through service learning and children’s use of their creative talents, students could become engaged in philanthropy at a young age, and experience firsthand how they could make a difference in the lives of children living with a life-threatening illness. Not only would healthy children be helping disadvantaged children, but they would also be helping themselves by becoming involved in meaningful service learning. The community at large would benefit as well, and hopefully would begin to address the needs of these special families.

The very first project of Noah’s Children was the sale of prints and note cards made of the original piece. Additional student groups created more artwork, and soon there were other forms of fundraising, including dance marathons, children’s benefit concerts, and charity athletic events. Word spread through civic groups, schools, faith-based communities, and the news media. Within six months, Noah’s Children Hospice and Palliative Care, the first pediatric home-based hospice in central Virginia, was founded. We have been in transition ever since.

From the beginning, our non-profit hospice has been dedicated to enhancing the quality of life for children and their families facing life-threatening illness. Noah’s Children remains unique in its approach: it only serves children; it accepts patients from the time of diagnosis (not from the time of imminent death); families may continue to pursue aggressive treatment while receiving palliative supportive care; children with a wide spectrum of illnesses are accepted; and it accepts referrals from all hospital networks (eight hospitals) in our community. Children and families receive comprehensive, compassionate care from a team of professionals and a dedicated group of volunteers, and each family continues to receive support for a minimum of three years after the child’s death. Our physician and nurses are available to these families 24 hours a day. No family has been required to pay for the palliative care services that we provide.

During times of change and transition, difficult and multi-faceted decisions must be made. This is true for patients and families when they face the many challenges of living with a life-threatening or life-limiting condition. It was also true for me, as the founder of a community-based grassroots organization that was
providing a new concept of compassionate care for children and families navigating a competitive and complicated health care system. Dealing with the many challenges of health care delivery and of fundraising, Noah’s Children has weathered many program transitions over the years. At one low point of problems with staffing, the hospice partnered with a non-profit home nursing agency in the hopes of providing families with a stable source of nursing personnel. This decision stymied the growth and vitality of the palliative care program and nearly led to our demise.

I carefully weighed the options. Noah’s Children Hospice had raised community awareness of the needs of these special children and families for the previous ten years. Despite the difficulties, its patient base had grown steadily in the community and the region. The hospice had an excellent track record of providing quality care, and our staff could look back on those years with pride. At every opportunity, I had spoken passionately all over the city about the needs of these children. For the initial eight years of the hospice’s existence, I had donated considerable financial support and an average of thirty hours per week of pro bono services: managing the program, fundraising, and visiting families. I had spent many of these hours late at night and on weekends. All this had occurred while I worked a full time job in my general pediatric practice. My wife and two children had tolerated my many absences from home, because they were proud of my efforts. Maybe it was time to transition into retirement.

I just could not do it. I had been inspired by children and challenged by them to help, and I had promised them that I would do just that. The need was too critical, the families too desperate for help. I had to figure out how to ensure the program’s long-term viability and stability. With my family’s encouragement, I studied to become qualified for board certification in hospice and palliative medicine. In 2006, at the age of fifty-eight, I earned my specialty certification by the American Board of Hospice and Palliative Medicine, the eighteenth pediatrician nationally to have accomplished this goal. (I was recently, at the age of 65, recertified in Palliative Medicine by the American Board of Pediatrics and the American Board of Medical Specialists.)

Armed with certification as an expert in end-of-life care, I approached several community health care organizations with the possibility of assimilating Noah’s Children. In 2007, the decision was made that Noah’s Children would become a program of the Bon Secours Richmond Health Systems. The hospice and palliative care program has been dramatically expanding its patient base ever since.

About this time, Noah’s Children was consulted by a local county health department to help a family new to Richmond from Africa. The father, a minister, had come here to establish a church in the area. The couple was expecting their first child. Unfortunately, the pregnancy was complicated by the in utero diagnosis of a genetically defective fetus. Our interdisciplinary team became involved weeks before the expected due date. Through education, communication, and shared decision making, the parents and the team developed a complex birth plan that addressed whether the infant would be stillborn or born alive, and whether the child would live minutes, hours, days, weeks, or months. The team was present at the delivery to support the family. Their infant daughter lived for one hour. At his child’s funeral, the father gave the eulogy and said, “I didn’t just lose a child, I gained a family.” Since that first perinatal palliative care situation, we have now become very actively involved in providing perinatal palliative care in our communities NICUs and nurseries.

