

Myth Busting

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Issue Topic: Myth Busting

Welcome to the 57th issue of our Pediatric e-Journal. This issue explores some of the many myths that appear to be attached to pediatric hospice and palliative care in the minds of many lay persons, family members, and even some professional care providers. The issue begins with three articles by parents whose child received pediatric hospice/palliative care before the child's death, plus an article by a teenager who is currently receiving such care. After that come 10 articles, each of which addresses a common MYTH about pediatric hospice/palliative care coupled with a TRUTH as described by authors familiar with the realities of this mode of care. We hope all of the articles in this issue will spark discussion among readers about misunderstandings versus the actual realities of pediatric hospice and palliative care.

Of course, we cannot claim that the collection of articles in this issue covers ALL of the MYTHS and ALL of the TRUTHS about pediatric hospice and palliative care. So, we invite readers to share with us what they view as important MYTHS and even more significant TRUTHS about this important mode of care. In an effort to make this e-Journal more interactive and providing topics and issues YOU, our readers, want to see addressed, we are adding this as a new column titled, "Give Us Your Questions!". We are trialing it in this issue to see if there is interest in it as a regular column. So please send your thoughts on Myths or Truths to Christy Torkildson at Christina.Torkildson@bannerhealth.com, or to Ann Fitzsimons at ann@here4U.net, or to Chuck Corr at ccorr32@tampabay.rr.com—or to all three of us. Then look for us to address your myths or share your truths in future issues of this Pediatric e-Journal.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Ann Fitzsimons. Chuck Corr is our Senior Editor. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of NHPCO's Pediatric Advisory Council, 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 legislative updates, ethical issues, the dying process, and self-care for future issues in 2020. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at Christina.Torkildson@bannerhealth.com or Ann at ann@here4U.net.

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Issue #57: Myth Busting

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

Ainsley’s Story

p. 7

Major Kim "Rooster" Rossiter, USMC

In this article, Ainsley’s father describes some of the challenges faced during the year between Ainsley’s referral to hospice care and her death. During that time, he praises the care offered by the staff of EDMARC Hospice for Children. As he writes, “We looked forward to visits. Not just because of the medical care, but more so for the love and affection, as they genuinely cared about Ainsley’s well-being, and our family’s well-being...EDMARC helped us gain confidence that we were making the best decisions for Ainsley.”

With You Through the End

p. 9

John M. Kaptan

Johnny Kaplan died of a pediatric brain tumor. In this article, his father contrasts the efforts of first responders with those of hospice providers. He writes that, “Quiet deaths at home are not as dramatic as car accidents or fires. But they are far more common. That these deaths are increasingly accompanied by dignity, and as much comfort as possible, is due to the constant attendance of hospice caretakers.” As he explains, “Hospice providers aren’t the first ones in when bad news hits, but they are the ones who are with you through the end.”

Freight Trains & Airplanes: Conversations about Child Loss

p. 10

Dannell Shu, BFA, MWS

Here the metaphor of a passing freight train is used to capture the experience of trying to talk about child loss with a fellow parent who has not had such an experience. As Levi’s mother writes, “Both of us fall silent, waiting for the train to pass. I wait because I know nothing I say next will be heard. The train is too loud. They wait unknowing of what to say next as they are confronted with the reality of child loss...the freight train is the sound of their fear.” If this were all that was to be said, we might conclude that it is impossible to talk about the life of a child born with disabilities and medical complexities, as well as his death seven years later. That would be the myth. But in this article the author mentions that on some rare occasions and unlike the effects of a passing freight train, the truth is that the sound of an airplane taking off can initiate “a new and deeper conversation,” a conversation that the hospice philosophy seeks to promote.

“Meet Me where I Am”: An Interview with a Teenager on Palliative Care

p. 13

Jessica Sturgeon, MT-BC, HPMT

This article offers an interview with an 18-year-old girl by a pediatric music therapist working in home-based hospice and palliative care. Gaps are noted in the information provided by hospital personnel to both the teenager and the palliative care team. Also, “there was a lot of confusion and disconnect that prevented Bianca’s mom from providing that information to her. In addition, Bianca had a difficult time being able to communicate what she wanted to know and

how she wanted to know it.” The lesson to learn is that we must “be vigilant to identify the future emotional implications that illness and medical care/communication also has on pediatric patients.”

Myth #1: Pediatric Palliative Care Means Stopping Care and/or Treatment *p. 16*

Suzanne S. Toce, MD

Truth #1: Pediatric palliative care is intensive care and treatment with a goal of maximum comfort; emotional, psychosocial, and spiritual support for the child and family; logistical support; and decisional support/advance care planning. (Note the absence of discontinuing anything!)

Myth #2: Pediatric Palliative Care Can only be provided by a Pediatric Palliative Care Specialist *p. 17*

Suzanne S. Toce, MD

Truth #2: All pediatric providers and support personnel should have some training in pediatric palliative care. Children with more complex needs should be cared for by providers with experience and/or specialist training in pediatric palliative care.

Myth #3: Pediatric Palliative Care is only for the Child *p. 19*

Marta Friedman, LCSW, ACHP-SW, JD

Truth #3: It’s a family affair. Pediatric palliative care also provides support and services to those identified as family, friends, and communities of support. Interdisciplinary teams and many specialists are integral in addressing the care of patients and those who hold them dear.

Myth #4: Pediatric Palliative Care Must Wait until the Patient and Family are “Ready” *p. 22*

Jared Rubenstein, MD

Truth #4: Pediatric palliative care involves working with children and families all across the illness spectrum; it should not be regarded as optional.

Myth #5: It’s Not OK to Use Opioids in Children at End of Life *p. 25*

Melissa Hunt, PharmD

Truth #5: When used appropriately, opioids can be safe and effective for treating pain in children, allowing the child to be more comfortable and therefore live the best life possible.

Myth #6: Research over the Past 20+ Years has shown that Most Barriers to Pediatric Palliative Care have been Overcome *p. 29*

Christy Torkildson, RN, PHN, PhD, FPCN

Truth #6: Barriers continue and the most cited include the health care providers’ perception that the family is not ready to discuss preferences for life-sustaining treatments, that the families are not ready to acknowledge the terminal diagnosis, and the family’s discomfort with possibly hastening death of their child.

*Myth #7: Pediatric Palliative or Hospice Care Doctors and Services Will Take Over All Care**p. 32***Sasha Griffith RN, BSN, CPLC, CHPPN**

Truth #7: Successful pediatric palliative or hospice care programs aim to provide interventions and supportive measures that complement the treatment plan and care provided by the child's primary care team.

*Myth #8: Children are Afraid and/or Unable to Talk about Death**p. 35***Hania Thomas-Adams, CCLS, MA**

Truth #8: Grieving children need honest and age-appropriate information, direct language, and permission to express themselves.

*Myth #9: Disclosure of the Child's Condition/Progress is Harmful as It Takes Away Hope**p. 40***Suzanne S. Toce, MD**

Truth #9: Disclosure supports hope, emotional adjustment, full participation in decision-making, and advance care planning and should, generally, be the standard of care.

