

ChiPPS E-Journal

Children's Project on Palliative/Hospice Services

Released in collaboration with the National Hospice and Palliative Care Organization

National Hospice and Palliative Care Organization
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ChiPPS E-Journal
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Issue Topic: Transitions

Welcome to the 54th issue of the ChiPPS E-Journal. This issue of our E-Journal explores some of the many transitions that children, adolescents, family members, and care providers experience in the course of pediatric palliative or hospice care. We acknowledge that the 13 articles in this issue can only cover a limited number of examples of such transitions, but we hope that they can spark discussion both of the transitions they describe and of the larger range of transitions that occur in real life. In any event, our goal is to provide at least a beginning in discussing such matters.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by the ChiPPS's E-Journal Workgroup, co-chaired by Christy Torkildson and Ann Fitzsimons. 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. We are currently discussing topics such as Integrative or Complementary Therapies and Myth Busting for future issues in 2019. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at ctorkildson@mail.cho.org or Ann at ann@here4U.net

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Issue #54: Transitions

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

Unpolished Silver

p. 5

Scott Newport, Evan’s father

In this article, our resident poet and essayist describes how another bereaved parent now working as a volunteer introduced him on Valentine’s Day to a young girl with neuroblastoma. They bond over their joint interests in writing about their experiences and what a physician said to the girl: “You still have time on your clock.” As he drove home, Scott reflected that the bereaved parent who introduced him to this girl “reminded me of the losses in our lives and how we’ve learned to find love in the most unusual places.” He concluded that this was his best Valentine’s Day ever and expresses the hope that next week he could work jointly with his fellow bereaved parent on “a poem where the first line will be, ‘When heartaches turn to gold.’”

Justin’s Gift

p. 7

Christy Torkildson, RN, PHN, PhD, FPCN

In this article, the Co-Chair of our ChiPPS E-Journal Workgroup introduces a boy who was diagnosed with Ewing Sarcoma at the age of 11. Then Justin tells the story of his journey with cancer and his involvement with the Peter Pan Foundation as a way of giving back. As he writes, “To go from hospital bed to performing for the children who need a little light was a magical experience.” Justin concludes that “The important takeaway is no matter how dire a situation we are in, there is always a glimmer of hope that we need to just hold onto and let it take us where we need to go.” Justin is now 17 and cancer free.

Still Transitioning . . .

p. 9

JoAnn Mosel, Richard’s mother

Here a mother describes the many challenges she and her son (now 31) have experienced as he made the transition from the pediatric to the adult care system. Richard has a rare disorder called Duplication 15q (Isodicentric 15q) Syndrome which manifests in autistic traits, sleep disorder, pervasive developmental disorder (PDD) and epilepsy, among others. JoAnn focuses on where to start in this process, the many dimensions involved in assuring quality of life, and thoughts about the future.

Help during the Storm

p. 12

Rebecca McClary

What about the easily-overlooked challenges involved in the many transitions arising from moving from one state to another with a five-year-old daughter with a chronic lung disease? In this article, Savannah’s mother illuminates some of these challenges and provides a checklist for moving out of state.

Holding Hope with Families through the Ups and Downs of Their Medically-Complex Journeys with Their Child

p. 14

Ann Fitzsimons, BS, MBA

Many professional care providers are challenged to appreciate the hopes that families may hang onto during their journeys with a child with multiple complexities. In this article, the Co-Chair of the Workgroup that produced this E-Journal draws on her experiences and those of her family when her niece, Riley, “was ‘born dying’ with only a week’s notice that something ‘really bad’ had happened in utero.” As she writes, “it was hard to know what to hope for” when Riley only lived for eight days. In fact, “I realize now that ‘Hope’ shifted and changed so many times.” The point for families is to appreciate that they can still hold onto hope, however much it may be limited and fluctuating. The point for professional care providers is found in the concluding principles that can enable them to engage with these families in “holding hope.”

The Infertility Journey: A Map for Care Providers

p. 17

Joelle Ehre, MA, LMFT

Pregnancy Loss: A Minimized Grief

p. 20

Donna Rothert, PhD

These two articles describe losses encountered when a desired pregnancy is not achieved or when it leads to a loss. In both cases, there may be intense grief, compounded by the fact that the losses and the



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grief are often not recognized. Both articles explore the complexities of such losses and suggest constructive ways in which loved ones and professional care providers can help.

Transitions: Never Ending; Always Changing p. 23

Suzanne S. Toce, MD

The Rocky Road: The Transition from Pediatric to Adult Services for Adolescents and Young Adults with Complex Chronic Conditions p. 28

Suzanne S. Toce, MD

These two articles explore transitions within pediatric palliative care and in the specific circumstances related to moving from pediatric to adult services. Both articles display the precision, detail, and comprehensiveness that we have come to expect from the many contributions that Dr. Toce has made to our E-Journal over the years. There is a certain overlap here, especially in the lists of Resources, but we have chosen to let that stand on the principle that it is better to have more richness than less, especially for readers who may primarily be interested more in one of these articles than in the other.

How One Pediatric Hospice Program Covers Care Transitions across a Broad Continuum of Ages and Medical Conditions p. 32

Elizabeth Rocha, RN, BSN, CHPPN

This article provides an example of how three programs under one organizational umbrella provide a broad range of services including: support for seriously-ill pediatric patients who are not yet ready for or who do not meet the qualifications for hospice care; emotional, social, and clinical support for expectant parents who learn that their unborn child may be facing a life-threatening or life-limiting illness; and an experienced team of pediatric-trained staff to care for terminally-ill children and their families. The article includes a half-dozen lessons learned.

Creating Connections: A Social Work Perspective in Connecting with Medically Complex Children and Families p. 36

Amanda Hedrick, ASW

Here a person with a background in county child welfare and for-profit adult hospice social work, describes her new role as a social worker in pediatric hospice and palliative care. She focuses especially on the challenges presented in making this transition and the awe she felt in connecting and building rapport with a family with a non-verbal, non-ambulatory child.

Partners for Children Program: Disrupting the Status Quo p. 38

Natalia Simon, MBA, and Ken Pituch, MD

The authors of this article describe a program designed to disrupt the cycle experienced by many families with a child with a chronic complex illness in which life revolves around frequent trips to specialty clinics, pediatrician visits, and emergencies that often result in hospital stays. The program does this by transitioning to at-home care and visits from social workers and nurse practitioners, 24/7 provider access, and coordination of care. They argue that a program like this serves the interests of families, children, providers, and payers.

Induced Positive Transitions: A Model for Developing Hope, Resilience, and Joy in Seriously-Ill Children p. 40

Rabbi Dr. David Fox

“Induced positive transitions” (as opposed to the inescapable negative transitions associated with the process of illness) seek to reintroduce positive experiences for children with a serious illness. This is done through a planned-respite model “wherein the family is guided in a time-limited reversal of the patient’s veritable withdrawal from social interactions and positive activities. This is facilitated through providing intervals of out-of-home opportunities to engage with other children, to participate in age-appropriate ‘normal’ activities, and to access creative-productive skills through art, acting, music, and movement therapy.” The program provides activities camps for children and siblings, plus parent support groups.



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ADDITIONAL NOTES

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpc.org/pediatrics.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its E-Journal Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

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

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UNPOLISHED SILVER

Scott Newport

Evan's father

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Paula was standing next to me when she leaned down and whispered, "Hey Scott, you don't have much time left."

It wasn't till I walked out of the kid's activities room, I remembered it was Valentine's Day. The clock on the wall read just past four p.m. and my friend Paula had been trying to prompt me about rush-hour traffic. Unfortunately, that was an hour or so ago. Now it would take well over 90 minutes to make the fifty-mile trek home.

While I waited for the elevator on the pediatric oncology floor at C. S. Mott children's hospital I was reminded again about February 14th. Before I left the room, Molly, a child-life specialist, offered me a heart chocolate from a small decorated basket. I unwrapped it and popped the candy into my mouth.

After hearing the ding of the elevator doors opening, I stepped in and was greeted with smiles from a couple of cardiac nurses from the tenth floor. One was corralling a heart shaped balloon. The other talking about her anticipation of going out with her husband. This year I had no valentine to go home to. No candlelit dinner to attend.

While driving home, I thought about my first encounter with Brittany that afternoon. Brittany is a young adult who has cancer. I'd been at the children's hospital for a meeting and decided to stop by to see one of my colleagues on the seventh floor. Before I left, Paula said, "Hey Scott, I want you to meet someone special."

When I stepped into the activity room with Paula, I noticed a young lady with dark skin and short curly hair. She was sitting in a plastic chair alongside her steel, IV pole. I counted five pumps of medication going into her. The quintet of clear plastic lines drooped a bit and then seemed to connect somewhere, hidden by her top.

"So Brittany, I hear you've been doing some writing," I said.

Before I could say another word, she started to rattle off a project she had been working on. She had been invited to help write lyrics to a song for a fundraiser for sick kids. She had also mentioned writing some raps and the occasional poem in the past.

"Well if it's OK with you, would you read me the words?"

I never told her but her note book looked exactly like mine. There were words written in all kinds of directions. There were paragraphs completely scratched out. Every line was crudely doubled spaced, the same way I do, so there's plenty of room for self-edits. The whole scene reminded me of unpolished silver.

"When I help people refine their writing," I said, "I will often have them read their piece and then I will repeat it back to them. Is it OK, Brittany, if we do that?"

Before I could say another word, her nurse walked in the room to silence one of her alarms. That's when Britany questioned, "Where did this guy come from? Why haven't I seen you before?" The other folks in the room didn't say a word but seemed to wonder, too. That is, except, for my friend Paula. Paula's boy died of cancer awhile back, her husband the year after. She now volunteers on a weekly basis.



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In that moment, there seemed to be a beautiful bond being made between this old white guy and a young black chick. I must be close to three times her age.

Nudging her IV pole with my elbow, I said, "So how long has Bob been hanging around?"

She giggled a bit about me referring to the statue of medication as Bob. I knew then, from past experiences with patients and families, she would start to unravel her story from the beginning.

"It was a couple of years back when I started to have stomach problems," she said

"Before I knew it, my mom, sister, and auntie were all sitting alongside me in a doctor's office and heard the words, 'Maybe six or seven years.'"

She started to cry a bit and told me another doctor came in shortly after and said, "The other doctor was incorrect in what he said."

She continued, "That was the first time I heard the word neuroblastoma."

I interrupted and said, "I just love what you said a couple of sentences back."

"What's that?"

"It's what you told me that the second doctor said, 'You still have time on your clock.'"

At that moment, I wasn't sure if I was doing the right thing, but I suggested we both write a poem and the first line would be, "You still have time on your clock."

On my long drive home, I called Paula and thanked her for one of the best Valentine's days ever. She reminded me of the losses in our lives and how we've learned to find love in the most unusual places. I agreed.

Yea, I thought and became even more excited to finish my poem while Brittany and I still have time on our clocks. I think I'll ask Paula next week if she'll work with me on a poem where the first line will be, "When heartaches turn to gold."

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JUSTIN'S GIFT

Introduced by
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Justin is a teenage boy I met through the Peter Pan Foundation. The Foundation is a not-for-profit group that "is dedicated to inspiring children of all ages to reach their full potential by building confidence, character, and creativity through music and theater, while instilling the value of community outreach and philanthropy" (peterpanfoundation.org). Justin is a member of the Bay Area Magic Makers (BAMM Squad), the teen council of the Peter Pan Foundation. Not only is Justin a talented singer, dancer, and actor; he is also a cancer survivor.

Justin's cancer journey was complicated, challenging, and painful—for him, his family, and his friends. There were times when side effects were unbearable, and a successful outcome was not a certainty. Thankfully, Justin has now been cancer free for 5+ years and is a high school senior busy completing applications for college. He is also extremely busy giving back.

The Peter Pan Foundation formed a partnership with the Make-A-Wish Foundation in 2018 because the Foundation had often been asked to help create a memorable moment informing children that they would be getting their wish or providing the entertainment for their wish! In December 2018, the BAMM Squad organized a concert fund-raiser for the Make-A-Wish Foundation. It was during this concert that I heard Justin tell his story, a story I thought should be shared with all our readers!