Currently, Noah’s Children remains the only community-based pediatric hospice and palliative care program in central Virginia. The hospice has cared for hundreds of children and family members. Referrals of patients to our program come from the three major health care systems in our area: Virginia Commonwealth University (VCU), Hospital Corporation of America (HCA), and Bon Secours Health System (BSHCS). These entities manage eight hospitals in the Richmond area. Forty percent of referrals to Noah’s Children come from VCU, thirty percent from HCA, and thirty percent from BSHCS. Although to date there are no third party studies of the results of our program, I measure the success of Noah’s Children by these simple facts: all competing health organizations were interested in assimilating us, and all regularly refer patients to us. Noah’s Children clearly has solid and ever-increasing support in our medical community.
The average length of stay for patients in most hospice programs across the country ranges from seventeen to twenty-four days. Noah’s Children has been a proponent of providing palliative care from the time of diagnosis of a life-threatening illness, when services can be most meaningful and effective. Such services are offered concurrently with curative and life-extending efforts. Our success is also reflected in the fact that in the past five years, the average length of stay of a patient in the Noah’s Children program is 256 days. Children in our program often live longer than their diagnoses would predict. When quality of life improves with comprehensive palliative care, there are often fewer reasons to transition care to hospitals and emergency rooms, and the child and family experience less turmoil. All transitions of care are smoother. Death of the child occurs with greater comfort and dignity. An ever-increasing number of our patients choose to die at home.

Children in my experience, have an uncanny ability to know when they are transitioning and are about to die. Six years ago, a bright, husky twelve year old with muscular dystrophy and end stage heart disease was referred to Noah’s Children by a community pediatric intensive care unit. The patient and the family were visited at home on a regular basis by the interdisciplinary hospice team. When asked what he wished for, this very stoic boy said he wanted “to live” but if he could not live, then he wanted “to die at home.” More than anything else, he needed to know his family would “be okay.” Nine days later, he asked his mother to stay with him in his room that evening. The two talked most of the night, sharing stories and expressing their love for each other. Realizing his death was imminent, the mother asked the boy several times if he wished the nurse to be called. He kept answering her that he did not need the nurse yet. Early the next morning, with no apparent or visible change in his condition, he told his mother, “You can call the nurse now.” Moments later, the nurse arrived, but the brave boy had already died. In essence, he was telling his family that he did not need the nurse for himself, but he wanted the nurse there to help his family. Later, the mother called the pediatric intensive care unit to thank them for Noah’s Children. She said, “More was done for us by Noah’s Children in ten days then had been done for us in twelve years.”

There are many reasons why I stay so committed to Noah’s Children Hospice and Palliative Care. I now have a clear understanding of the difference an interdisciplinary approach to end-of-life care can make for a dying child and family. Each situation that requires difficult decision-making renews my resolve and my dedication to these special patients. Now that the program has firm support in the medical community, I want to draw again on the creative inspiration that led to the organization’s formation. I hope to continue finding ways to apply my understanding of what constitutes good health in normal children, to those children who live with the challenge of life-threatening conditions.

I do understand that a palliative care organization must have a clear mission and vision. The staff must be passionate about the program. Flexibility is a key, but so is persistence. Fundraising is a necessity. In our community, we have established a large and growing base of individual and corporate donors, and adult volunteers and school children continue to find artistic and creative ways to help. Finally, I believe in what I term the “Circle of Care for Children with Complex Chronic Conditions.” The circle encompasses all of the following principles that must be clearly understood and promoted: 1) communication, 2) comfort, 3) choices, 4) continuum, 5) coordination, 6) comprehensive and interdisciplinary, 7) care plan that is interdisciplinary, 8) caregiver distress is dealt with, 9) culturally-sensitive, and 10) community-based. If each of these principles are dealt with, then it will result in meaningfully and effective transitions.