*Myth #10: You are a Pediatric Hospice and Palliative Care Provider? You Must be Sad All the Time**p. 42***Holly Davis, MS, APRN**

Truth #10: Caring for children and their families has given me such a greater appreciation for life; I have learned to be in the moment, appreciate the people around me, and cherish time with others.

ADDITIONAL NOTES

The Pediatric Advisory Council is a council 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, Pediatric Advisory Council and its E-Journal Workgroup, 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 e-Journal from a friend or some other source, please send an email message to Pediatrics@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and "opt-in" for communications from Pediatrics. Member

Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the Pediatric Web page at www.nhpco.org/pediatrics for previous issues of this E-Journal, additional materials, and other resources of interest.

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AINSLEY'S STORY

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This essay provides a few thoughts to be shared with families that recently learned or will learn that their child has been referred to hospice care.

You are likely terrified, confused, and uncertain, as we were in February 2015 when our sweet Ainsley was referred to hospice. You, like us, have preconceived ideas of what hospice care means and your friends and family are likely not sure of what this means for you and for your loved one's future.

Well, prepare to be relieved and feel a sense of security, as all of your preconceived notions are proven to be myths. From the moment we met for the very first time with Nurse Theresa, we felt instant relief to have EDMARC Hospice for Children by our side for this next phase of Ainsley's journey.

As our weekly and monthly check ups endured, Madelyn, Abbey, and the nurses became like family. We looked forward to visits. Not just because of the medical care, but more so for the love and affection, as they genuinely cared about Ainsley's well-being, and our family's well-being. Together, we enjoyed countless comforting visits and loads of smiles, hugs, and downright enjoyable company. EDMARC helped us gain confidence that we were making the best decisions for Ainsley.

Two months before Ainsley's passing in February 2016, EDMARC brought Santa Claus to come visit her and the entire family. As we joined in lyrical glee, caroling together, as Santa sat near Ainsley, everyone was unified in the most uplifting of experiences. You must know that these people of hospice are not just nurses or caretakers, the ladies that came into our lives are saints, they are angels, they are our sisters and comforted us and loved us from day one. They were the first ones to provide comfort on Ainsley's final day and did so in the most professional way, yet with empathy. You don't want to think about that day for your loved one, which is perfectly fine, as EDMARC will ensure you have all the resources to make the right choices for loved one and for your family.

EDMARC's love is a love that endures. The summer following Ainsley's passing, our family was invited to Camp M.A.G.I.C. - a place where you learn that "My Active Grieving Instills Courage." A lot of wonderful things occur at Camp M.A.G.I.C. and we were truly humbled by the opportunity to be there amongst so many amazing people. To connect with others who are

traveling a similar journey and to learn that we all grieve, we all do so in our own ways, and we can do so forever.

Today, we find ourselves with Ainsley not with us in the physical, but we find ourselves with the courage to go and to honor Ainsley, while knowing it is okay to make those decisions, that allow us to be happy.

Thank you, EDMARC family, for your love, compassion, empathy, and patience along this journey, as we learn the way, together, piece by piece.

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WITH YOU THROUGH THE END

John M. Kaptan

Johnny's father

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Our society rightly esteems first responders. We recognize the particular type of courage demonstrated by those who selflessly “rush in, while others rush out.” Another set of professionals, though less recognized, is similarly selfless and committed to serve in difficult circumstances. Hospice providers may not rush in, but they **stay in**, till the often-painful end.

Quiet deaths at home are not as dramatic as car accidents or fires. But they are far more common. That these deaths are increasingly accompanied by dignity, and as much comfort as possible, is due to the constant attendance of hospice caretakers.

My experience with hospice was over the months leading up to my son's death to a pediatric brain tumor. The hospice providers permitted us to spend our final weeks as a family in our home. Instead of an exhausting cycle of taking turns keeping vigil at the hospital, while the other saw to our three healthy children, my wife and I peacefully prepared our family for the next chapter, one without our precious son.

He made memories up until the end. His siblings would climb onto Johnny's bed and build Legos with him, paint pumpkins with him, or just curl up next to him and enjoy his presence. Our hospice nurses would come to our home, administer medicine, take labs, aid in care, and consult with us over how to best make our son comfortable.

These months were painful, incredibly so. But they are not bitter memories. In large part, we credit our hospice nurses for the blessing of peace that mingled with our sorrow. They did not treat our son as a patient, but as a person. They performed their duties, not first as paid professionals, but as personal caretakers. Our hospice nurses became our friends. The relationship didn't end with our son's passing; they have loved us as a family even as the composition of our family changed.

Hospice providers aren't the first ones in when bad news hits, but they are the ones who are with you through the end.

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FREIGHT TRAINS & AIRPLANES: CONVERSATIONS ABOUT CHILD LOSS

Dannell Shu, BFA, MWS

Levi's Mother

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Have you ever been within 50 feet of a freight train as it rode by at a quick pace, blaring its whistle, warning those nearby? The rhythm of the engine chugging, steel wheels upon the steel tracks, wind rushing, whistle blaring. Do you know that sound?

Have you ever been near the edge of an airport runway, as a large passenger airplane lifted up into the air? The shake, whirl, and whine of twin turbo engines. The aerodynamic noise as steel and people are thrust forward and up into the air. Do you know that sound?

I do.

I hear it every time I meet a new person and they start asking about my children. If they ask enough questions, or do so in a particular order, eventually they will learn about my son, Levi, who died over a year ago.

This is when I hear the sound. As if a freight train has just shot between us.

We could be standing just two feet apart, on the edge of a playground, watching our living children play together. And still the freight train manages to shoot between us.

Have you noticed how the sheer intensity and volume of sound, when trains pass by and planes take off, causes all other sounds to fall quiet? Or seem as if they do, simply because nothing else can be heard.

It is as if the sounds of freight trains and airplanes produce a surrounding silence. Automatically we stop talking and wait for the train or plane to pass.

This is what happens when I speak of my child who has died to someone who has not had the opportunity to meet my child during his lifetime.



Broaching the subject of child loss with a fellow parent triggers the freight train to shoot between us. Both of us fall silent, waiting for the train to pass.

I wait because I know nothing I say next will be heard. The train is too loud.

They wait unknowing of what to say next as they are confronted with the reality of child loss. I can see in their eyes, the turning away of their gaze, the freight train is the sound of their fear.

No parent wants to outlive their child, particularly their young child. My son died at 7 years old.

The sound of the freight train is deeply familiar to me. It is the same sound I heard when my son was alive. He was a child born with disabilities and medical complexities. His challenges were stark and obvious.

When Levi and I were at the park or a restaurant, I heard the train pass between myself and other parents as they looked at us. When I was away from Levi, and a fellow parent would ask about my children, I heard the sound of the train when they learned Levi was not a "typical" child.

For me, then and now, the silence surrounding the freight train is the sound of loneliness and isolation.

Most of the time that silence is the end of our conversation. Nothing more is said between us about anything. I can literally see them drift off into another direction even as we continue to stand just a few feet apart.

Today, sometimes after the train passes, the person comments about the sadness of child loss. Or maybe asks how my younger son is doing.