Justin spoke eloquently of the transitions in his life and what they meant to him, from the boy who once had his own Make-A-Wish, to the young man he is now, helping to grant wishes. He spoke of the emotions he experienced that ranged from terror to pure delight. He spoke of how it helped him realize the impact his cancer had on not just himself, but also on his family and his friends. And he spoke of smiles, the impact of seeing children receiving their wish and how it touched him—what giving back in this way was doing for him.

After hearing Justin speak, it seemed that his words would fit in with our issue focused on transitions. Although different than most of our articles, I hope his message touches a cord with each of our readers as they did with me. The following are Justin's words.

When given a second chance at life, you take it and place it somewhere it will shine brighter than ever before. Through the darkest moments I found my strength and defeated all odds against me. The people around me, my family and friends, helped me through that time. Most of all it was my inner determination, my hope and desire to come out on top and do something extraordinary with the life I fought so hard for.

My story begins at 11 years old. A pain in my right femur had taken over my life. Months went by and no doctor could tell me what was wrong with me since my x-ray looked normal. The pain became unbearable, which led to an MRI and then a biopsy when that scan revealed what looked like a tumor. That is when they found the disease that would change my life. At 11 years old on March 5th, 2013, I was diagnosed with Ewing Sarcoma. It had spread from my leg to a few spots on my spine. I was young enough that my parents and doctors shielded me from the truth of the severity of my cancer, which is what actually helped me defeat this beast. It never occurred to my 11-year-old self that this was something I wouldn't get through. I went through nine months of extensive treatment: chemotherapy, radiation, and a stem-cell transplant. Some moments were pretty miserable, but I always tried to stay upbeat and positive, and now I can hardly remember those bad times. My positive attitude never faded for I thought this was just another sickness I needed to get through, but this one just took a little longer.



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Along with a positive attitude, I had faith, and most importantly...hope. I had the hope that I would fight this fight and go and do incredible things with my life. In October 2018 I was pronounced five years cancer free. Now I spend a lot of time giving back to the community that had helped me so much when I needed it most.

I am so thankful to have found and be a part of The Peter Pan Foundation, which is a non-profit organization that raises money for Children's Hospital Oakland programs along with other special needs groups all around the Bay Area. Through my association with the PPF I have found my voice and learned so much about the importance of giving back. This past November I got the chance to come to the hospital as the beloved character, Peter Pan, and perform for the hospitals 'CHO show.' That experience was unreal for me. To think I had come so far was very emotional for me. To go from hospital bed to performing for the children who need a little light was a magical experience.

My story is but one of many out there. I am so happy I've been able to share mine with everyone who reads this. The important takeaway is no matter how dire a situation we are in, there is always a glimmer of hope that we need to just hold onto and let it take us where we need to go. I believed the entire time I would come out victorious. Isn't that the most magical thing?

To believe. To have faith. To hope.

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STILL TRANSITIONING...

JoAnne Mosel

Richard's mom

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The transition of a child with a brain-based developmental disability from the pediatric to the adult care system is an issue of large concern today in Canada, and many parents like myself, who have been through this step, continue to face challenges despite our child now being an adult.

My name is JoAnne and my son Richard is now 31 years old. He has a rare disorder called Duplication 15q (Isodicentric 15q) Syndrome which manifests in autistic traits, sleep disorder, pervasive developmental disorder (PDD) and epilepsy, among others.

The Start of Transition

When my son entered his teens, I began to grow more aware that we would need to prepare for his adult years. School had been our main service provider and we knew he would soon age out. The school took over responsibility for many therapies that he needed such as speech therapy, occupational therapy and physical therapy. During his teens, he even received applied behavioural analysis therapy, which is usually reserved for children under the age of 5 with autism. This was provided on a one-on-one basis and his therapist was an excellent match for his personality. He made good progress, from which he benefits still to this day.

But other services and professionals were growing more elusive.

His neurology team had taken a back seat since an EEG revealed atypical spikes but no clear reason to medicate him or follow up regularly.

His pediatrician only saw him for emergencies such as earaches or other such issues.

And although behavioural specialists and psychiatrists were still in the picture, as the years went by, therapists fell to the wayside. It became more and more difficult to access services. Budgets were being cut and getting an appointment with a social worker or coordinator took months.

Where to Start?

As I prepared for his transition, I wondered where to turn. Was transition a subject to be broached with the education system or the social services system?

In our case, we wanted to pursue two options in particular: access to a rehabilitation day centre or a specialized education adult centre. When he was about 14 or 15 years old, I began to ask questions about these options and was told we'd have to wait. In our case the age of 18 would be pivotal for the medical side whereas 21 would be the age-out for educational purposes.

At the age of 21, he started going to a rehabilitation centre where he was doing productive activities, but over time, these were abolished. And contrary to the name, no rehabilitation services were included.

Transition Happens Everywhere

One thing I learned by watching Richard grow from a teenager to an adult is that transition is about more than medical care and services... it's about supporting the entire child. In 2012, Dr. Peter Rosenbaum and Dr. Jan Willem Gorter, Co-Founder and Director of [CanChild](http://CanChild.org) respectively, published a paper titled "[The 'F-words' in Childhood Disability](#)" that introduced 6 words that the authors believed should be the



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focus of childhood disability: Function, Family, Fitness, Fun, Friends, and Future. These resonated with me, and I'd like to share the impact of transition on these 6 crucial fronts for Richard:

FUN – My son used to enjoy going to concerts and shows. Music is his one great love and when he was young, going to children's shows was fun, inexpensive and very doable despite always struggling with crowded open spaces. The noise, movement and unpredictability caused him distress and affected his behaviour.

As he grew older, kids' shows were no longer an appropriate venue and he became more and more difficult to manage in public due to his growing strength and the impact of his seizures and medication (effective or otherwise).

Music class seemed like a good option and we found one geared to individuals with disabilities, but he was asked to withdraw after 3 weeks. They judged him to be too able. Most of the participants were in wheelchairs and they said he was too mobile and disturbed them.

We tried other activities but as he grew older, those also became problematic. He couldn't keep up in Boy Scouts; his skiing instructor found him too big and heavy to pick up or guide down the hill, etc.

He was losing access to the activities he most enjoyed.

FITNESS – While my son was in school, he had access to the school gym. This gave him an outlet for his pent-up energy and he enjoyed shooting baskets. The gym also had climbing equipment, bean bags to throw, and the staff ran exercises to promote hand-eye coordination.

Once out of school, the burden was on me and my family to find activities that would keep him strong and healthy. Most organized activities offered by the community became competitive, and these did not suit him. During his teens, he participated in track and field in the Special Olympics but after a few years of this, it became less and less worth going. There was too much waiting in line for him. The large environment was overwhelming with its high ceilings and echoes. His sensitivity to noise also resulted in worse behaviour rather than better.

He now goes to the pool at our local Y to swim.

FAMILY – As my son grew older and stronger, his behaviour became more unpredictable making family get-togethers with my small extended family more difficult. He started to exhibit more signs of aggression and violence. He had difficulty tolerating the noise and couldn't handle many people speaking at the same time. He made his displeasure known.

His siblings tolerated his breaking their belongings but made sure to let him know, in no uncertain terms, they were not happy. Richard also increasingly wanted their attention; wanting to sing together, read together, go for walks. His younger siblings did their best to dedicate this time to him—they would sing and read to him—but as siblings do, they also often picked on each other.

FRIENDS – Like many kids with his type of disabilities, my son's friends are few and far between. While he was integrated in a regular school and class (with an aide), a few children took an interest in him. They would volunteer to help, say, bring him to the school gym or to another activity. They would throw around a ball with him in the schoolyard.

But once out of an integrated setting, there were no friends to speak of. He lacks the independence or skills needed to be in groups of verbal individuals, or to participate in their activities. His interests lie in one-on-one socializing. Back and forth verbal interaction is not possible in groups of non-verbal individuals with whom he is placed.

FUNCTION – In transition, much emphasis is placed on developing activities of daily living. For some reason, academic skills are left behind. I don't understand why this is so often the case. I believe it is a



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misunderstanding and dogma surrounding the ability to learn once one is outside of school age.

Collecting bottles and returning them in the bottle return machine at the grocery store is an activity that has taught him concepts more concretely than a classroom setting could provide. The voucher emitted from the machine meant it was time to go shopping and he could purchase what he wanted. This was a critical milestone. It meant gaining a bit of control over his life.

Like most of us, he went through a period of having a strong need for control over his life. I feel this need cannot be overstated. It occurs perhaps at a time when even more control is being exerted by outside forces. Parents, teachers, time schedules... all infringing on his need to want to sleep in, eat when he felt like eating, do what he wanted to do. When trying to structure his time became too exhausting, we'd let him go on YouTube to watch videos. He was initially unable to navigate using a mouse, but quickly became extremely adept at it. I noticed, after watching what he was doing for a while, that he was capable of much more than I'd realized.

Which leads me to the final word: FUTURE

At this point, there is no plan in place; we are still searching for ways to best support Richard as a now 31-year-old adult. There are no interesting goals laid out, only vague words such as 'increasing independence' or 'functional skills'. But as long as he is medically stable (seizures under control, side effects of the meds minimized, etc.) I'm hoping he will be offered many learning opportunities, socially, functionally and academically.

On my end, I am doing what I can to help improve the system for children like him in the future. I am now a patient-partner on a research project called [READYorNot](#), funded by the [CHILD-BRIGHT Network](#) and co-led by Dr. Gorter (one of the authors of the F-Word article that I referenced above) as well as Dr. Ariane Marelli and Dr. Khush Amaria. In this project, we are developing and evaluating e-health aids to help patients and families take charge of this transition. The project is supported by Canada's Strategy for Patient-Oriented Research ([SPOR](#)) initiative, which endorses the active partnership of patients, researchers, health professionals and decision-makers in research to build a sustainable and accessible health care system that optimizes the health of all Canadian citizens, including my son. By sharing my story here, and my experience within the READYorNot team, I hope to help make the lives of children like my son better in the future.

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HELP DURING THE STORM

Rebecca McClary
Savannah's Mother
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For many people, the first thought of moving can quickly stir up a whirlwind of emotions and stress. The thought of having to keep your house clean for open houses, packing, leaving the comfort of family and friends, and then meeting all new people ... it can be overwhelming! Research by University Hospitals claims that moving is one of the top five most stressful life events. They also list: death of a loved one, divorce, major illness or injury, and job loss. So, what happens when you mix two of the five most stressful life events together? Dare I say that you now have a perfect storm? Well, that's probably how it will feel when moving out of state with a child who has a chronic medical condition. At least, that is how I felt when our family moved from Ohio to Alabama, during the fall of 2018, with our 5-year-old daughter who has chronic lung disease.

One of my biggest fears is tornados. A little out of left field, I know, but hear me out. Tornados are strong, and unpredictable. I don't cope with "the unpredictable" in a calm or practical matter, in most cases. Instead, I plan. Remember when Y2k was approaching and so many people rushed to clear out the milk and bread at the local grocery stores? Okay, I'm not that bad, but I feel more in control and at peace with a plan. So, when we moved to Alabama and everyone told me about the tornados they can experience, I planned. My husband and I purchased a safe shelter (yep, it is bullet proof too) and I have that bad boy stocked with water, and food, and a list on the door of what not to forget ... including the dogs and the pet hedgehog! The point is, the most chaotic of events can turn your world upside down, but if you are prepared and proactive, you can have some peace. This is exactly the reason I turned to Stephanie Allen, our RN with the Palliative Care Group at Akron Children's Hospital, when I found out we were moving out of state. I needed a plan to give me the control and peace that a special needs mother craves!

The amount of details that goes into caring for a child with special needs is exhausting. The moment I found out we were moving from Ohio to Alabama, for my husband's job, I started my lists. The number of doctors I had to find, the medical supply companies, the insurance changes, the therapies, and what about school and medications? The tears came and the stress mounted greater than I had felt in a long time. I was content with our 14 hours of nursing, the specialists we had found over the past five years, the therapists who my daughter had grown to know and trust, and my pharmacist who delivered my daughter's multitude of medications to my doorstep. When I finally came up to breathe and admit to myself that I was not super mom, I picked up the phone and dialed my Palliative Care RN.