When I first started Noah’s Children I had no idea that it would become a second full-time career, and that for it to succeed, it would require the amount of time and personal financial support that it has. Currently, as medical director of Noah’s Children under the management of the Bon Secours Health Care System, I am very proud and humbled by the generosity of the Bon Secours Richmond Health System, who provide for all of Noah’s Children’s administrative and program costs. As a result, all the philanthropic money that is currently raised is placed in a Noah’s Children Fund, which is used for direct services for the children and families in the Noah’s Children Palliative Care and Hospice Program. This includes an array of services, such as, gift cards for food and gas or essential supplies, a Winter Holiday and Summer outing for the children and families, Summer camps for the siblings and patients who are able, book bags for all the siblings and the patients who attend school, Thanksgiving meals for families, Christmas gifts for all the patients and siblings in our program, and an extensive music therapy program for patients and
siblings. For the families in bereavement we offer most of the above benefits and also sponsor bereavement camps, journaling workshops, and bereavement support groups.

Pediatric palliative care is in its infancy but is a growing concept across the country. Noah’s Children has promoted an acceptable and effective model of palliative care that has been embraced and supported by an entire community. Noah’s Children and pediatric palliative care programs in general, will continue to be involved with transition; the transitioning of our children with devastating illness and the families who unconditionally love them and provide care, and the transitioning of our health care environment that searches for the best way to provide pediatric palliative care.

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A ROCKY FOUNDATION OR THE HUMAN FACTOR?

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Hospice is a unique area of medicine focusing on alleviating symptoms and providing comfort to terminally-ill persons through an intricately involved “interdisciplinary delivery unit.” This “unit” is made up of multiple individuals—patient, family/friends, care partners, social workers, nurses, chaplains, and physicians, just to name a few. For this unit to be a seamlessly functional and effective unit, involving several individuals with the singular goal of ensuring the patient’s comfort, implies that communication becomes an invaluable tool. In other words, the very cornerstone that makes for a solid hospice foundation is communication. In its absence or with its poor use, things can go wrong pretty quickly, but with its proficient use the worse situations can be easily ameliorated. So considering in sheer numbers how many individuals are involved with each hospice patient’s care, the potential for all kinds of communication mishaps/failures is limitless, and often based on our various individual differences to include but not limited to—gender, age, religious beliefs, values, cultural background, personal life experiences, professional experiences, marital status, and even whether or not you have children. All these issues being of exponential factor in the pediatric population in whom death is unacceptable. This quandary may lead one to then think that maybe having only one person with this perfect combo of personal and professional qualifications involved in a patient’s care may be close to optimal.

Let’s journey back and consider for a moment Dr. Cicely Saunders’ (a nurse, social worker, and physician) concept of “total pain.” Dr. Saunders directed one of the first hospice institutions, St. Christopher’s Hospice, opened in 1967 in London, England. Barring any medical or psychiatric ailments such as dissociative identity disorder, schizophrenia, and bipolar disorder, I imagine she may have had fewer interpersonal conflicts with this integrated modality for delivery of services since she was at least three healthcare professionals wrapped up in one. Today, this is a rather unlikely combo and as such the challenges of communication abound as illustrated by the case presentation that follows.

Debriefing/ Case Discussion:
NN was born on 10/10/2010 with dandy walker malformation that conferred several findings: agenesis of the corpus callosum with midbrain malformation, left eye coloboma, undeveloped right eye, tracheomalacia, adrenal insufficiency, and global developmental delay. His course as expected was very complicated resulting in protracted seizures requiring multiple anticonvulsants, as well as trach and PEG tube dependency. After several hospitalizations his parents arrived at the decision to have him on the pediatric hospice team at 11 months of age. They never “gave up” on him. They simply realized the rush back and forth to a tertiary care center which on previous hospital admissions was incapable of reversing his diagnosis or his course was a disruption to their family unit and their daily way of life. It had also become increasingly clear that a “cure” was impossible. As well, efforts at various treatments often resulted in significant discomfort and were merely temporary.

The transition from the acute aggressive care model to the hospice model was tough for sure. The parents required plenty of reassurance that staying home and not running to the emergency department, as they had previously become accustomed to, was not necessary as the focus was on controlling symptoms in his natural habitat, home. As rapport grew between the hospice team and the family, a proportional growth in confidence by the family was also observed.