I find myself dampening my response, as if to make the conversation easier for them. For I can see in their eyes they can still hear the freight train traveling down the tracks.

This extends our conversation by only 2-3 minutes until they too drift off into another direction.

Rarely, and I do mean really rarely, does a fuller conversation happen after the fact. Usually it is because the person I am standing with has also experienced child loss or their job brings them in contact with traumatic situations like mine.

Only then do I know if what has passed between us was a freight train or an airplane.

A freight train ends the conversation.

An airplane initiates a new and deeper conversation.

Still there is a silence that continues around these rare conversations.

People ask about how I or my younger son are doing. Once in a long while someone asks how my husband is doing. We talk about the tsunami of change since my son's death, how life is different.

Maybe someone will ask how my son died. Maybe.

No one asks about my son.

There isn't a doorway to share a story, talk about his personality, his favorites, or memories we cherish because of him.

It feels as if the personhood of my son gets lost.

Quite honestly, I'm often not sure how to bring these aspects of him into the conversation.

Perhaps this is a skill bereaved parents develop over time? Perhaps?



Instead we talk about my son and death as if they are one. About life since his death.

I recognize child loss is a frightening topic to consider, let alone confront as you are standing two feet from a fellow parent who has experienced this.

I recognize the freight trains that pass between me and possible new friends are not my own. They are the unspoken fears within fellow parents and our community at large.

I recognize the silence and drifting off that follow these freight trains is not intentional. It is an expression of our inability as a culture to be fully present with one another in hardship and loss.

I recognize the silence about the personhood of my son that follow airplanes is not intentional. It is as much a reflection of my own challenges as a grieving parent as it is the overall brevity of a conversation alongside the playground.

I imagine someday, when I meet a potential new friend, and we are able to talk holistically about my son, his death, and his personhood, it will feel like stepping into a hot air balloon.

The buoyancy of the lift off will be greater than the sound of the balloon rising.

“MEET ME WHERE I AM”: AN INTERVIEW WITH A TEENAGER ON PALLIATIVE CARE

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Bianca*, age 18

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“Well, children are not dumb. That’s for sure. We know what we want, and we know what’s going on.”

There are numerous research-based articles, perspective pieces, and theoretic frameworks that indicate children have better physical and emotional outcomes when they are supported psychosocially during life-threatening or terminal illness. Studies have summarized and replicated that children who experience heightened stress related to medical situations experience lowered and/or anxious mood, sleep problems, poor concentration, decreased self-esteem, depressive symptoms, emotional disturbances, and even developmental regression (Sutter & Reid, 2012). The aforementioned remain a concern when children face chronic/terminal illness and medical trauma. In a Florida-based study, 90% of respondents identified that they feel they “live on a rollercoaster” (Knapp et al, 2010); this is easily transferred to children as we see behavioral and emotional changes in children who have illnesses with an exacerbation if dialogue is not present. When the truth about treatment and prognosis is disclosed, children’s long-term anxieties are lessened (Sutter & Reid, 2012). Yet, as adults, there is an instinct to shield them from what is happening and be less forthcoming on basic information. As a pediatric music therapist working in home-based hospice and palliative care, I have worked closely with children facing illness that have questions and are looking for answers. Bianca, a teenager on palliative care, has been receiving services inclusive of music therapy for the past four years. In that time, we have worked closely together to identify how her illness and her experiences have impacted her life and her perspective of the world. The lack of knowledge she had about her illness, including the severity and the long-lasting implications, made it difficult to build relationships and trust later in life and will be something she will have to consciously work on for a long time.

“There was one time in the hospital: they came into my room when I had all the lights off and the blinds closed. They were convinced I was depressed. The doctor came in and did the regular assessment, and this guy came in an hour later out of nowhere to tell me the doctors were

concerned. It's like, who are you? It completely closed me off. If they don't understand me now, then they're not going to understand me later. They didn't even ask."

Interdisciplinary connection and collaboration are key when working with children who have illnesses. In this case, there was no direct communication between the hospital and the home palliative care team. What I was seeing in the home was much different than what the staff at the hospital had seen. I had also been more exposed to her home environment, family, activities, etc., that allowed me to be able to more broadly assess her coping and expression. A call and collaboration could have sated many concerns identified in the hospital; however, it would have also allowed the palliative care team to have more information and be educated by the hospital team on their concerns.

"When I think about it, I don't think I ever knew I was going to be on peritoneal dialysis until I was just on it and doing it. No one ever told me why I was doing it or what it was about. I knew I was sick; I knew I was in the hospital for a long time. I even knew I would eventually need surgery someday. But I didn't know what dialysis was, I didn't know what it was doing, and I didn't know how serious it was."

Dialysis can be very trying for a young child to go through, especially when they're on it for years. For Bianca, we talked at length at how this affected her ability to make and keep friends since she was either driving 2-3 hours to go to the hospital for her dialysis appointments or receiving dialysis at home and being forced to stay in her room for the majority of the day. To think, she was going through all of this and not knowing why it was happening?

"There's a limit to knowing what's going on. I wouldn't have wanted to know everything about everything because it probably would have made things confusing and scary. Not knowing at least some of what's going on, though, you don't know what the next step is until you live the next step. When I was going through all of the procedures, I had no idea what I was giving up. I couldn't stay at friends' houses, I had to be home at 7, and I couldn't keep doing my dance class at school. Even to this day, I've never gotten to do a dance performance and that makes me the saddest."

Children are often not the primary point of contact for information. It is the hope that the parent/guardian will disseminate the information best. In this case, there was a lot of confusion and disconnect that prevented Bianca's mom from providing that information to her. In addition, Bianca had a difficult time being able to communicate what she wanted to know and how she wanted to know it. Child life specialists are valuable assets in the hospital as they have the ability to educate the family and the patient in a developmentally and medically appropriate manner. In addition, child life specialists have the ability to prepare and structure visits, provide information and activities to enrich understanding (Sutter & Reid, 2012). Other creative art therapies, such as music, art, play, and drama therapy provide supportive environments to review, process, and validate in a creative and meaningful way. It also opens the lines of communication and empowers children to ask their own questions in their own time.

“Kids can tell you what they want, but they don’t always have the right words. Adults might take it too seriously. Like, when my cousin says, “I hate you, mom,” we know she doesn’t mean that she actually hates her; but someone who doesn’t know her wouldn’t know the difference. Because the doctors came into my room and made an assumption that I was depressed without even asking or listening to me, it ruined their chance at actually getting to know me or understand me. I don’t feel like anyone has ever had my back 100% on anything. I feel like I usually understand where the doctor’s coming from, but they never understand where I’m coming from. It leads me to eventually just not care. When you no longer care, it’s hard to get back.”

In many of our music therapy sessions, Bianca identified many songs that spoke to strained relationships and mistrust of others. She was able to identify that her lack of trust in others stemmed from many of the traumas she experienced related to her illness and hospitalizations. Families are often educated to take into account the future physical implications that illness will have on children; however, we must also be vigilant to identify the future emotional implications that illness and medical care/communication also has on pediatric patients in the future.