Stephanie, or "my person" as I often referred to her as, was there for me, as always. After she calmed my anxiety and my "I can't do this" attitude, she implemented a plan. There it was ... a proactive plan! She created a storm shelter against the unpredictable stressors that were undoubtedly about to surface. Not only was there a plan, but Stephanie offered to take part of the plan and add it to her plate. She helped me find medical supply companies for my daughter's prescription tube feeds, send referrals for several specialists, and navigate Alabama Medicaid options. If you lost count, she saved me from having to make like a million phone calls. This is better than a perfectly wrapped gift under the Christmas tree!

All jokes aside, the assistance I received was priceless and drastically cut my stress levels down. I was able to focus on house hunting, dealing with the moving company (maybe I should have asked her to do that too), getting my daughter to all of her therapists and specialists for one last check up, checking my daughter's medical supply inventory, and nagging my husband to get some last-minute projects done in the house. Moving out of state, with a chronically ill child, will inevitably create the perfect storm. However, when the storm starts to stir, be proactive, make a plan and call your Palliative Care RN. They want to be the help in the storm.

If you find this storm stirring up in your life, I hope that your Palliative Care team will be there to help you



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as much as mine was. Here is a simple list to start you off so you can be proactive and have a plan when your storm hits ... I hope it helps bring some calm and peace to you.

Checklist for moving out of state:

1. Don't feel like you have to do this alone. Call your local Palliative Care team! They have so many useful resources and they WANT to help!
2. Make a list of each type of specialist/therapist your child needs. As crazy as it sounds, you may forget one, so just write them down. Once you have found one in your new state, make a consultation appointment so your child is considered a patient. This way, if an emergency occurs, you already know where to go.
3. Call your new insurance company. Make sure you are prepared for any changes in co-pays and if they require you to have medications filled at a specific pharmacy. This may seem like a little thing, but it can help reduce more stress once you are moved.
4. Take inventory of all the medical supplies you have on hand. Note when you will need specific things reordered. I suggest finding supply companies before you move and have your child registered with them. I personally took my daughter's supplies with us during the move, rather than putting them on the moving truck.
5. Join Facebook groups. You can find all kinds of helpful Facebook groups for special needs parents or just local happenings for your new town. The locals are a great source for recommendations!
6. Most importantly, don't forget to breathe. Think of how far you have come and the storms you have survived. You will survive this storm too ... I know you will!



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HOLDING HOPE WITH FAMILIES THROUGH THE UPS AND DOWNS OF THEIR MEDICALLY-COMPLEX JOURNEYS WITH THEIR CHILD

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“Hope knows no fear.
Hope dares to blossom
Even inside the abysmal abyss.
Hope secretly feeds
And strengthens
Promise.”

--Sri Chinmoy

Hope is fragile and can be fleeting, but it can also be that lifeline of courage or hopefulness that can carry parents through the ever-changing trials they experience with their medically-complex, or dying, children. Not surprisingly, hope is so many different things to so many different people. But to a family with a baby or child who is medically-fragile, or who is dying, hope constantly takes on new meaning...month by month, day by day, minute by minute. Importantly, holding space for families to “hope” through the transitory changes in their child’s condition over a short, or long, period of time, may just be the support they need to get up and face another day. Holding hope with families is imperative, so attendance to it and nurturing of it, by the care team supporting them, can make all the difference in whether or not they can remain. Or become whole. On the other side of this journey, wherever it may take them.

When my niece, Riley, was “born dying” with only a week’s notice that something “really bad” had happened in utero, it was hard to know what to hope for. At her birth, the hopes that night were that she’d even live through the night and that we could get my sister out of surgery, and then recovery, to be able to see her. We had caring nurses who “got this” and who bent the rules to get my sister wheeled down to the NICU in her hospital bed to greet her baby girl...so she could hold her hand, study her face, and realize she shared some physical traits with her brothers, and just love her.

After my sister was settled back in her room, the nagging “we need to baptize her” in case something happens ate at me, so the hope then was that she’d be “christened in the faith” that was so important to our family’s beliefs. While there was a pseudo-baptism done by us with holy water from the chapel, with the help of an intuitive social worker, we were able to get my niece baptized the next morning before she was transported down to a local children’s hospital for tests and highly-specialized care.

With this move (and my sister being left behind in the suburban hospital where she delivered), our hopes shifted to praying that there would be SOMETHING they could do...an operation, a treatment, some course of curative care to remove this brain tumor from this precious babe. After MRIs and a consult with a neurosurgeon, none of these proved to be viable options. The tumor was too big, too invasive, and growing too fast, and it had destroyed any viable brain tissue my niece had. So, hope shifted yet again to finding ways to let Riley know she was loved and to get my sister reunited with her daughter as time was now so precious.

I can recall after the consult with the neurosurgeon, going back to Riley’s isolette in the NICU and just staring at her and crying. A nurse who had been in the consult followed me and wrapped her arms around me and asked me what I was thinking. My response was, “I just hope and want her to know how much we love her.” Her response was a compassionate, “She already does.” And hope shifted again to going to work to get the mother and daughter reunion in the works.

Over the next eight days of Riley’s life, I realize now that “Hope” shifted and changed so many times. In a way, “Hope” had become a companion, a traveler of sorts, on this journey with us and Riley. It was as if “Hope” had become a person who morphed and changed with each new decline or transition in Riley’s



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health status. Upon completion of one item on our unspoken “Hope Bucket List,” a new “Hope” would show up in its place. There were hopes that:

- My sister would get to nurse her daughter, and when that wasn’t possible, that she could at least feed her her own breastmilk through Riley’s g-tube
- My sister would get to dress Riley in some of the outfits she had bought for this long-awaited baby girl after two boys
- Everyone who wanted to come see her and give her their love would get there in time
- Grandma, who was in the throes of early-onset Alzheimer’s in her early ‘60’s, would love and embrace this baby and not poke fun at or stare like a child might given my Mom’s diminished cognitive capacity (Side note: It was a beautiful Grandma moment and nothing like we feared. “Hope” did not disappoint us.)
- My sister, her husband, and their two young boys would get some family time with Riley to create whatever memories they could, which were now going to have to last them a lifetime. (Note: This actually happened, and Riley was taken home for a day trip and then again overnight on New Year’s Eve for a night with her family)
- ...and so much more

And in the end, the last ounce of hope that was held out for was that Riley would not die in pain (she didn’t) and that my sister and her husband would get to be with her when she died (and they were).

The point to all these examples, is to help illustrate that we can never guess or imagine what a family or Mom, Dad, or sick or dying child is “holding out hope for,” so as professionals working with these kids and/or their families, we need to ask, and ask, and ask again, as the answer to the question, “What are you hoping for now?”, can change with each new time this is queried. As pediatric palliative care providers joining with families in hope, this is, or should be, a natural extension of the PPC approach to preventing and relieving suffering, instead, by offering comfort and support to these families. However, to do so is brave and takes courage, as one never knows what the answer to the question, “What are you hoping for now?”, is going to be, and, whether it is something that the family should be holding out hope for (i.e., a cure when there is none).

While much has been written about “holding hope” with families, I think the core elements can be distilled down to the following few principles for providers caring for these medically-complex kids, and their families:

- Invite and be open to the conversation about “hope,” and what it is/what it means to the child and/or family; don’t presume you know what they’re hoping for, nor what “hope” means in their world. Ask, ask, and ask again.
- Build trust through these conversations so that when/if hope may need to be redirected (e.g., away from curative thinking), the child/parents “hear” this and together hope can be shifted to new goals of care (e.g., “What else are you hoping for just in case this doesn’t work out the way you are hoping?”)
- As the child’s condition changes, check-in again (and again and again) on “What they are hoping for now...”
- Empower the care team to actively listen to the hopes expressed and be creative about how the hope(s) can perhaps be addressed. Sometimes you may have to “break the rules” to make the hope a reality.
- Do not underestimate the power of small gestures to help address their hopes (and fears) ...a kind word or reassurance, a hug, a touch of a hand, a smile, a sharing of the hope. Not everything they are “holding hope” for requires a trip to Disney.

Hope is a formidable force that can be transformative and which can be that one thing that helps get seriously-ill or dying children, and/or their families, through a circumstance or situation no one can possibly even imagine surviving. And like the poem says, hope lives even in “abysmal abysses,” while secretly feeding and strengthening spirits and souls. These pediatric palliative care/hospice journeys can



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certainly look and feel like “abysmal abysses” to these families. So be a partner in “holding hope” with them. It may be the ONE THING that gets them through this and to the other side as “whole” as they can be and be the best support you can offer when you are out of any other treatment options for their child.

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THE INFERTILITY JOURNEY: A MAP FOR CARE PROVIDERS

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The inability to conceive and give birth to a much-wanted child is a devastatingly painful experience. But why write about infertility in a journal devoted to pediatric hospice and palliative care? One reason is that there will be parents of children who access this care who themselves have experienced infertility—and the psychological effects of infertility do not automatically disappear once a person becomes a parent (Burns, 2006). Infertility impacts identity. Thanks to modern reproductive science, many people who would have remained childless in the past now go on to have children with the assistance of medication or surgery, through assisted reproductive technology, or with the help of sperm, egg, or embryo donors or gestational carriers, as well as through adoption or foster parenting. More and more, it's important for people who work with children and their parents to understand how infertility and third party reproduction operate. It may also be useful to consider whether an infertility history impacts future experiences of loss.

The World Health Organization defines infertility as “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (Zegers-Hochschild et al., 2009). Infertility affects men and women equally (American Society for Reproductive Medicine, n.d.). In the United States, approximately 12.1% of women ages 15-44 suffer from some form of infertility (Chandra, Copen, & Stephen, 2013). It is estimated that over 8 million babies have been born through assisted reproductive technologies worldwide (Science Daily, 2018). Same-sex couples and single intended parents may also struggle with infertility on top of the need to use assisted reproduction and gamete donation to achieve a pregnancy for social reasons. Because former infertility patients who become parents tend to blend in with the general population, it isn't always evident to medical providers who they are (Burns, 2006).

Historically and across cultures, the inability to conceive and give birth has been experienced as a major life crisis (Burns & Covington, 2006). Infertility can bring forth feelings of tremendous grief and loss, as well as shame, guilt, isolation, a sense of not being good enough, of being broken or defective. It affects people's finances, social status, and self-esteem (Mahlstedt, 1985). Infertility can damage relationships, especially when partners respond to it differently. It can also strengthen a relationship when a couple creates a sense of being in it together.

For most people, the crisis of infertility unfolds over time as a series of ever-deepening losses. Clinicians at the Ackerman Institute for the Family in New York developed a five-stage model of the infertility journey that captures the transitional nature of the experience. These stages are: Dawning, Mobilization, Immersion (Early, Middle, Late), Resolution, and Legacy (Diamond, Kezur, Meyers, Scharf, Weinshel, 1999). These stages are a helpful framework for understanding the experience of infertility.

For heterosexual couples who have spent their adult lives avoiding pregnancy, there is often the assumption that, once off birth control, pregnancy will happen right away. The Dawning stage of the infertility journey begins when, after a period of cycling through the hope and disappointment of trying to conceive on their own, couples first begin to suspect that something may be wrong. At this point, the couple may decide to seek medical consultation, entering into the Mobilization phase. A diagnosis of infertility may trigger feelings of shock, of a loss of faith in one's body, and a loss of privacy, as what was once an intimate joyous experience moves into the medical arena (Mahlstedt, 1985; Diamond, et al., 1999). Feelings of not being a “real” woman or man, are common.

The Immersion phase is the active period of fertility treatment and may last for years. The effort to conceive begins to dominate all other aspects of life, especially for women, for whom treatment may require constant medical appointments, multiple daily hormone injections, and regular invasive



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ultrasounds. Failed cycles lead to increasing emotional distress and the fraught decision of whether or not to try again. Many people struggle with the loss of control, as hopes for the future slip away and short-term planning is hindered by never knowing when one might be pregnant. Treatment takes a toll on people's sexuality and on finances, as couples spend more money on expensive procedures or delay career changes due to the constant uncertainty (Mahlstedt, 1985). Couples often become isolated from their communities, skipping difficult family events like baby showers and children's birthday parties, or avoiding peers who are caught up in the frenzy of early parenthood. Many people express feelings of guilt, longing to be happy for their pregnant siblings and friends but finding it painful to witness others' joy in the midst of so much sadness. Well-meaning, but insensitive comments from friends and family—such as “maybe it just wasn't meant to be” or “why don't you just adopt?”—may also contribute to the decision to isolate. If pregnancy isn't achieved, medical providers may recommend the use of donor gametes or gestational surrogacy, which is a tremendous leap for most people, as using a donor is not a cure for infertility, but a new kind of family building (Diamond, et al., 1999; Pasch, 2018).