Three and half weeks before his third birthday and two years after joining the pediatric hospice team, a much needed lengthy family conference was had with the family at their home with the entire pediatric hospice team present, as requested by the parents. A couple of days later and after difficult consideration the decision was made by the parents to have NN on supplemental oxygen via trach collar and off CPAP.
They no longer felt their son was “present” in all the ways they had always seen him. Shortly thereafter, he was no longer able to tolerate PEG feeds no matter how miniscule and so they were discontinued.

The transition by the parents to withdrawal of care was by any measure extremely difficult for them and by no means taken lightly. There had been some “pre-death grieving” that had begun as a result and additional support was necessary even though NN was visibly still alive. Despite this huge but expected challenge for the family, what we had not envisioned or anticipated was that the home health team that spent 18 out of 24 hours of the day in the home with the family caring for NN, would monumentally fall to pieces.

The home health team had two key players with some occasional fill-in help on their off days. The home health team was at odds. Finger-pointing reared its ugly head. There were reports, allegations, and suspicion about whether certain persons were giving more fluid through the PEG tube than the patient could handle despite all PEG feeds being discontinued except for medications and free water flushes. It was morally and ethically wrong for the hospice team to have persuaded the family to starve NN. NN was doing fine on CPAP and now he was being deprived of oxygen under the leadership of hospice. Then, who in the first place on the home health team actually observed and documented residuals with PEG feeds because this was never observed by some on the home health team. These concerns were never reported to the manager of the home health team and most importantly, never relayed to the hospice team. We were sure NN’s mom who now had a newborn son would unravel when one of the two key home health nurses quit the case. Fortunately, confident in her conviction and faith, NN’s mom remained resolute and steadfast. Another home health nurse left the team, for similar reasons because she didn’t agree with current plan of care. Excuses were made for abandoning NN and the team. Nonetheless, NN was the most at peace through it all. Six weeks after discontinuation of PEG feeds and seven weeks after discontinuation of the CPAP and placing NN on trach collar for supplemental oxygen, NN died at peace, at home, and surrounded by his loving family. A peaceful end to a tumultuous and rocky path.

Lessons learned:

- Communication is always key and indeed constitutes the hospice foundation. Communication between the home health and hospice teams definitely could have been better in order to minimize splinters/fractures in NN’s care and the entire unit.
- Assumptions can serve as road-blocks or speed bumps to effective communication. To assume that being involved with the provision of hospice care implies one’s comfort with death and dying is a mistake.
- To assume that the absence of questions means there are no questions would be false. Equally, to assume that all parties involved are of equal/similar understanding and are on the same page as concerns the care plan in particular, also can be inaccurate.
- Caregiver fatigue is a real entity.
- Lines can easily be blurred between being a professional and a friend, especially when the home is the care nucleus. Like NN’s mom accurately pointed out and paraphrased here, one of the key home health nurses had started acting like she was a grandparent seeming to be more of an advocate for NN than were the parents.

Systems adaption:

- Scheduled educational courses are being provided to the home health team to boost their knowledge and comfort level with caring for the pediatric hospice patient.
- Widely publicized available sessions to provide support to the caregiver.
- Emphasis on proactive collaboration/meetings amongst ALL team members participating in a patient’s case particularly when there is a change in the plan of care however minor.
- Presented proposal that those most comfortable and experienced with pediatric hospice and certain circumstances unique to a patient be included in their care whenever possible.

In conclusion, the human factor being the ability to effectively communicate IS hospice care.
Sunday night at 9:58 p.m. I was standing in a hospital room at Vanderbilt Children's Hospital. I'd been watching the clock drag on for a little over an hour and with each minute that passed I was anxiously watching for each time her little chest would rise and fall until eventually, it didn't. I'd spent the better part of two hours with her family trying to reassure them and help them through the most difficult journey they most likely will ever encounter. We laughed, we shed tears, we hugged, and we held each other close as we knew her time was short. As her mother rocked her quietly with her grief pouring out, I winked at her silently to say "it's gonna be ok. God's got this." My precious girl, my miracle baby, she wasn't supposed to make it two days, but she did. She wasn't supposed to make it a month, but she did. She wasn't supposed to make it to her first birthday, but she did. She fought her way to two-and-a-half years against the odds. But despite her fighting spirit, here we were. In the dimness of a hospital room on the fourth floor late on a Sunday evening we were trying to prepare our hearts to say goodbye. As I stood there, I began to think of how blessed we were by her short life and the many lessons she taught us. Never give up—no matter how hard it gets and no matter who tells you that you can't, you can. Love with all your heart—boldly and shamelessly as too often, the opportunity is gone far too quickly. I thought of how blessed her family was at that moment to have the opportunity to hold her close and love her straight into the waiting arms of our Savior. What a beautiful, precious moment, one that I got to be witness to and a part of, for I loved her too. Words cannot express the absolute honor and privilege I felt to be a part of that experience.