**Name changed for confidentiality*

Knapp, C. A., Madden, V. L., Curtis, C. M., Sloyer, P., & Shenkman, E. A. (2010). Family support in pediatric palliative care: How are families impacted by their children's illnesses? *Journal of Palliative Medicine*, 13(4). doi:10.1089=jpm.2009.0295

Sutter, C., & Reid, T. (2012). How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients. *Journal of Palliative Medicine*, 15(12). doi:10.1089/jpm.2012.0019

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**MYTH #1:
PEDIATRIC PALLIATIVE CARE MEANS STOPPING CARE AND/OR
TREATMENT**

**TRUTH #1:
PEDIATRIC PALLIATIVE CARE IS INTENSIVE CARE AND TREATMENT
WITH A GOAL OF MAXIMUM COMFORT; EMOTIONAL, PSYCHOSOCIAL,
AND SPIRITUAL SUPPORT FOR THE CHILD AND FAMILY; LOGISTICAL
SUPPORT; AND DECISIONAL SUPPORT/ADVANCE CARE PLANNING.
(NOTE THE ABSENCE OF DISCONTINUING ANYTHING!)**

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Ideally, pediatric palliative care (PPC) should be integrated into all stages of the care and treatment of all children with complex medical conditions regardless of the goals of treatment (curative, life-prolonging, palliative, or end-of-life care). PPC and curative or life-prolonging care are **not** mutually exclusive. Early in the course of a disease or condition, PPC is ideally provided **concurrent and supplemental** to the curative or life-prolonging treatments. It is clearly **not** isolated to end-of-life care. With one successful model, a diagnosis or prognosis automatically triggers a PPC consult. PPC is fully integrated into care prior to the end-of-life phase. Thus, attention to symptoms, emotional/psychosocial/spiritual, family support, logistical support, and decisional support/advance care planning is continuous and transition to care at end of life is seamless. Unfortunately, it is often the case that the focus shifts to palliative care later in the course of the disease or condition when life-prolonging treatments are no longer beneficial, or the suffering is greater than the benefit. Regardless of the timing of the introduction of palliative care, the only care or treatments that should be discontinued are those that are overly burdensome and/or no longer helpful in meeting the goals of the child and family.

Words matter! There is nothing that I dislike more than hearing from a health care provider: "There is nothing more that we can do..." WRONG! If life prolongation is no longer a realistic goal, the primary goal should be palliative. Care and treatments that meet the goals of care and provide comfort, child and family support, and decisional guidance should be intensified and those that don't should be stopped.

Palliative care = good care

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**MYTH #2:
PEDIATRIC PALLIATIVE CARE CAN ONLY BE PROVIDED BY A PEDIATRIC
PALLIATIVE CARE SPECIALIST**

**TRUTH #2:
ALL PEDIATRIC PROVIDERS AND SUPPORT PERSONNEL SHOULD HAVE
SOME TRAINING IN PEDIATRIC PALLIATIVE CARE. CHILDREN WITH
MORE COMPLEX NEEDS SHOULD BE CARED FOR BY PROVIDERS WITH
EXPERIENCE AND/OR SPECIALIST TRAINING IN PEDIATRIC PALLIATIVE
CARE.**

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Pediatric palliative care (PPC) education can, in some ways, be considered in the same light as other pediatric specialty care. Both newborn intensive care and trauma care are examples of fields where there are designated levels of care. All providers are educated/trained in basic care. Some seek additional education and training to care for more complex patients. Fewer yet have post graduate training/licensing and can provide the highest levels of neonatal intensive care or pediatric trauma care. PPC is not there yet.

Increasingly, those caring for children with medical complexity have received at least some basic training in PPC. Most medical and nursing school pediatric curriculums include information on pain and symptom management, communication of “bad” news, ethics, and decisional support/advance care planning. Those providing basic care for children should be able to manage uncomplicated pain and symptoms, sensitively deliver “bad” news, and support uncomplicated decision making. Even state licensing organizations are increasingly expecting providers to be skilled in basic symptom management. In the mid 90’s when I became involved in PPC, I knew every doctor specializing in PPC in North America. There were no PPC fellowship programs. Over the last 3+ decades, there have been increasing numbers of providers (doctors, advance practice nurses and PAs, and social workers, etc.) who sought further education and training in PPC and were available to care for more complex patients and their families. There is now an EPEC (Education in Palliative and End-of-Life Care) Pediatric curriculum among other PPC curricula. There are pediatric tracks at the meetings of the National Hospital and Palliative Medicine Organization and American Association of Hospice and Palliative Medicine and in their Pediatric Special Interest Groups. PPC fellowship programs are available and pediatricians completing at least one year of hospice and palliative medicine fellowship are eligible to apply for a Hospice and Palliative Medicine certificate.

The field of PPC is still behind other areas such as newborn and trauma care, in the routine inclusion of the PPC curriculum in basic provider education. (There are no boards in PPC for physicians.) However, the child and family should be able to expect that their basic PPC needs should be met by their pediatrician, family practitioner, or bedside nurse. If the child/family's needs are complex, a referral to a PPC specialty team is in order. Generally, children's hospitals and other centers caring for the sickest children have providers and support teams who are trained and skilled at providing pediatric palliative care for even the most complicated patients.

For further enlightenment:

American Association of Hospice and Palliative Medicine Pediatric Special Interest Group list of pediatric palliative care fellowships 2/18,
http://aahpm.org/uploads/2017_Pediatric_Palliative_Care_Fellowships_and_Pediatric_Tracks.pdf

Downing J, Ling J, Benini F, Payne S, Papadatou D. What competencies do you need to work in paediatric palliative care? A summary of the EAPC White Paper on core competencies for education in paediatric palliative care. *European Journal of Palliative Care*, 2014; 21(5)

Hospice and Palliative Medicine Certificate. <https://www.abp.org/content/hospice-and-palliative-medicine-certification>

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**MYTH #3:
PEDIATRIC PALLIATIVE CARE IS ONLY FOR THE CHILD**

**TRUTH #3:
IT'S A FAMILY AFFAIR. PEDIATRIC PALLIATIVE CARE ALSO PROVIDES
SUPPORT AND SERVICES TO THOSE IDENTIFIED AS FAMILY, FRIENDS,
AND COMMUNITIES OF SUPPORT. INTERDISCIPLINARY TEAMS, AND
MANY SPECIALISTS, ARE INTEGRAL IN ADDRESSING THE CARE OF
PATIENTS AND THOSE WHO HOLD THEM DEAR.**

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But for the gift of this shared journey, the road would be a difficult one to travel. The journey for the patient inherently impacts all members of the family. It is not exclusively a medical journey, but often a spiritual, social, and emotional journey as well. Being part of an interdisciplinary and interdepartmental team is essential to providing comprehensive care and support for our young patients, and for those who love and hold them dear. It is, indeed, a family affair. As well, it is a team affair.