The Resolution stage involves the end of medical treatment for infertility. For those who become pregnant, there is often tremendous anxiety. The transition from the fertility clinic to the OBGYN office may even involve feelings of loss. Some may decide to pursue adoption, while others choose to seek meaning in ways that don't involve parenting. This stage involves grieving and beginning to let go of the infertility identity (Diamond, et al., 1999).

The Legacy period is the aftermath of the fertility journey. Regardless of the outcome, infertility's impact may last long after a resolution is found. Couples often emerge from years of trying to conceive with depleted finances and damaged relationships. Those who have conceived with the help of third-party reproduction must navigate the realities of a new kind of family, including how to talk to children about their origins. And infertility's impact on identity can linger. Even for couples who become parents through assisted reproductive technologies, infertility's impact can show up, sometimes in surprising ways. An unexpected pregnancy announcement might reignite old feelings of jealousy. A comment about a donor-created child's resemblance to one parent might bring up sadness about a lack of genetic relatedness for the other. Still, most studies of parents and children in assisted reproductive families suggest that these families are doing well, physically and psychologically. Few differences have been found between IVF families and their infertility-free peers. If anything, parents who have suffered through infertility seem to be more attuned and involved with their children than their non-fertility peers (Golombok, 2015).

An initial search of the literature found no research into the effects of an infertility history on a parent's later experience of the illness or death of a child. But it is not a stretch to imagine that the way one's child came into the world will affect a parent's experience of future loss. Infertility patients who experience perinatal loss (miscarriage or stillbirth) often find that the loss is intensified by the years of cumulative disappointment and by the tremendous effort that went into creating the pregnancy (Kohn & Moffitt, 2000; Leon, 2015). Former infertility patients who give birth to special needs children frequently have feelings of guilt, wondering whether they had “tempted fate” by using assisted reproductive technology (Glazer, 1998). One mother whose IVF-conceived daughter was diagnosed in utero with a life-threatening condition and died shortly after birth wondered if she and her husband were “cursed” and “not meant to be parents.”

How can healthcare providers support families with histories of infertility? Simply knowing that others understand the infertility experience and its physical and psychological tolls is important to those who have been through it. Asking about fertility history on intake forms can give providers insight into potential problem areas—for example, does a mother who had extensive negative experiences with the medical system during infertility suffer from post-traumatic stress disorder that might be triggered by interactions with hospitals and doctors? While a full discussion of donor conception is beyond the scope of this article, it is important for all healthcare providers, as well as teachers and caregivers, to be aware of its prevalence and of the needs of donor-conceived people—both psychological and practical, as when taking family medical histories. Disclosure of gamete donation to offspring is now highly recommended (Ethics Committee of the American Society for Reproductive Medicine, 2018) and, according to Pasch, no longer optional due to direct-to-consumer DNA tests and the internet (Pasch, 2018). However, it is important for providers who have information about donor conception to know who knows and who



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doesn't and what the child understands about it. Finally, we can all be aware of the ways that our cultural assumptions about fertility affect those impacted by infertility. Everyday questions such as, "do you have any children?" or "when will you have a second one?" are fraught for people who have struggled to conceive. We can all make shifts in the way we talk about having babies that can benefit not only people with infertility, but anyone whose experience of becoming or not becoming a parent is divergent from the norm.

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PREGNANCY LOSS: A MINIMIZED GRIEF

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Pregnancy loss is a transition from the beginning of something momentous to a heartbreaking ending. Whether it's a miscarriage, the loss of a stillborn baby, or a termination of a wanted pregnancy due to a prenatal diagnosis, pregnancy loss can be an especially difficult set of changes and needs to address.

Our U.S. culture, with all of its focus on “moving forward” and “having a positive attitude” tends to show discomfort with grief in general. When that loss involves the ambiguous and confusing aspects typical of a loss during pregnancy, the discomfort can be increased as assumptions and anxiety get in the way of offering support to those affected. Pregnancy loss is an example of “disenfranchised grief,” a phrase coined by Dr. Kenneth Doka that refers to a loss that is not acknowledged or validated by society. In the instance of pregnancy loss, it is often a case of not understanding the impact of what has happened to those who grieve a baby, as well as not understanding what they might need. In addition to being sad, a pregnancy that ends in a loss can feel like an unfinished and confusing story that friends and loved ones don't know how to acknowledge and one that lacks clear societal rituals that can offer comfort.

Occurrence

Pregnancy losses are not uncommon. According to the March of Dimes, 20% of all pregnancies end in miscarriage. The Centers for Disease Control state that 1% of all pregnancies end in stillbirth (after 20 weeks gestation). Another type of pregnancy loss—terminations due to fetal abnormality—are also not rare, although accurate statistics are difficult to find.

Miscarriage

Miscarriages can involve a disenfranchised grief for a number of reasons. Because they happen in the first half of pregnancy, and most typically within the first trimester, friends and family may not have known about the pregnancy and may not even be told about the loss. People may know that miscarriages are common and may mistakenly assume that they are not a significant life event. Specific information about the real-life experience of miscarriage is often not discussed. Michelle Obama speaks to this in her book *Becoming*, writing “If I were to start a file on things nobody tells you until you're right in the thick of them, I might begin with miscarriages.”

Friends and loved ones may assume that the loss is insignificant because there was not time to attach, or that the loss can quickly be replaced by another pregnancy. They may feel they are doing a kindness to not mention the loss, or to just focus on potential future pregnancies. Since attachment is part of a normal pregnancy, and often happens quite quickly, this may be the opposite of what someone needs. Even though a woman and her partner may feel ambivalence about a pregnancy, it is normal to begin to picture a version of life built around a new member of the family. Images of the birth, future holidays, and a changed sense of family start to preoccupy the pregnant woman and her family. There is a psychological and physical investment made in a pregnancy and an unwanted end leaves feelings and dreams that must be grieved.

The physical reality of what a woman might have undergone is often ignored, leading to a minimization of the experience. Although most miscarriages proceed without danger to the woman, they often involve intense physical pain and blood or a hospital procedure such as a D&C or D&E. Medically, unless there are recurrent miscarriages, there is less of a push to find answers or to consider that this is a high needs time for the woman or couple, which can also lead people to feel that their loss is not seen as significant.



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Stillbirth

Stillbirth is the loss of pregnancy at 20 or more weeks. These later losses are more likely to be visible to others, with accompanying effects on identity, cultural responses, and investment in the relationship with the unborn baby. Such losses may receive more attention, but still involve a disenfranchised grief for many reasons. Some friends and family might find themselves overwhelmed at the news of a stillborn baby, not knowing how to react. Myths or assumptions regarding the causes of stillbirth (e.g., she must have done something wrong) may also lead to judgments by others.

If much has been done to prepare for and welcome the baby, professionals as well as loved ones may not know how to change from that place of involvement in expecting a baby to supporting a grieving family that will not be bringing a baby home. There may be initial discomfort with the protocol that most hospitals now have for encouraging seeing and holding a baby who has passed away, taking pictures, footprints, and other activities that allow time with the baby and opportunity for memory making and tangible evidence that the child was here. Decisions about naming the baby, what to do with the remains, and whether to have a funeral or memorial service may also be upsetting and daunting not just to the bereaved individual or couple, but to the friends and family, who may find themselves pulling away in discomfort.

Medical treatment, in the form of a vaginal delivery, D&E, or C-section may be a big part of the focus early on and physical recovery may be an initial priority. Lactation may be a part of the picture for any loss after the first trimester, with the possible accompanying distress and physical discomfort of a body ready to feed a baby who is not present or alive. The fact that women may need medical treatment concurrent to their loss may lead to an over emphasis or under emphasis of the woman as a medical patient vs grieving woman. What type and length of maternity leave or other work leave is appropriate may be hard for the woman, couple, and employer to assess, and may be yet another area where a woman and her family feel that the loss is not validated.

Termination due to prenatal diagnosis

Advances in prenatal diagnosis through ultrasound, amniocentesis, and other modern tests mean that many severe issues are now detected in utero. Chromosomal issues such as trisomy 13 or trisomy 18 carry known issues of serious medical concerns and extremely short life expectancy. Other issues such as severe neural tube defects and known syndromes and disorders may indicate such poor prognoses for babies that a therapeutic abortion is indicated or chosen. Lastly, problems with the pregnancy, such as premature rupture of membranes, preeclampsia, or other dangers to the pregnant woman may lead to a decision to end a wanted pregnancy.

These types of losses may be disenfranchised by the simple fact that it may not feel safe to tell even friends and family the whole truth of what happened. Abortion is surrounded by political and religious controversy that may challenge previously held beliefs by the pregnant woman, partner, and support system. Ending a wanted pregnancy can feel like a bizarre and heartbreaking process as a woman must sign consents and participate in a physical process to end the pregnancy despite usually a desperate wish for keeping the baby in healthier and more viable circumstances.

Those who experience the loss may feel that, in addition to feeling unseen, they do not have a right to engage in mourning rituals or behavior due to their participation in ending the pregnancy. Even trusted loved ones may misunderstand both the situation the woman or couple was in and what they may be feeling after the loss. These types of terminations tend to happen later in the pregnancy, often resulting in more physical changes for the pregnant woman as well as feelings about those changes. There may be a complicated set of needs that go unseen or unaddressed for this group of grieving people.



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Cultural Shifts

There are signs of cultural changes in the recognition of pregnancy loss. Perhaps it is because millennials, now in their reproductive years, are accustomed to less privacy and more discussion in the form of blogs and social media about all aspects of life. Perhaps it's in part affected by the wave of women, such as in the Me Too movement, insisting that the stories of their lives be heard. Regardless of the reason, we are seeing more interest in talking about pregnancy loss as a relevant part of many women's lives.

There is evidence of the interest and relevance of pregnancy loss in our popular culture. We see pregnancy loss addressed in one of our most popular TV shows, "This is Us," and movies ("Return to Zero," 2014, the documentary "Don't Talk About the Baby," 2018 and "Roma," 2018). Writers such as Elizabeth McCracken, Ariel Levy, and Mira Ptacin have struck a chord with readers with their memoirs of perinatal loss. Celebrities such as Beyoncé, Carrie Underwood, Brooke Shields, and Michelle Obama have shared their stories and made it seem more normal to talk about losing a baby during pregnancy.

Ideas for Loved Ones and Professionals

Presence and kindness go a long way, showing up and saying "I'm so sorry" or "I'm here. If you want to talk, I'll listen. If you don't want to talk, I'm still here," can make a difference.

Listen without assumptions or imposing your narrative. Resist the urge to speak about why the events happened (as in religious explanations or stating that everything happens for a reason). Let the person use their own words without imposing technical/medical terms or assumptions about whether the family considers the loss a fetus or a baby, whether the baby has a name, whether those involved consider themselves parents, etc.

Don't try to minimize or fix the loss. Making statements that start with "at least" are usually not helpful, even if the family is making such statements. Making statements about future pregnancies or children may lead those affected to feel that the current loss is being disenfranchised. Instead, you may want to say, "I can only imagine what you're feeling right now," or "What would you like me to know about your pregnancy/baby?"

Respect what is shared. If a name is shared, use it. If you are shown pictures, respect how meaningful this is. If you are asked to participate in a memorial or memory making event, remember that this is the family's only time to honor this pregnancy or baby.

Don't disappear. You may want to make offers such as "I'd like to _____ (bring a meal, walk your dog, do your laundry, etc.) on _____ (day and time), would that be OK?" You may want to call or text to remind the person or family that you care and are available to talk. Don't assume there are clear or short time limits for this type of grief.

Pregnancy loss is a high needs time that can be extremely heartbreaking and confusing for all involved. Although historically we have shied away from the emotional stories of pregnancy loss, cultural shifts may be allowing more grieving families to be seen and heard. Considering the needs of those affected by these losses and refusing to minimize them can go a long way in helping those experiencing this type of grief to heal and grow.