I lost four patients this past week. To say that it was a rough week is a gross understatement. I'd begun to question if I could keep doing this work. Each time I lose one of "my babies" I feel as if they take a piece of me with them when they go. A small piece of my heart goes with them when they leave this earth and eventually, it catches up to me. It did last night as I drove home. I began to silently think about what I would say to the team when I told them I was leaving. I envisioned what I would do in my next job—would I stay with pediatrics? Would I maybe go to work at Vanderbilt? Would I maybe go back to school? The possibilities were endless. But as I drove home in the darkness an image came to my mind. The image of her beautiful little fingers reaching up to touch my face when I held her. Her sweet little crooked smile and the way she looked when she slept in my arms. My precious girl. I began to realize—she's not the only one. There will be others. If I leave now, I will miss the opportunity to care for other children and families who will most likely touch my life and heart the way she did. Selfish? Maybe. More like the realization of how blessed I am to be able to do this work. To make a difference in the life of a child, especially one facing the end of her life—that's my true reward.

So go ahead and take a piece of me with you when you go, God will give it back.
ITEMS OF INTEREST
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. ELNEC TRAIN-THE-TRAINER COURSE ON PEDIATRIC PALLIATIVE CARE. Sponsored by the Hospice and Palliative Nurses Association (HPNA) and the End-of-Life Nursing Education Consortium (ELNEC), this course will be offered in Rosemont (Chicago), IL, on July 29-30, 2014. Register online.

2. TWO USEFUL LINKS:
   a. A policy statement from the American Academy of Pediatrics, Section on Hospice and Palliative Medicine and the Committee on Hospital Care, entitled "Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations," was originally published online in Pediatrics on October 28, 2013 (DOI: 10.1542/peds.2013-2731).
   b. An April, 2011, article "Financing Pediatric Palliative and Hospice Care Programs," is available from the Catalyst Center, Health & Disability Working Group, at the Boston University School of Public Health.

3. PEDIATRIC CONCURRENT CARE BRIEFING AND IMPLEMENTATION TOOLKIT AVAILABLE. NHPCO is pleased to offer a Pediatric Concurrent Care Briefing and an Implementation Toolkit, available free of charge online. These and other resources are available at www.nhpco.org/pediatrics.

4. PEDIATRIC PALLIATIVE CARE TRAINING SERIES IS AVAILABLE ON E-ONLINE. The 10 module training series on pediatric palliative care is available on NHPCO’s E-Online education portal. Sign up for the individual modules or the complete series that will furnish you with the latest trends in pediatric palliative care provision.

5. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL. In the many of our past issues, we have addressed a wide range of subjects. For upcoming issues, we are thinking about addressing issues related to logistics around the time of death and memorization, and a starter kit or "how to" tools for new programs in pediatric palliative/hospice care. 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 any of the following: Christy Torkildson at christytork@gmail.com; Maureen Horgan at horgan.maureen@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

In the meantime, you can visit archived issues of this e-journal at www.nhpco.org/pediatrics. Among them, you will find articles on bereavement, sibling bereavement, self-care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, the role of pediatric palliative and hospice care in creating systems to support children, families, and the community, children are not little adults (i.e., respecting differences in providing pediatric palliative/hospice care), honoring volunteer perspectives, perinatal palliative and hospice care, perspectives of fathers and other males, differences between pediatric hospice care and pediatric palliative care, and the Affordable Care Act and concurrent care.

6. READER’S CORNER. Our occasional Reader’s Corner column provides 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 palliative/hospice care, but that may not be known to all readers of this newsletter. Contributions to the Reader’s Corner typically include an abstract of the publication, a description of the audience for this information, comments on
what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles following the model described. Please send all such suggestions to Christy Torkildson at christytork@gmail.com.

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 Communication 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 Pediatrics@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, the Solutions Center will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page for further materials and resources of interest.