Whether a family comes into focus for our Fetal Medicine teams during the course of pregnancy, or for our pediatricians and/or specialists closer to the time of aging out of pediatric care; and whether the family is seen in the setting of terminality and abbreviated prognosis, or in the setting of chronicity and a lengthy but complicated trajectory, rarely is the intention of care directed solely at, and for, the child. In Pediatric Palliative Care, the care is both patient-centered and family-centered.

We take great care to acknowledge the impact of illness, or injury, or trauma on individuals within a family, as well as the impact on the family unit as a whole. In fact, learning about who family is for any one child is an important element of the assessment process that then lends towards formation of more relevant and comprehensive treatment plans and interventions. This is particularly true, and frankly imperative, when engaging in conversations about goals of care, plans of care, wishes, preferences, ethics, values, fears, and hopes.

Patients and families deserve to be seen, to be heard, to be witnessed. How do we accomplish this?

Working in close collaboration with members of the interdisciplinary team (IDT), and across the many departments who touch a child's life, is key in assuring that the varied needs of patient and family are identified. We come together to share information, perspectives, suggestions, expertise, and support. We do our utmost to determine which members of the team are best situated to provide a certain element of care. In totality, we provide medical care, emotional care, spiritual care, psychological care, social care, bereavement care, and anticipatory guidance in all realms.

Take, for example, the care provided for Jenni and her family. Jenni was an exuberant and precocious 7-year-old who was diagnosed with a rare form of cancer. Jenni and her family had immigrated to the U.S. from Pakistan 1 year prior. Her older brother, Jay, was 11, and quite gregarious in his own right. Jay was a keen observer of all that went on around him, and he engaged with staff from the start. Early on it became apparent that there were many matters that deserved attention and focus, some for individual members of the family, some for the family as a whole.

Jenni's parents came from different faith practices. They also ascribed to different perspectives on how to approach health care. One parent felt strongly that the healing practices of their family and community of origin in Pakistan were to be trusted more than what the doctors and other providers in the hospital were endorsing, while the other had full faith in the local providers and the interventions they recommended. These, and other issues, had a major impact on how the family navigated their decision-making processes. These issues also impacted how we, as providers, walked the journey with them. Drawing from the expertise of many, and directly involving providers of different skillsets and experience, was essential in working with Jenni and her family.

At times, we met with the parents together. At times, in individual sessions. Both expressed their need for this individual time, to feel greater latitude and freedom in expressing their wishes, without furthering the tension between them. Both emphasized their desire that Jenni have a good quality of life, that she enjoys a "normal" childhood, and that she not suffer. They differed dramatically in terms of what they believed she needed in order to achieve these goals. When it ultimately came time to make the most significant decisions, they did so in unison.

Additionally, Jenni's parents wanted Jay to have some exclusive time with members of the team—in part because they felt, at times, that their own fears, guilt, pain, and sorrow might overshadow their ability to focus on Jay's needs, and in part because they experienced the value of having the one-on-one time. They expressed appreciation for the breadth of support, and all that it brought to them as a family.

Over the course of three, very complex and emotional years, and until Jenni's death, the interdisciplinary and interdepartmental approach to care was key. A partial list of some of the disciplines involved with Jenni, her parents, and her brother includes; Medicine, Nursing, Respiratory Therapy, Child Life Specialist, Social Work, Spiritual Care, Teachers, Music Therapy, Interpreters, and Therapy Dog. Some of the specialty practices include: Oncology, Pediatric

Intensive Care, Pulmonology, Nephrology, Gastroenterology, Cardiology, Psychology, Trauma, and Palliative Care. Our involvement spanned the inpatient and the outpatient worlds of the institution and included very close collaboration with the local community-based agency providing Pediatric Palliative Care in the home. Outside of the medical community, the family was supported by family, friends, their faith communities, and the school counselors.

I would like to highlight, for a moment, the role and the impact of the interpreter in working with this family and the team, as it exemplifies just how much we—the IDT—are interdependent. She not only provided us the opportunity for relevant and appropriate communication and expression, she had a key role in helping us understand the interface of both community culture and family culture. She, in essence and in truth, was the only member of the treating team to see, to hear, and to witness all that transpired over the course of our time with the family. She was important to every member of the team and, most importantly, she was important to every member of the family.

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**MYTH #4:
PEDIATRIC PALLIATIVE CARE MUST WAIT
UNTIL THE PATIENT AND FAMILY ARE “READY”**

**TRUTH #4:
PEDIATRIC PALLIATIVE CARE INVOLVES WORKING WITH CHILDREN
AND FAMILIES ALL ACROSS THE ILLNESS SPECTRUM; IT SHOULD NOT
BE REGARDED AS OPTIONAL**

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There are few topics that historically have been as rife with mythology and misconception as sickness and the end of life. Many of these myths persist to this day. As a palliative care physician, encounters with myths are a daily occurrence. While certain myths we encounter come from patients and families, others come from our colleagues in other spheres of healthcare that we work with every day. There are two particular intertwined myths I would like to discuss in this piece: One is the feeling from families that palliative care is for children who are dying, and since their child isn’t dying, they are not “there yet” so don’t need support of a palliative care team. The second is that the primary medical team feels they need to wait until the patient and family are “ready” in order to ask for a palliative care consult.

The first myth can be challenging to confront as it likely comes from a place of fear. A parent may perceive they are being put in a situation in which they are forced to confront the possibility that their child may not survive. In some cases, a patient may be dying at the time of palliative care involvement. However, as pediatric palliative care teams are getting involved earlier in the course of illness, this is often not the case. In my experience, I have found this myth to be amenable to gentle education. I often say to patients and families I meet, “While palliative care is sometimes associated with taking care of children at the end of their lives, we work with children and families all across the illness spectrum. While you have lots of medical teams working to treat your illness, our goal is to maximize your quality of life so that you can live your best life no matter what else is going on.”

In a wonderful study of patient and family perception of pediatric palliative care in the pediatric oncology population, Levine, Mandrell, and Sykes

(<https://jamanetwork.com/journals/jamaoncology/fullarticle/2608282>) showed that when patients and families were given a definition of pediatric palliative care, only 1.6% of children

and 6.2% of parents expressed opposition to involvement of palliative care team at time of diagnosis. Even more striking were the data when family learned that aside from symptom management and quality-of-life care, palliative care teams also provided end-of-life care. While 15.5% of patients and 14.7% of parents reported this knowledge would make them less willing to meet with palliative care at time of diagnosis, 26.4% of patients and 17.8% of parents actually reported this would make them more willing to meet with the palliative care team!

My interpretation of these data is that although contemplation of these topics can be unimaginably scary for children and parents, many people actually perceive benefit in having more help with the scary things. It is in supporting patients and families through their fears that pediatric palliative care teams can truly excel. This common scenario, from initial fear to ultimate welcoming of palliative care once experienced is represented in this video:

<https://www.youtube.com/watch?v=PKlvigbG6rc>.

As palliative care teams continue to be involved closer to diagnosis of a serious or life-threatening illness, hopefully a normalization will occur that allows palliative care to be seen as a typical part of the healthcare continuum. This will entail culture change, of which much has already occurred, but of which more still needs to come. My belief is that a combination of data-supported literature and memorable public messaging is the best way for myth busting and ultimately culture change to occur.