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TRANSITIONS: NEVER ENDING; ALWAYS CHANGING

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In the context of pediatric palliative care, there are multiple transitions involving multiple participants in care. To make things even more complicated, there may be more than one transition occurring at the same time.

This is what the Merriam-Webster Dictionary says about *transition*:

- Noun
 - Passage from one state, stage, subject, or place to another: **CHANGE**
 - Movement, development, or evolution from one form, stage, or style to another
- Verb: transitioned; transitioning; transitions
 - To make a transition

Transitions occur in:

- The child/adolescent with complex medical conditions
- The family including parents, siblings, grandparents
- The community
- The health care providers

Most of the literature concerning transitions in children/adolescents with medical complexity focuses on the transition between pediatric and adult care. However, there are many more types of transitions.

Consider:

- Change in the child/adolescent's health status and phase of the disease/condition
 - Being well vs. being "sick" vs. dying
 - Before and after the diagnosis
 - Trajectory of condition/disease –
 - Improving
 - Stable
 - Relapse
 - Deterioration
 - Dying
 - Prognosis
- Change in goals of care: Of course, palliative care principles pertain regardless of the primary goals of care. These transitions in goals of care can be very difficult for the health care providers as well.
 - Cure
 - Life prolongation
 - Primarily palliative
 - Hospice/end-of-life care
 - Bereavement care
- Change in role
 - Parent of a well child to parent of a child with medical complexity or parent of a dying child
 - Parent to bereaved parent - "*How many children do I have now?*"
 - Bereaved sibling where there is now a change in birth order, i.e., now an oldest child or youngest child due to death of a sib
 - For women with pregnancy loss, loss of role as mother

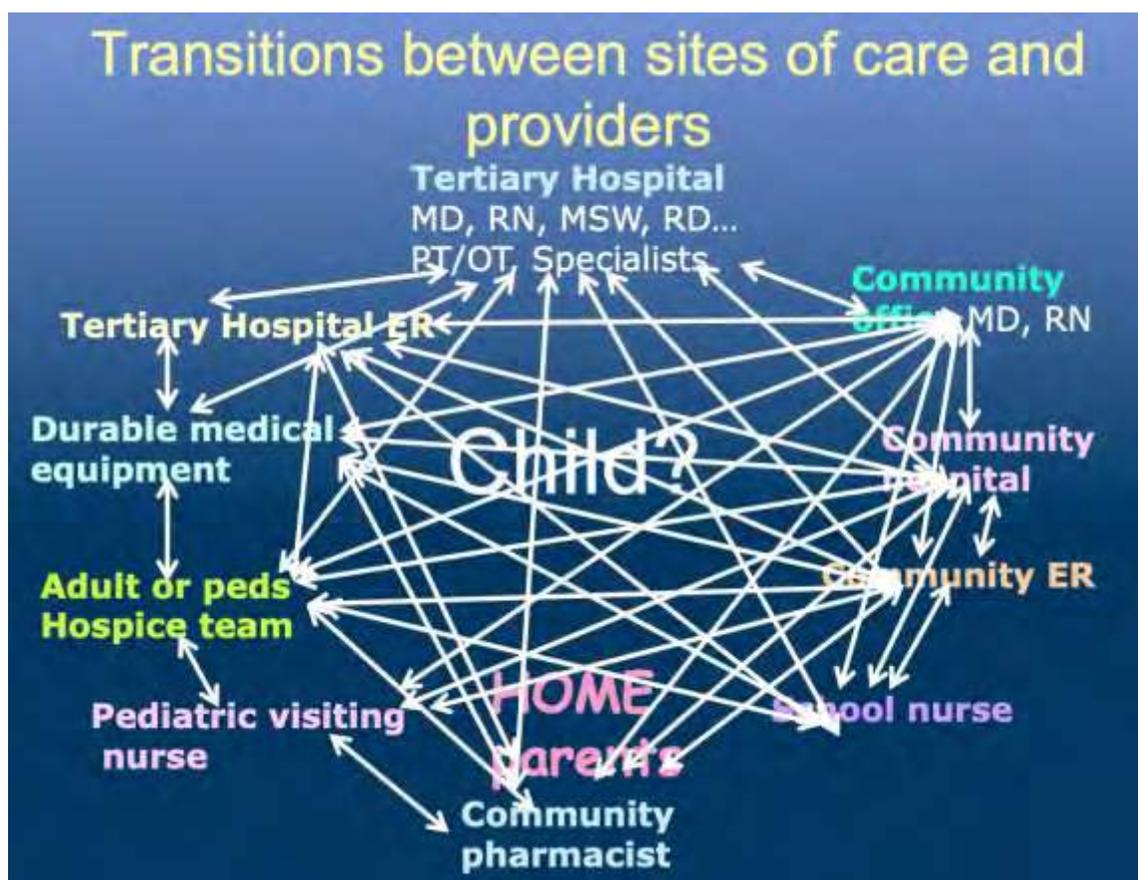


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- Change in sites of care, organizations, providers, disciplines
 - Hospital to home
 - Home to hospital – this may occur during the course of the disease/condition or at end of life if home care is not feasible
 - Multiple consultants and home care providers
 - Pediatric to adult providers
- Change in developmental stage. In conjunction with a complex medical condition, this can be very challenging.
 - Child to adolescent to adult
- Change in concept of hopes. Hopes frequently need to be reassessed and readjusted during and after transitions.



Barriers to successful transitions between providers and/or organizations:

- Poor coordination
- Lack of preparation
- Inadequate transition models
- Provider or family reluctance
- Lack of access to or funding for trained adult providers
- Fragmentation
- Organizational focus rather than child/adolescent focus
- Few quality guidelines
- Finance/insurance barriers



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Tools to aid in transition:

- The palliative care model is a framework for continuous coordinated care focusing on the child/adolescent and family (Ajayi 2014)
- Facilitators (Doug Arch Dis Child 2011)
 - Focus on child and family
 - Individualize transition planning
 - Identify decision maker
 - Access to services
 - Flexibility
 - Individualize
 - Accommodate any entry point
 - Encompass diversity of interventions within any program
 - Resilience and changing concepts of hopes
 - Coordination
 - Key coordinator
 - Anticipate and plan for transitions
 - Partner with child/adolescent and family
 - Shared documentation/communication
 - Structured hand off
- Sample models of care involving multiple providers
 - Transition within a medical home (Cooley 2011)
 - Co-management
 - Transition to adult care models
 - Condition specific model, i.e. adult congenital heart disease clinic, adult cystic fibrosis clinic
 - Direct transition to adult provider
 - Blended pediatric and adult services
 - Pediatric services to transition clinic to adult clinic
- Documentation tools
 - Physician orders for Life Sustaining Treatment (POLST)
 - Advance care planning documents (Toce 2015)
 - Portable records or “health care passport”
 - Transition summary
 - Emergency information form for children with special health care needs (AAP 2010)
 - Emergency department plan of care

One could think about navigating transitions in the same way as one would consider traveling to a new destination. You start in the logical place along the road of life only to find that your way is blocked, perhaps by a new diagnosis of a disease or condition or a change in trajectory. You need to find a new path with new rules and obstacles. What are the road maps and signs directing you? You need to find new tools and supports to navigate this new life along this different path. You need to adjust your hopes and goals to this new reality. Supported by your family, health care providers, and the community, you need to find your own way along this new path.

Resources

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- Children's Hospital of Philadelphia. http://policylab.chop.edu/sites/default/files/pdf/publications/Transitions_Of_Care.pdf



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- Got Transition resources www.gottransition.org
<https://www.gottransition.org/resources/index.cfm>
- POLST Legislative Comparison Chart (updated 4/18) <http://polst.org/wp-content/uploads/2018/08/2018.08.16-POLST-Legislative-Comparison-Chart.pdf> Includes “applicability to minors” by state. *By my count, the POLST is specified as legal, at least to some extent, for minors in over half of the states. Many states require a signature by the parents/legal guardian.*
- Together for Short Lives. Moving to Adult Services <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/FamRes-Moving-To-Adult-Services-Guide.pdf>
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- National Diabetes Education Program www.YourDiabetesInfo.org or www.ndep.nih.gov
- Tools from SSM Cardinal Glennon Children’s Hospital (FOOTPRINTS) and Seattle Children’s
<http://www.promotingexcellence.org/glennon/> <http://www.promotingexcellence.org/childrens/>
- University of Washington, Adolescent Health Transition Project
<http://depts.washington.edu/healthtr/resources/tools/guides.html>
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THE ROCKY ROAD: THE TRANSITION FROM PEDIATRIC TO ADULT SERVICES FOR ADOLESCENTS AND YOUNG ADULTS WITH COMPLEX CHRONIC CONDITIONS

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Increasingly, adolescents and young adults (YA) with medical complexity survive to adulthood. In addition to negotiating the transition from adolescence to adulthood, they need to navigate the health care system, moving from their pediatric medical home to adult services. These transitions are complex and there is no road map. While ~250,000 children with complex medical conditions will require adult care each year, only between one in five and one-half will receive transition planning and support (Berens, 2017; Lebrun-Harris, 2018).

It is essential that the multiple health care professionals involved in the individual's care collaborate with the adolescent/ YA and family to provide a consistent direction of care. Providing decisional support, the medical team can facilitate conversations about goals of care. Preferred treatments should be documented utilizing any of the established advance care planning tools used with adolescents (Toce, 2015).

Care should not be site, organization, or provider specific; it should focus on the individual. Important characteristics of transition pediatric to adult models of care for children with medical complexity include:

- Anticipation and preparation including:
 - Emergencies
 - Hospitalization
 - After-hours access
- Adjusting to the needs of the individual
- Involvement of the adolescent/YA and family
- Flexibility and accessibility
- Accommodating multiple entry points, including at varying ages
- Diversity of services and interventions within one program or between multiple coordinating programs
- Support of the growing health care independence of the individual, as appropriate
- Support of the family/caregivers as they adjust to the emerging independence and privacy rights of the adolescent/YA
- Goal identification and decisional support
- Resource identification including links to non-health education, employment, and independent living
- Support for individuals with social and cultural complexity
- Documentation and dissemination of an advance care plan that addresses (Toce, 2015):
 - Pain and symptom management
 - Emotional, psychosocial, and spiritual issues
 - Communication
 - A plan for response to emergency situations
 - Identification of and plan for improvements or deteriorations
 - Need for subspecialty referral
 - Response to inability to meet needs at home
 - Transition to end-of-life phase
- Mechanism to ensure coordination and consistency between care providers



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- Outcome assessment and quality improvement activities
- Special services for youth with development and/or intellectual disabilities that interfere with their ability to participate in their own health care decisions

There are many barriers to successful transition to adult health care, including palliative care. They include (Doug, 2011; White, 2018):

- Fear of change on the part of the individual and/or family
- Poor planning, communication, coordination, and documentation
- Organizational rather than individual focus
- Different practice styles between pediatric and adult providers
- Lack of anticipatory guidance, preparation, and planning
- Little support of developing the individual's self-care skills
- Few transitions models
- Inattention to cultural and socioeconomic influences
- Individual, family, and/or provider reluctance
- Lack of access to adult providers trained in conditions originating in childhood
- Fewer supports and auxiliary services such as care coordination, care planning, and social services in adult practices
- Loss of insurance coverage/lack of funding for adult services
- Fragmentation of services

Transition is more likely successful when the focus is on the adolescent/YA and family's individual needs. A clear decision maker is crucial. Clarify the competency/capacity of the adolescent/YA. Ensure access to current and future potential services. A key contact person/care coordinator will facilitate all aspects of transition and future care. Documentation and shared communication will enhance coordination and a smooth transition.

Existing models of pediatric to adult palliative care (Doug, 2011):

- Use of a transition manager/case-manager/key contact person – **very typical component of successful models**
- Healthcare transition support incorporated within the medical home model
- Adult provider with easy access to pediatric subspecialists for pediatric onset diseases
- Continued care in the pediatric subspecialty clinic
- Use of an adult medical home staffed by medical-pediatric (med-peds) trained physicians
- Condition specific model
 - Adult congenital heart disease
 - CF
- Direct transition from pediatric to adult care provider
- Blended pediatric and adult services
- Pediatric service to transition clinic to adult service
- Use of peer and/or community health workers
- Drop out – **this is obviously the model with the worst outcome!**

The Six Core Elements of Health Care Transition available on the Got Transition website provides processes of care that are very helpful regardless of the transition model.

Given the steadily increasing numbers of such adolescents/YA, improved training is warranted. It is already included in the curriculum of family practice and med-peds residents. More training in adolescent/YA health and transitions, especially for those with medical complexity, would be beneficial for both pediatric and internal medicine residents and practicing physicians. Revised payments systems should reflect the increased time and resources required to provide care coordination, transition planning, and collaboration between pediatric and adult providers.



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Teamwork with coordinated, collaborative transition planning does improve outcomes. Results include (White, 2018):

- Improved satisfaction with transition process
- Shorter gap between pediatric and adult services
- Increase attendance at adult visits
- Improved adherence to treatment plan
- Improved perceived health status and quality of life
- Slightly decreased hospitalization

For the adolescent/YA, the goal or destination is accessible, consistent, coordinated, and comprehensive adult services appropriate for the individual. While the destination is the same, there is no single “right” path for adolescents/YA making the transition to adult services. Early collaborative planning is all crucial to ending up at the “right” destination for the individual making this challenging journey.

Resources

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- American College of Physicians Pediatric to Adult Care Transitions Initiative <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative> **Tools include transition readiness assessment, medical summary/transfer record, self-care assessment, and condition specific tools.**
- Children's Hospital of Philadelphia. http://policylab.chop.edu/sites/default/files/pdf/publications/Transitions_of_Care.pdf
- Got Transition. Six Core Elements of Health Care Transition. Resources 2014. www.gottransition.org/resources/index.cfm? **This is a process of care that is particularly pertinent for the individual with special health care needs.**
- POLST Legislative Comparison Chart (updated 4/18) <http://polst.org/wp-content/uploads/2018/08/2018.08.16-POLST-Legislative-Comparison-Chart.pdf> **Includes "applicability to minors" by state. By my count, the POLST is specified as legal, at least to some extent, for minors in over half of the states. Many states require a signature by the parents/legal guardian.**
- Together for Short Lives. Moving to Adult Services <https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/FamRes-Moving-To-Adult-Services-Guide.pdf>
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HOW ONE PEDIATRIC HOSPICE PROGRAM COVERS CARE TRANSITIONS ACROSS A BROAD CONTINUUM OF AGES AND MEDICAL CONDITIONS

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There can be nothing more devastating to a parent than hearing that their child faces a potentially life-limiting illness, no matter what the age or health condition of the child. Their world seems to stop, and they don't know where to turn. This article provides insight into our pediatric hospice's model to stretch and tailor our services from the tiniest of prenatal hospice babies to adolescents and young adults who present with a wide range of medical conditions across a whole host of stages.

A MICHIGAN MODEL FOR SUCCESSFUL TRANSITIONS

Families with seriously-ill children in Michigan are fortunate to have a set of specialized resources available offering a variety of programs designed to facilitate a smooth transition from curative care to hospice care across a wide range of ages and conditions. The Jo Elyn Nyman Anchors Programs for Children exists as the umbrella program to help children and their families navigate the rough waters of life-limiting illness, eliminating gaps in service and providing care team continuity.

The three unique programs offered through the Jo Elyn Nyman Anchors Programs for Children—*Compass Support Services*, the *Anchors Perinatal Program*, and the *James B. Fahner MD Pediatric Hospice Program*—each serve a distinct need for the most vulnerable patients and their families facing a journey no one wants to take. The creation of these three programs allows us to cover the diverse pediatric population we care for and service our state in a way that just one pediatric hospice program may not be able to.

Compass Support Services

Compass Support Services is designed to provide timely resources and guidance to support seriously-ill pediatric patients who are not yet ready for, or who do not meet the qualifications for hospice care. Recognizing life-threatening conditions puts a tremendous strain on families, *Compass Support Services* is highly flexible, ready to provide a range of support services to help guide the way for families coping with the day-to-day challenges that their child's condition brings. This unique, social work-based program is available when and where it is needed, helping families of children with complex, chronic illnesses access community programs to make their lives less stressful. Experienced pediatric social workers provide emotional, social, and decision-making support for the child, parents, and siblings, connecting them with specialized community resources to assist with financial, emotional, social, legal, and other needs. Importantly, they work directly with the child's current medical team and treatment plan.

It is important to note that *Compass Support Services* is a short-term, goal-oriented program. Once the family has met the goals established with their social worker, they transition off the program, armed with the tools they need to be successful in the community. However, should the child's condition change and they become hospice appropriate after they leave the program, the Compass and hospice team is able to reconnect with them and make it a smooth transition for the child and family as there is already a trusting relationship established because of their experience with the Compass program. This has also proved helpful as some of the children who come to this service are actually "hospice appropriate" from a clinical standpoint, but the families may not quite be there yet. By the social workers getting to know and support the families, they can work with the families to address their issues and concerns, so that when they are ready, the move to hospice is not as disruptive to the child or family. *Compass Support Services* is funded entirely through private donations.



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Anchors Perinatal Program

For expectant parents who learn that their unborn child may be facing a life-threatening or life-limiting illness, the *Anchors Perinatal Program* offers the support of trained pediatric social workers to help families identify and understand the challenges and decisions they may encounter.

The *Anchors Perinatal Program* provides emotional, social, and clinical support to expectant parents as they anticipate and prepare for the birth of their child, while also grieving the anticipated loss of the child during pregnancy, birth, or shortly after. The program assists parents with birth planning, hospice education, grief and loss support, memory-making activities, and even provides support for siblings through therapeutic interventions.

In cases where hospice care is a consideration, *Anchors Perinatal Program* social workers connect with their colleagues from the *James B. Fahner MD Pediatric Hospice Program* early, to identify needs and align goals to ensure families have the time they need to make thoughtful decisions prior to the birth. This also allows families the ability to focus on the precious time they will have with their child. The collaboration between the two programs becomes a key component to easing the transition to the hospice care.

James B. Fahner MD Pediatric Hospice Program

First offered in West Michigan in 1995, the *James B. Fahner MD Pediatric Hospice Program* is now available to families throughout the state. Recognizing that children are not little adults, the *James B. Fahner MD Pediatric Hospice Program* provides an experienced team of pediatric-trained staff to care for terminally-ill children and their families.

Because all children and their families are different, the *James B. Fahner MD Pediatric Hospice Program* tailors its care plans to meet their unique needs to ensure comfort and peace. Whether the need is physical, spiritual, or emotional, the pediatric-trained staff is prepared to help, working closely with the child's current doctors and serving the child's/families' needs at home or in the hospital. The support available to pediatric patients and their families includes symptom management, social, emotional, and spiritual support, access to community resources, decision-making assistance, comfort care education, sibling support, pet and music therapy, individualized bereavement services, and volunteer support.

Providing Unwavering Support across the Age and Care Continuum

Jo Elyn Nyman Anchors Programs for Children provides a range of support that is flexible enough to meet the specific needs of each patient and their family. In many cases, children have transitioned from one program to another within the Anchors Programs for Children structure—from the *Anchors Perinatal Program* to the *James B. Fahner MD Hospice Program*, from *Compass Support Services* to the *James B. Fahner MD Hospice Program*. Patients may also transition from the *James B. Fahner MD Hospice Program* to *Compass Support Services* or transition off (i.e., graduate) hospice altogether.

Jo Elyn Nyman Anchors Programs for Children, and its dedicated staff of pediatric end-of-life specialists, has quickly become a respected resource for families and the medical community due to its ability to not only minimize gaps in care, but also by providing consistency, confidence, and comfort for our most fragile patients and their families.

Lessons Learned

So, what have we learned from each of these programs and how they help us to help families make the difficult transitions so many of them face—from curative to hospice care, perinatally from planning to a birth to a potential death of the baby, from palliative support care to end-of-life care, and so many others? Not surprisingly, our lessons are not unique to the experience of other programs across the country who care for these children with medically-complex children or who are dying. That is, whether you have one pediatric hospice program, or three, the core foundational elements of caring and supporting these families are the same.



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Communication is Key

Good communication is the key to everything we do in life. When it comes end-of-life care, particularly when caring for pediatric patients facing challenging treatment choices, strong communication is critically important to help manage expectations and create a productive clinical relationship. Establishing a dynamic that encourages open discussion and keeps conversations patient and family-centered is critical to identifying goals and aligning care to meet their needs as their child and/or they are transitioning through the continuum of care. In addition, this goal-focused approach can help families make tough choices when they arise.

Timing is Everything

Timing is another significant aspect to a productive experience with the family. Ideally, end of life conversations should occur early on in the patient's disease process, so patients and families have more opportunity to benefit from the services available to them. With having pre-hospice programs like Compass to a dedicated pediatric program in our James Fahner Pediatric Hospice Program, we are able to meet the family wherever they are and walk with them wherever their journey takes them. We are equipped to be there through the stable and unstable periods of health, and ultimately, also there, when there is nothing more medically that can be done for their child.

Hospice is NOT Giving Up

Despite shifting perspectives in recent years, the myth that hospice means giving up persists. It is perhaps even more difficult to overcome in pediatrics, as for many, the focus is on the life that was not lived long enough vs. the quality of life that can be lived. With that in mind, choosing to elect hospice care is the complete opposite of giving up. Choosing hospice care means living each day to its fullest. Living each day with comfort and dignity.

Pediatric hospice care does offer a unique benefit, thanks to the Affordable Care Act, which has a provision that may allow a child under the age of 21 to receive curative treatment and hospice care simultaneously, without feeling forced to choose one or the other. In fact, concurrent care conversations are an effective way to open the door to the hospice conversation. Shifting to the hospice conversation often leads to discussions and decisions centered around time - *When will it be time to stop Chemo? When will it be time to decrease visits to specialists?* While there is no one correct answer, concurrent care allows families the time to make these decisions and transition to a more palliative or hospice care plan for their child. Also having a program like Compass which is a supportive non-hospice program gives us an entry into the family when they are not in medical crisis mode. This allows the family time to get to know us and how we can help when/if their child should actually need hospice care down the road and if the child doesn't, then we graduate them back to the community with a skill set that hopefully helps them navigate life's daily challenges with a child with a medically-complex condition.

Education and Collaboration are Imperative to Successful Care Transitions

Successful transitions to hospice care occur when the patient and medical team are informed and work together. Providing education to both the community and local physicians about the resources and benefits of hospice care will facilitate earlier referrals. It also opens the door to collaboration with hospital and community-based palliative care teams, encouraging them to identify pediatric patients early in their disease progression. Our program believes strongly in working with the child's current care team and medical plan when under the Compass Support Program, as well as should they transition to the Fahner Pediatric Hospice Program at a later date. We understand families have relationships with their current care providers, many of whom have become like "family," and to cut off contact with them when a family most needs them does not make for a good transition from curative care.



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Dedicated Specialized Resources Help Bridge Diversity of Population Needs

Three dedicated programs tailored to specialized needs of our pediatric population allow us to provide what families need, when they need it, whether that be palliative support perinatal hospice, or comprehensive pediatric hospice care for the child and his/her family. As noted, they also provide services that help transition and grow with the child and family as the baby/child ages and/or their needs change from say palliative to hospice or more social-worked based to more clinically-based. Whatever arises, we have a program and staff who can help.

None of this Happens Without Funding/Financial Support

While it goes without saying, none of this would be possible without funds to run these programs. Hospice of Michigan has been fortunate to receive significant funding for these programs from many generous benefactors who believe in our mission of maximizing the life of every one of these children under our care. While some hospice programs struggle to even establish one pediatric hospice program, many of them, part-time, we, and our families, are benefitting by having three—a pediatric early care support program, a perinatal, and a pediatric hospice program—with a dedicated pediatric staff, so that whatever the child/family needs and wherever they are in their journey, we are that anchor of support and care they need to take the next transitory step, wherever it may lead.