The second myth, having to wait for family to be “ready” before consulting palliative care, is the more challenging in my opinion. Clinicians so often project this lack of willingness to discuss palliative care onto families that there has even been a term coined for it, the “they are not ready syndrome” (<https://onlinelibrary.wiley.com/doi/full/10.1002/pbc.25877>).

This is really a combination of two separate beliefs: One is the belief that clinicians have an accurate perception of what families are or are not ready to hear and discuss. The second is that a medical consult should be dependent on patient or family “readiness.” Again looking to the article previously cited from Levine and colleagues (<https://jamanetwork.com/journals/jamaoncology/fullarticle/2608282>), we can see that what has historically been a belief about family perception and readiness is not supported by the data. Ninety-eight percent of patients and 69.8% of parents had never heard the term “palliative care.” Of those who had heard the term, none reported a negative attitude toward it. So, it would seem that in most cases a perception of a lack of readiness to meet the palliative care team may be more of a projection from the clinical team than an actual feeling about palliative care held by the family. Patients and families are perceptive of subtle and implicit messages in the language clinicians use. As one parent memorably said to me during a new consult, “They said they were calling palliative care, but not to worry. I didn’t know why I should be worried.”

The second belief, that use of a medical consult team should be based on patient or family readiness is somewhat more sinister. My feeling is that embedded in this is the belief that palliative care is “optional” in ways that other medical specialties are not. While in training, a

psychiatrist I was working with once posited, “Why do families get asked if they want a psychiatry consult, but get told they are getting a cardiology consult?” That insightful question has always stuck with me and I feel the same question applies to palliative care. While it is true that given the nature of our work, patient and family engagement are important in most cases in order to be able to provide care, embedded in this question is also the sense that palliative care is optional.

If one were to tell an oncologist about a patient with newly diagnosed metastatic cancer yet ask them not to get involved in the care because the patient wasn’t ready to meet a cancer doctor, this would be viewed as preposterous. If a patient had newly diagnosed end-stage heart failure, yet the cardiology team was asked to hold off for several months since the family wasn’t ready to talk about heart disease yet, this would be considered similarly outrageous. Or consider alerting the fire department to a house fire, yet asking them not to enter for fear of sending the wrong message to the family (<https://www.youtube.com/watch?v=BbNi-wYXJE>).

Yet why when a patient has similarly urgent palliative care needs, do clinicians often not feel the same sense of urgency to involve palliative care specialists? It is our role to slowly, but doggedly to continue to chip away at some of the emotional baggage that affects perceptions of our field. One day as I entered oncology clinic to see a patient, an oncology colleague said to me, “I like you, but it always makes me sad to see you in our clinic. I know it means someone is having a really bad day.” I gently responded, “This is a whole clinic for children with cancer, they’re all already having a bad day. I’m here to try and help one child have a better day.”

There are myths in palliative care because palliative care deals with issues that are important and timeless. There has been so much work already done in advancing palliative care and public consciousness of the field. I am honored to be part of this field and privileged to be able to stand on the shoulders of giants that have come before me. While the amount of myth and misconception still surrounding our field can seem daunting work, it is also invigorating to think of the impact we can all make by working together.

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**MYTH #5:
IT'S NOT OK TO USE OPIOIDS IN CHILDREN AT END OF LIFE**

**TRUTH #5:
WHEN USED APPROPRIATELY, OPIOIDS CAN BE SAFE AND
EFFECTIVE FOR TREATING PAIN IN CHILDREN, ALLOWING THE CHILD
TO BE MORE COMFORTABLE AND THEREFORE LIVE THE BEST LIFE
POSSIBLE.**

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Eli* was a happy, rambunctious 3-year-old until that fateful day his family learned he had neuroblastoma. The disease and treatment brought so many new symptoms, but the worst was the fact that he just wasn't himself any longer. No longer did he want to run and play outside. He was in too much pain and just wanted to sleep. That was the only peace he could find.

Myth: It's not ok to use opioids for pediatric patients at end of life

Parent & Caregiver Fears

- Increased pain may mean disease progression
- Admitting to increased pain may result in further painful testing
- Treating the pain means giving up
- I will no longer be able to interact with my child once opioids are started
- Opioids will make my child stop breathing
- My child will become addicted to opioids
- Earlier opioid use may make pain management more difficult as the disease progresses

Reality

Most children admitted to hospice experience pain due to their underlying condition. Uncontrolled pain increases patient suffering and can lead to worsening of other symptoms, such as anxiety or difficulty sleeping. Adequately treating a child's pain can help the child be more comfortable and therefore live the best life he or she can for the time the child has left.

Children often use play as a distraction from disturbing symptoms. Just because a child is playing, does not mean pain isn't present. Children have all four of the neurological pathways necessary to experience pain. The final pathway that helps the body overcome pain is the last to develop. Infants may actually feel more pain than expected due to this lack of modulation. Children perceive pain based on their stage of development and may not be able to interpret the different discomforts they are feeling. When pediatric pain is inadequately treated, the child may be predisposed to chronic pain as he or she gets older.

Infants and children require the same types of analgesic medications as adults, just dosed appropriately for age and size. Differences in patient factors are taken into consideration when starting opioids. For example, infants less than six months of age use a much smaller dose per weight due to how their body metabolizes and eliminates medications. Opioids are no more dangerous to infants and children than they are to adults when used appropriately. Initiation of opioids is done under the care of a dedicated hospice or palliative care team, including a hospice nurse, physician, and clinical pharmacist. Symptoms are treated with the lowest effective dose needed to minimize potential side effects. Children are monitored closely when an opioid is started.

Parents may be concerned when the opioid dose must be increased to control their child's pain. However, there are numerous reasons this may be necessary. The child may have gained weight and simply needs a weight-based dose adjustment. Or, the patient may be tolerant to the initial dose. Tolerance is the body's physiologic response to medication, meaning as the body adjusts to a medication, over time higher doses are required to achieve the same effect. Essentially, pain is one of the body's ways of alerting the brain that something is wrong. When we alter this response within the body with an opioid, the body works to overcome this blocked signal. The receptor the opioid binds to changes over time, more easily pushing the opioid off the receptor and having less of a response from the same dose. Requiring a higher dose does not mean the patient is addicted.

- *Drug tolerance* is the body's physiologic response to medication, where the body adjusts to a medication, requiring higher doses over time to achieve the same effect.
- *Drug dependence* means that a person needs a drug to function normally. Suddenly stopping the drug leads to withdrawal symptoms.
- *Drug addiction* is the compulsive use of a substance, despite its negative or dangerous effects.

A person may have a physical dependence on a substance without having an addiction. For example, blood pressure medications do not cause addiction, but they can cause physical

dependence and must be continued to keep blood pressure under control. Using medications, including opioids, within the prescribed dosing, will not induce addiction, without a genetic component or psychological predisposition.

Caregivers may be concerned that the earlier opioids are used, the more difficult it will be to manage the pain as the disease progresses. But there are numerous ways to manage tolerance: utilizing non-pharmacological therapies, increasing the opioid dose, adding appropriate adjuvant medications (e.g., corticosteroids to treat inflammation), or rotating to a different opioid.