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CREATING CONNECTIONS: A SOCIAL WORK PERSPECTIVE IN CONNECTING WITH MEDICALLY COMPLEX CHILDREN AND FAMILIES

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Connection is a large part of end-of-life care. Some connections are built, some are felt, and some have to be created. Connecting with non-verbal, non-ambulatory children is one of my biggest challenges and most rewarding experiences. Building rapport with others without verbal dialogue or body language rivaled everything I knew about social and professional relationships. Working as a pediatric hospice and palliative care social worker, I've learned the most valuable and reliable way to set the stage for connection is approaching each family with a sense of humility and honor. I couple this approach in making the parents experts on their children and share their joy and sorrows as they naturally occur. In this article, I describe my first visit with a pediatric patient and her lovely family.

I had my list of assessment questions tucked into a file folder, nestled in my rolling bag which held my agency issued laptop, resource guides, and memory making activities. All things necessary for my initial home visit. I felt ready for my first pediatric palliative care patient. Considering I'd waited 9 months to meet her, I was more than ready. My feet were wet with agency orientation, shadowing, sending faxes, and phone calls, but there is something different when it comes to having my caseload. With my own caseload I could be creative with my approach and build a professional bond that only a home-based social worker could do. I watched my coworkers build profound connections with families in the midst of medical complications, even death, and I was honored to begin that journey.

Before my current position, I was employed at a for-profit adult hospice. An 80-patient caseload is not uncommon at a for-profit agency nor are endless to do lists, and a schedule that would make even the most energetic worker sigh. Before hospice work, I was a county child welfare social worker, on call at night and in the field during the day. I will never forget the day I worked for 24 hours straight. After that, I swore off required on-call shifts and non-mandatory, but expected, overtime. Years after building my "social work chops" and "paying my dues," I found a non-profit organization that did not require on-call shifts. Finally, I was employed by an organization that offered me the opportunity to blend my social work passions, children, and end-of-life care. I was ready, even eager, for my patient and her family.

Walking down their street I wondered what the patient would be like. I'd read through her medical record, I could tell you her diagnosis, recent temperature and weight (in Celsius and kilos mind you), but I couldn't grasp who she was. That is my goal, to learn about who she is and share it with her home-based medical team, so we could coordinate optimal care for her.

The American medical system has progressed drastically when it comes to patient care. From a time when all information needed about the patient was their diagnosis, we have evolved to include a multi-faceted approach that includes culture, religion, and family dynamics to name a few. In the early 1900s, social workers began working in the hospital and had a crucial role in order to treat the patient as whole. My organization also feels that expressions including art, music, massage, and child life therapies are important in enhancing quality of life for pediatric patients. But before I could integrate the various resources and therapists, I needed to get in the door.

Her mother, father, and toddling younger brother welcomed me. Two sweet and smiley adults with looks of appreciation that only parents who know the struggle of caring for a medically fragile child have. Faces previously streaked with tears as they wondered if their daughter would live until tomorrow or see her younger brother run someday. Faces wrought with exhaustion and honor, providing medical interventions day in and out that trained nurses perform in a hospital. I am humbled in their presence, which usually translates to shyness by smiling at the ground and bowing my head. They're younger than me, in their twenties and have lived a life that I am so new to understanding. A life dedicated to the comfort, care, and health of their daughter. Their lives are dedicated to keeping their daughter alive.



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I have been in relationships before, and I would say I've been in love before. But what I witness in these parents is a love I never gave or received firsthand. A love that keeps you awake at 11:00 pm then wakes you at 2:00 am, then 5:00 am, and every three hours thereafter to provide an hour-long breathing treatment. A love that makes you neglect your biological and visceral need for food and sleep well after the infant and toddler years. One that demands the complete elimination of self-indulgences and frivolousness. To be in the presence of such pure and true love is like seeing all the wonders of the world in one place, awesome, in every sense of the word.

I met my patient, who sat in her pink wheelchair, and stared mouth agape. "Hello," I say to her, trying to make eye contact and then realizing that due to neurological devastation, she may not be able to see me. From what I learned about the brain and senses is that they can work like a poorly functioning lightbulb, sometimes flickering on and off, other times completely out. Nevertheless, I knew that it is always important to look at every patient regardless if they could do the same. She was never able to walk or talk and dependent on her parents or machines for every aspect of her life. All of this information I read in the medical record but knowing her on paper was not the task at hand. I wanted to know *her*.

It's easy to build a connection with someone who can communicate, smile, and interact, but when it comes to children without these abilities, this type of connection needed to be created. From her parents I learned that she loves princesses, Minnie Mouse, and all things girly. It was like a page of my childhood was thumbed to and splayed right open. They went on with grins and explained that she enjoys the movie Frozen and children's music. They know this because she will wake up from her slumber just so she could listen to the familiar tunes. Like a flashback, I saw myself singing songs from The Little Mermaid at the top of my lungs and making a point to swim with my two legs together as one "fin." She would also whimper when her favorite songs or movie ended, a feeling I was all too familiar with as a child. We watched a few of her favorites on a cell phone, smiling and dancing as a way to encourage the patient's happiness. Finding the similarities between her and me helped create our connection beyond conventional or familiar forms of communication.

A priority for this particular family is to eat together. They told me about her favorite foods and eating habits. They said that when she is eating well and gaining weight she will develop a double chin. They look at each other and laugh adoringly as they say how much they love the chubby little deposit on their daughter. Her mother starts stroking the daughter's chin lovingly. I laughed too, because in my entire life I've never heard a double chin discussed so endearingly. She doesn't have a double chin anymore because eating has become more difficult. The connection between the mind and body has frayed to the point where the brain can't communicate to the throat muscles when to swallow, resulting in coughing fits. When parents can no longer nourish their children there's a sense of shame, embarrassment, and failure. Like a new mother whose baby won't latch, there's frustration, pressure, and feelings of inadequacy. These feelings don't dwindle; if anything, they're magnified when children are unable to eat at 8 years old. The mood shifts from laughter to somber and a period of silence falls as tears well up in the mother's eyes. There's no need to change the topic, no need to find a silver lining because there is none. The only need at this very moment is to hold the space for her to experience her grief. To give her permission to feel profound loss, which is the sum of little losses, compounded over time. And there I was again, staring at the wonders of the world, right in the face.

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PARTNERS FOR CHILDREN PROGRAM: DISRUPTING THE STATUS QUO

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For the majority of parents of children with chronic complex illnesses, life revolves around frequent trips to specialty clinics, pediatrician visits, and emergencies that often result in hospital stays. The cycle can be overwhelming, frustrating, time-consuming, and full of anxiety. The **Partners for Children** program (PFC), housed at the University of Michigan, with support from the Michigan Health Endowment Fund and Hospice of Michigan, was designed with these children and families in mind. Its goal is to disrupt the cycle by transitioning to at-home care and visits from social workers and nurse practitioners, 24/7 provider access, and coordination of care.

There are hundreds of Michigan children with complex conditions who receive care from neurologists, orthopedic surgeons, otolaryngologists, rehabilitation specialists, gastroenterologists, lung specialists, pediatric surgeons, urologists, and mental health providers. Many of these children have limited mobility, take more than nine medications daily, and depend on technology to help them to survive and integrate themselves into their families and communities. Many have a combination of feeding tubes, respiratory devices, and mobility aids. PFC is enrolling 100 children with such chronic complex diseases. The program provides an extra layer of support to the children who do not fit certain criteria or a category (referred to as “medical unicorns” by one parent), which typically means their cases are not evaluated in a holistic, comprehensive way. This program’s purpose is to change that.

With the help of the University of Michigan’s Child Health Evaluation and Research unit, the program is coordinating parent survey data, as well as assessments of clinical outcomes and claims data. Initial interviews revealed the challenges the families face every day:

- *Specialist appointments*: Bringing medically complex children to specialist appointments isn’t just a matter of distance. For many families, the logistics of transportation are complicated (e.g., two adults needed so that one can ensure that medical equipment is working, finding childcare for other children). Parking and long waits at the clinic are common and test the endurance of both parents and children.
- *Telephone advice*: Many parents describe their pre-PFC options for telephone advice as inadequate. While some are fortunate to have a direct cellphone number or email for a key specialist or nurse, most use the standard on-call service for some or all specialties that their child sees. Parents describe the advice from on-call providers as rudimentary, lacking in knowledge of the child’s unique medical history, and overly reliant on basic strategies that have been tried previously and found not to work. Fairly often, the on-call providers just encourage parents to go to the ER.
- *Inter-specialty cooperation*: Parents express a desire for someone to look at their child holistically. They perceive that many specialists think only about their specific specialty area, and don’t consider how problems can cross body systems. Outside of the palliative care team, parents perceive there were few conversations between specialists. The lack of communication is particularly frustrating during inpatient stays, when specialists were likely to be in close physical proximity but are not called in for a consultation.



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Given these challenges, the program seeks to encourage communication among providers caring for the children. Although patients maintain a relationship with the primary pediatrician who agrees to the patient's enrollment, the coordination of care is assumed by the program. A social worker and nurse practitioner, backed by PFC physicians, provide an initial home visit to learn about the child's medical and social history, go over the program design, answer questions, and provide reassurance that it is, in fact, acceptable to call the program at 2 A.M., if an urgent situation or question occurs. Follow-up visits are scheduled in 4 to 6 weeks, either at home, or with a specialty clinic visit. The program involves ancillary support from hospital nutrition, pharmacy, rehabilitation medicine, and education. The contacts from those departments work to get to know the child's case and remain in contact with the nurse practitioner and PFC physicians.

- When a child transitions to the program, a lot of work is done “behind the scenes” to facilitate care, such as working with specialists to devise a clinical strategy for ED doctors prior to the child's arrival. PFC nurse practitioners and physicians also receive input from several specialists during an inpatient stay and explain a child's unique needs.
- Parents appreciate proactive check-ins from PFC. When done outside a clinic appointment or medical emergency, these contacts help parents think about the child's day-to-day needs, and prompt them to ask questions or request assistance related to things that might enhance their child's quality of life – things that often do not come up during medical appointments.
- Consistent communication between providers and the parents builds a relationship and trust in the program and the system. During the time of crisis, parents need to be able to talk to a person who understands the child's complexity, and who is willing to spend time brainstorming for solutions that may have not been tried before. Thanks to that, several ED visits and hospital stays were prevented or shortened.

For the **parents**, transitioning into the program means receiving guidance from someone who knows the child's specific history, and who can help bring together the perspectives of different specialists. It gives the parents a feeling of support, and alleviates anxiety surrounding the daily life. For the **child**, it is a shift in how the care is being approached. It provides an opportunity to focus on improving the child's quality of life and keeping them in the comfort of their home. This model also brings **providers** together to deliver the best possible solutions for the medically complex children. Additionally, the **payers** are interested in the program design, having realized the potential to provide improved patient and family support in a cost-effective and sustainable way. Disrupting a status quo and transitioning to a new model are not easy tasks. Yet, when achieved, a question often emerges: “How could we ever go back to the old way?”

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INDUCED POSITIVE TRANSITIONS: A MODEL FOR DEVELOPING HOPE, RESILIENCE, AND JOY IN SERIOUSLY-ILL CHILDREN

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A life-limiting medical condition poses innumerable challenges for the pediatric patient and family alike. The logistics of providing care, the apprehension about risks and vulnerability, the stresses of tending to the needs of this child and one's other children, and the specter of the encroaching unknowns, can engender multiple complications for both psychological coping and physical wellbeing. Becoming cognizant of the stages which the illness will follow can create its own worries, including the anticipatory anxiety of waiting for the demands and realities of the condition to unfold.

Dr. Viktor Frankl has often been quoted as saying that “an abnormal reaction to an abnormal circumstance becomes a normal reaction.” Thus, it is quite normative for depressive symptoms to arise, for fear and worry to surface, and for the entire range of clinical distress indicators to abound in reacting to the abnormality of a child's decline of health and its concomitant limitations on functioning. In short, “normal” happiness, joy, and humor are very seldom part of the patient's repertoire, the siblings' experience, or the parents' focus. Families may find that joy is neither natural nor comfortable when serious illness is present. The “pathological” or abnormal reactions are the new “normal” when the trauma of serious illness makes life painful and frightening.