Morphine is considered the gold standard for hospice pain management. Many opioids must be metabolized in the body to morphine in order to provide benefit. Morphine has been studied extensively in controlling severe pain in children and is considered safe and effective for most patients. Methadone is another opioid used to manage severe pain. Methadone works differently than other opioids, making it preferred for chronic, complex, or neuropathic pain. Methadone is the only long-acting opioid that is available in a liquid formulation, allowing for less frequent administration when patients have difficulty swallowing tablets.

As with most medications, side effects of opioids such as sedation, nausea, and dry mouth usually lessen after a few days. Constipation from opioids does not usually go away and a scheduled laxative is needed to manage ongoing constipation. Discuss these side effects with your hospice nurse or physician.

Conclusion

After starting methadone, Eli was much more comfortable. He was able to communicate with his family again and the mother rejoiced when he wanted to play outside again. His personality “returned” because he was no longer in pain.

A patient that is no longer in pain can indeed enjoy life with friends and family. So, help your children live their best life. Even if that life includes opioids.

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**MYTH #6:
RESEARCH OVER THE PAST 20+ YEARS HAS SHOWN THAT MOST
BARRIERS TO PEDIATRIC PALLIATIVE CARE HAVE BEEN OVERCOME.**

**TRUTH #6:
BARRIERS CONTINUE AND THE MOST CITED INCLUDE THE HEALTH
CARE PROVIDERS' PERCEPTION THAT THE FAMILY IS NOT READY TO
DISCUSS PREFERENCES FOR LIFE-SUSTAINING TREATMENTS, THAT THE
FAMILIES ARE NOT READY TO ACKNOWLEDGE THE TERMINAL
DIAGNOSIS, AND THE FAMILY'S DISCOMFORT WITH POSSIBLY
HASTENING DEATH OF THEIR CHILD**

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Pediatric palliative care did not gain a foothold in the United States until the late 1990s, thanks to groups such as the Children's Project on Palliative/Hospice Services (aka ChiPPS), a project of the National Hospice and Palliative Care Organization (NHPCO) (retrieved from www.nhpc.org/pediatrics). Project Death in America and early support by major foundations such as the Robert Wood Johnson Foundation (RWJF) helped spur research and education in hospice and palliative care including pediatric palliative and end-of-life care. More than 20 years later there are significant collaborations, special interest groups, and national organizations aimed at improving research, education, and dissemination of information to promote the quality, expertise, and standards of pediatric palliative care. Yet we continue to face barriers to palliative care by both health care professionals, patients and families.

This article highlights the findings of a repeat study focused on perceived barriers by nursing professionals; the findings are consistent with similar studies of other interdisciplinary team members such as physicians. The original study was completed by Betty Davies PhD, RN and her colleagues in 2002 (Davies, Sehring, Partridge, et al., 2008). That same study was repeated in the same academic health system in 2017 (Bogetz, Root, Purser, & Torkildson, 2019). At the time of the original study, the palliative care program at this center had been in existence for approximately two years. The program has grown and evolved and now includes a full complement of disciplines, is a center of leadership, and has a physician fellowship in hospice and palliative medicine.

Sadly, the findings were consistent between both groups, 15 years apart. Barriers continue and the most cited included the health care providers' perception that the family is not ready to discuss preferences for life-sustaining treatments, that the families are not ready to acknowledge the terminal diagnosis, and the family's discomfort with possibly hastening death of their child. This is despite the increasing evidence that families can be hopeful and aware of the grim prognosis at the same time and appreciate more information and early communication about options.

More than 40% of the respondents also cited the perceived discomfort of the parents as to withholding nutrition/hydration, uncertain prognosis, and insufficient knowledge of palliative care. In this study, the two most often and least often cited barriers were the same, 15 years apart. Although this study was completed in only one academic children's health system, the literature demonstrates that barriers remain and "often these barriers have to do with provider perceptions about families' acceptance and understanding of their child's illness." (Bogetz, 2019). More research and education are needed to help mitigate these ongoing barriers to improve access to the services families need.

When the ChiPPS e-Journal first started in 1998, the goal was to provide information to the relatively small professional community of pediatric palliative care providers internationally. Now known as the Pediatric e-Journal, we are more focused on pediatric palliative care in the United States and our purpose remains to bring pertinent topics to our readers from a variety of perspectives inclusive of all interdisciplinary disciplines and family members. We are very interested in hearing from you, our readers. Let's start a discussion that we can continue!

- What barriers do you see limiting access for pediatric palliative care?
- What do you think would help improve access and decrease barriers?
- Can the Pediatric e-Journal be part of the solution?
- If so, how?

We welcome your thoughts and look forward to an ongoing discussion!

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**MYTH #7:
PEDIATRIC PALLIATIVE OR HOSPICE CARE
DOCTORS AND SERVICES WILL TAKE OVER ALL CARE**

**TRUTH #7:
SUCCESSFUL PEDIATRIC PALLIATIVE OR HOSPICE CARE PROGRAMS AIM
TO PROVIDE INTERVENTIONS AND SUPPORTIVE MEASURES THAT
COMPLEMENT THE TREATMENT PLAN AND CARE PROVIDED BY
THE CHILD'S PRIMARY CARE TEAM**

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The relationship that healthcare providers of children with complex chronic medical conditions (CCMC) develop with patients and their families is unique within the medical world. These intimate relationships are often built and sustained throughout the patient's childhood. Providers come to know these children and their families intimately: their hopes and fears; the worst days and the best days; the new brother or sister that comes along; milestones met, and milestones lost. For these providers, to think of opening the door to allow a new team member in can be incredibly difficult, especially if the assumption is that they will no longer be considered a central part of the child's care. They may also be concerned that the new provider will take over completely and that they will never know what comes of their patient's story in the end. These beliefs are deeply rooted in our medical society and are very difficult to overcome. In reality, a successful pediatric palliative or hospice care (PPHC) team aims to provide interventions and supportive measures that complement the treatment plan and care provided by the child's primary care team. One of the main focuses of the PPHC team is to strive to maintain open lines of communication at all times—with the intention of helping to enhance and maintain relationships between patients/families and their primary providers, especially when a more comfort-focused approach is initiated.

Memorial Hermann Hospice's pediatric program was established in 2014 to meet the ever-growing needs of children with life-limiting illnesses within the greater Houston area in Texas. In shaping the development of our pediatric hospice, we wanted to be able not only to optimize the family's experience but that of their medical team as well. Our approach was to facilitate open communication and continuity of care by providing routine updates on in-home assessments, changes to the plan of care, and needs/questions via secure email or fax to all

members of the patient’s care team. The recipients of these span to include team members from outpatient clinics, home health providers, and inpatient teams (physicians, nurse practitioners, nurses, palliative care teams, child life specialists, chaplains, social workers, therapists, school nurses, etc.). This modality has become the backbone of our program as we strive to work not against but together with the patient’s primary providers.