For some, particularly when a somber mood pervades the patient and the family, an upbeat, cheerful intervention or cheerful recommendation can seem false and shallow, or can be met with dismissal and rejection in view of its apparent disregard for, or denial of, the gravity of suffering, the intensity of discomfort, and/or the hopelessness which patient and family foresee. In truth, a poorly-timed attempt to “lift the spirits” of a patient in agony or their parents, can be perceived as grossly inappropriate, as cruel, and as part of a conspiracy to avoid and to ignore their personal realities.

In contrast, however, are findings which demonstrate that systematic efforts to reengage a patient with their previous ability—and personal entitlement—to experience positive excitement and to laugh once again, can provide comfort for both the child and the family. In short, this article will discuss a model for “induced positive transitions” [as opposed to the inescapable negative transitions associated with the process of illness] for reintroducing positive experience to these patients. To reframe Dr. Frankl's dictum, “recreating *normal* reactions despite abnormal circumstances can generate further normal reactions.”

The transitions which are endemic in the life of an ill child include, often,

- leaving school
- losing routine and schedule
- withdrawal from social milieu
- structuring medical visits and hospital stays into one's typical week
- changes in priorities with, and levels of attention, to other family members

and other adjustments to lifestyle. Those transitions are accompanied by associated adjustments for parents and siblings, as well. Life's structure, domestic schedules, family plans, marital routines...all are disrupted when home life centers around caring for the very ill child. These changes are stressful transitions.



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In the planned-respite model which this paper describes, we utilize an “induced positive transition” wherein the family is guided in a time-limited reversal of the patient’s veritable withdrawal from social interactions and positive activities. This is facilitated through providing intervals of out-of-home opportunities to engage with other children, to participate in age-appropriate “normal” activities, and to access creative-productive skills through art, through acting, through music, and through movement therapy. These activities within a well-planned environment are psychological catalysts for developing confidence and courage in the child who engages in new experiential learning, speaking up about their conditions in the company of other ill children, and perhaps most uniquely, undertaking these time-limited healthy transitions while away from parents and siblings. This respite model would be termed, in the simplified vernacular, “giving everyone a break.”

This model has been fostered through our organization, Chai Lifeline, at its state-of-the-art campus known as Camp Simcha. We have researched the psychological and medical conditions with which the pediatric patients live and have built a system whereby parents are able to entrust their child’s health care to the expert medical staff and the fully equipped medical facilities, while also accepting the challenge to give the child a normal experience of being a child...and having fun again. The patient is away from home, in a facilitative and safe setting, which in and of itself can be a catalyst for the return of normal “premorbid” psychological states. The clinical objectives of the comprehensive induced positive transition are:

- increased perceived independence
- self-confidence
- positive self-image
- realistic yet optimistic body-image
- resilience and calm

Those adaptive psychological states are in contrast to the psychological states associated with severe illness such as:

- perceived helplessness
- fearful dependency
- insecurity
- inferiority related to suffering from a medical condition
- perceived incompetence
- hopelessness
- agitation

Most of the patients who are served by Chai Lifeline’s medical case management team throughout the course of their illness are involved at some level with their own religious-cultural community. The patients are generally Jewish, with varying levels of religious backgrounds and affiliations. Camp Simcha accommodates all of the religious needs and practices of its families and campers, so that each child’s existing religious structure and routine can be maintained without compromise in a setting which also accommodates each patient’s specific medical needs. This is in contrast with hospital stays and other conventional patient services which despite cultural awareness and sensitivity may lack the means and know-how to provide for a patient’s personal needs in those spheres. In addition to religious sensitivity, the comfort which a child can feel within an environment which is supportive of personal culture can promote a willingness to explore their personal faith-based tenets, which clinical studies have correlated with healthy coping. These more “psycho-spiritual” coping tools, which can be developed and encouraged as part of the induced positive transition, include:

- Hope
- Discovery of Meaning
- Discovery of Purpose
- Mindful Spirituality
- Transcendence
- Acceptance



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- Values
- Faith

There is a very high staff to camper ratio, with each patient-camper assigned personal counselors, shadows, activities therapists, and bunk monitors so that each child's health and hygiene are paramount, yet exposure to normal appropriate individual and group experiences is part of the daily program. Thus, even when a child and their parents were certain that their child would be restricted from active participation in games, in races, in contests, and in learning skills of self-reliance and self-acceptance, the transition out of the home into an environment which is entirely devoted to the fun, fantasy, and self-actualization of the camper can free many children from the belief that illness means the end of hopefulness and elation. At times, the best intended parent's protectiveness of the child can lead to the child lowering their own expectations of self. The induced positive transition of living away from home in an activating and stimulating—and healthy—setting helps a child and a family recalibrate. These positive transitions mean that they so often will cross over former perceived thresholds and limits, and surpass horizons once clouded by fear and despair.

Concurrently, “back home”, parents also are given respite, but not passively so. The induced positive transition is for the rest of the family too, by way of parent support groups, expert coaching with guidance and tools for their own adaptation, making use of this transitional interval to renew and strengthen their own marital bond, to discuss techniques for maintaining the quality of family life, counseling for coping with their child's illness process, and recommendations for reinvigorating their bonds with their other children, who share in the stresses of having an ill family member.

Another nuance of positive transition relevant to having an ill child is that of the well siblings, who not infrequently feel that they have forfeited their roles in the family and their identities as children in view of the more serious needs and demands of the child who is a patient. Camp Simcha provides a “respite camp” experience for siblings to find support and to identify with other families who face the challenge of growing up with an ill child. This is another “induced positive transition” which allows for the expression of distress, the working through of ambivalence, and tools for addressing the internal and ambient pressures which are often a part of the sibling experience. Expression of and validation for those covert struggles can be instrumental in soothing the sibling while also circumventing the onset of anger, depression, and frustration which are often present when parents must devote time and energy to the patient-child at the expense of normal family flow.

The life experience of a seriously-ill child, and the experiences of his or her family, are predictably fraught with unavoidable and automatic transitions which occur with the onset and process of their medical conditions. Utilization of an induced positive transition by way of a providing a safe environment and a supportive and culturally attuned milieu away from the stresses that are a typical part of home life within a beleaguered and overwhelmed family can promote adaptation, coping, psychosocial growth, and hope.

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ITEMS OF INTEREST

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **TRICARE NOW ACCEPTING PEDIATRIC CONCURRENT CARE:**

Despite 2017 legislation allowing Tricare pediatric beneficiaries to begin receiving concurrent hospice care, the policy has not yet been fully implemented. Tricare will be issuing regulations in 2019 and until then Tricare now stands ready to approve claims waivers for any child enrolled in hospice care and simultaneously receiving curative treatments. Waivers will be reviewed and approved by the Chief Medical Officer of Tricare. Tricare for Kids Coalition will be assisting providers and families in the waiver process.

For more information on processing a waiver to receive concurrent care for your pediatric patients, please contact Kara Oakley kara@karaokley.com at Tricare for Kids Coalition.

TRICARE is the health care program of the United States (U.S.) Department of Defense Military Health System and is managed by the Defense Health Agency. It provides civilian health benefits for U.S. Armed Forces military personnel, along with military retirees and their dependents. The TRICARE benefit covers a wide range of medically necessary services such as primary care, mental health, and hospice care.

2. **NHPCO Palliative Care Online Resources:**

NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community –Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

3. **Pediatric Hospice and Palliative Care Resources:**

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org
 - *When Your Child is in Pain*
 - *Talking With Your Child About His or Her Illness*
 - *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
 - *When a Child Dies: A Guide for Family and Friends*
 - *Helping Children Cope with the Loss of a Loved One*
- **NHPCO's Palliative Care Resource Series** now includes pediatric palliative resources such as:
 - *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
 - *Consideration for Complex Pediatric Palliative Care Discharges*



Children's Project on Palliative/Hospice Services

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Learn more at www.nhpc.org/pediatrics

- *'Who You Gonna Call?'* Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning
 - *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*
 - *Nonpharmacological Pain Management for Children*
 - *Sibling Grief*
 - *Pediatric Pain Management Strategies*
 - *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*
- Researchers in Canada are working on a research project called: **'READYorNot' Moving Ahead with Transition of Care from Adolescence to Adulthood.**

Youth with brain-based developmental disabilities require seamless transition from the pediatric to adult health care systems. This transition can be disruptive for youth and their families and have a negative impact on a patient's health. In the majority of pediatric centers, there are no dedicated resources for transition of care. With the 'READYorNot' (READiness in Youth fOR traNsition Out of pediaTric Care) project, we are developing and evaluating e-health aids to help patients and families take charge of this transition. It includes youth 16-18 years of age.

For more information, contact:

Alicia Via-Dufresney Ley at alicia.via-dufresneley@mailmmcgill.ca

- "A Perinatal Pathway for Babies with Palliative Care Needs" from Together for Short Lives in the U.K., developed in conjunction with ethicists and clinicians working across obstetrics, antenatal and neonatal care, and children's palliative care. Full pathway available for free download via this press release and links here: http://www.togetherforshortlives.org.uk/news/11605_together_for_short_lives_launches_vital_resource
- Three Years ago Holland Bloorview Kids Rehabilitation Hospital launched [the Chronic Pain Assessment Toolbox for Children with Disabilities](#). The Toolbox has received over 6000 downloads to date! Since then three eLearning modules have been developed. The modules will introduce you to:
 1. Chronic pain in children with cerebral palsy and the development of the Toolbox
 2. The sections of the Toolbox and how to start with based on your needs
 3. A case study of a complex patient from one of our nurse practitioners, and how a chronic pain assessment tool supported her clinical examination.

Check them out here: <http://hollandbloorview.ca/Toolbox>

4. **Pediatric Hospice and Palliative Care Training:**

- **Upcoming 2019 Webinars provided by the Pediatric Care Coalition:**
 - February 21, 2019
Don't You Forget About Me: Caring for Siblings
Presenters: Yelena Zatulovsky & Dana Richmond
 - March 19, 2019:
Building Resilience in Children and Caregivers coping with Serious Pediatric Illness
Presenter: Abby Rosenberg



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- April 16, 2019:
Creative Conversations: Advance Care Planning in Pediatrics
Presenter: Kathy Perko & Debbie Lafond
- May 23, 2019:
Providing Spiritual Care with Pediatric Patients
Presenter: Rev. Travis C. Overbeck
- **2019 Perinatal Bereavement and Palliative Care Conference:**
The 2019 Perinatal Bereavement and Palliative Care Conference will have a strong focus on Perinatal Palliative Care. This conference will explain the history of Palliative Care, then and now, how to begin a program in a small hospital, how to define comfort care to parents and families, and the journey home. Keynote speaker Amy Kuebelbeck, well known author and loss parent.

Class Price: \$90.00 Early registration (Feb. 15). \$100.00 after. Free to Virtua Employees (Virtua employees must call 888-847-8823 for registration.)

"2019 Perinatal Bereavement & Palliative Care Conference-Making the Most of Precious Time" (www.virtua.org/PBPC)

- **National Perinatal Association - 2019 Conference**
Improving Access to Perinatal Care: Confronting Disparities and Inequities in Maternal-Infant Health
Wednesday, April 3 - Friday, April 5, 2019
Providence, Rhode Island
<http://www.nationalperinatal.org/2019conference>

5. Journal/News Articles

- **Torrance doctor has a special mission: To help dying children and their families:** Glen Komatsu, MD, is the chief medical officer at Providence Trinity Health Care Hospice in Torrance. Komatsu talks about an upcoming visit to the home of Eugene and Gabriella Mafi and their three-year-old son, Gabriel, who has a condition known as trisomy 18, a fatal error in his cell division. Read more [here](#)
- **Google honors pediatrician Fe del Mundo with new Doodle:** Google is paying homage to Fe del Mundo who financed the first pediatric hospital in the Philippines. Read more [here](#)
- **Health homes for chronically ill kids spark lame-duck battle:** A band of lawmakers and staff want to pass by year-end a controversial bill that would set up an optional health home program for kids with complex illnesses—and the federal government would pick up most of the Medicaid tab for states that want it. Read more [here](#)

6. **Subjects and Contributors for Future Issues of This E-Journal.** For upcoming E-Journal issues, we plan to address issues related to Integrative or Complementary Therapies and Myth Busting. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact Christy Torkildson at ctorkildson@mail.cho.org or christytork@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

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