In effort to best meet the needs of our referring providers and optimize continuity of care, our leadership team has routinely re-evaluated and refined our communication processes by eliciting feedback from a core group of providers with whom we routinely work. Based on this valuable feedback and through trial and error, a series of standardized templates was developed that our nurses use to provide consistent and concise updates to the teams.

Admissions – When a child comes on service with our program, we obtain a list of their various team members from the family and/or the referring provider. If our team has not previously worked with a provider, we will reach out via phone to introduce our services and provide a brief explanation of our electronic communication process. If they verbalize wanting to participate in our communication process, we will obtain any pertinent contact information needed. This initial electronic update is sent within 1-2 days of the patient signing onto hospice services with the primary goal being to tie together the patient’s whole team and present a comprehensive physical and psychosocial assessment. The standard format includes an opening paragraph, a brief “one-liner” on the patient, vital signs, a detailed assessment broken down by system, and a full medication list. Below is an example of the standard opening paragraph:

Good [morning, afternoon, evening] team,
 I am contacting you in regard to the care of [Patient Name]. I had a visit with [patient name] and [his/her] family on [date], and we signed them onto our hospice service. In order to provide coordinated care for our hospice families, we like to stay in frequent contact with the patient’s healthcare team. We typically send out weekly/bi-weekly emails with updates on how the patient is doing at home. We encourage other members of [Patient’s name] team to keep us updated as well via email or phone with any changes or concerns. Our team is very excited to be working with you, [Patient’s name], and [his/her] family. If you have any questions or concerns, please do not hesitate to contact us. Thank you so much!

Routine Visits – The frequency of home hospice visits is determined by the needs of the patient and family and can range from daily to only once every two weeks. Unless significant acute clinical changes occur, each patient will have a routine update sent out once every 1-2 weeks with the primary goal being to communicate a concise summary of all-important assessment findings and any changes/concerns since the last update submitted. The assessment excludes any normal findings, as well as any static abnormal findings. Plan of care (POC) elements managed by the hospice team are incorporated in greater detail, while the POC elements managed by primary and subspecialty providers are included in a more generalized statement. The goals here are to provide the primary care team with detailed information on what our

group is doing in the home so as to augment their assessment findings at clinic or while inpatient. We seek to help maintain a cohesive understanding of the POC for all team members, while also ensuring that the providers feel in control of the elements that they themselves manage. The standard format includes an opening paragraph, a brief “one-liner” on the patient, most recent vital signs, and a system update that includes new or changed assessment findings only. Below is an example of how this assessment is formatted:

- Pain: moderate intermittent RLE pain – morphine 4mg PO/SL available (3 prn doses since last visit)
- Neuro: Increased sleep time noted (18hrs/day); breakthrough seizures at baseline (no prn medications needed since last visit).
- Respiratory: LS coarse bilat, R side diminished, BiPAP sick settings (16/8) started on 8/4 related to increase WOB and desaturations; inhaled Tobramycin started on 8/6 x15days per pulmonology orders
- Hospice: Nursing to follow weekly; chaplain, social worker, and child life specialist will continue to work with the family; our entire team remains available 24/7; hospice emergency kit available in the home.
- Advance Care Planning: OOH DNR is complete, however family would want her re-hospitalized for any acute decline; goal for hospice is to optimize comfort and minimize clinic visits/hospitalizations.
- Appointments: 8/20: Dietician; 8/27; PCP; 11/14: Neurology; 11/20: PCP.

Acute clinical changes – Occasionally, events will occur that warrant communication outside of the routine window. These updates include a brief summary of the event, interventions implemented, and revised plan of care (i.e., remain home for end of life; admitted to PICU; plan to follow up with PCP in the morning).

Discharges – There are various reasons why a child may discharge from hospice care, including moving out of the service area or no longer meeting eligibility criteria. These updates include an explanation of reason for discharge and a description of any transfer of care plans that have been put in place prior to the actual discharge date.

Deaths – With any patient death, an update email is sent out to the team which includes a brief summary of end-of-life events, plan for bereavement follow up, and a personalized message from the child’s primary hospice nurse.

During the beginning years of our program’s development, we faced many successes and failures through trial and error of different modalities. The method of communication that was developed has allowed us to help the patient’s primary care team view us as an added resource and not an outside entity combating them. This new symbiotic relationship has made room for a space where both healthcare providers can benefit from and thrive on the combined care for these patients. Finally, the families of children with CCMC benefit from this unique modality as they feel that their children are being watched and cared for by not two separate teams but one team with the same goal in mind.

**MYTH #8:
CHILDREN ARE AFRAID AND/OR UNABLE TO TALK ABOUT DEATH**

**TRUTH #8:
GRIEVING CHILDREN NEED HONEST AND AGE-APPROPRIATE
INFORMATION, DIRECT LANGUAGE, AND PERMISSION TO EXPRESS
THEMSELVES**

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Would you like to go outside?

.....I asked the huddle of children, holding up a soccer ball, markers, and matchbox cars. They readily untangled themselves from the small waiting room chairs and tumbled down the hall and out the door to the courtyard. Their parents were inside with the body of their cousin, who had just been removed from life support. The children had been in the waiting room all morning. *They don't know what's going on, one parent had said. Can you take them to play? I don't want them to see us upset.* Outside I stepped away from a matchbox car race to observe the quiet, deliberate drawing of one of the children. *It's the dead boy, the child said.*

At our hospital's annual Day of Remembrance commemorating children who have died, I sat at the crafts table watching a nine-year-old girl with Autism make a memory box in honor of her little brother. She told me how he had given his heart to another baby who needed it because he didn't need it any more. She told me how she missed him, especially at night. She said she didn't know why he had died. She carefully wrote his name in purple letters and drew two little hearts. I asked if she wanted to share her box with her mother. *No, she said, looking nervously across the room toward her mom. When I talk about him with Mommy she cries, so I don't talk about him with Mommy.*

He's dead, isn't he? The teenager asked, his fists clenching and unclenching, his jaw set, his eyes darting around before meeting mine with a piercing request. A foster child with behavior difficulties, the boy had lived in a series of homes his whole life and been subject to untold insecurity and unkindness. This social worker had been his constant and had been killed in a car accident while driving the boy to another placement. A constant eddy of adults had been outside his hospital room for days, whispering about when and how to tell him, finally sending me in as the messenger. *Yes, he is.* I held his gaze. *I'm so sorry. How did you know?* He looked at his hands. *I saw him die, he said. I was awake. I could tell.* He'd been alone with this for three

days. *Plus*, he said, holding up his phone, *I Googled the accident*. After we talked for a while, he stopped me as I stood to leave. *Thank you for telling me*, he said.

Over and over again in my experience as a Child Life Specialist, I have encountered scenarios such as these, in which adults have hesitated to speak openly with children about a death. Assuming that the children do not understand or would be too upset by the topic, the adults have sequestered the children to the side or tried to carry on business as usual amid the torrents of grief swirling through the family. The children, ever observant and masters of social cues, have responded by formulating their own conclusions, internalizing their feelings, and saving their questions for situations in which they seem more welcome. *We can't talk about it with the children*, the adults say. *They'll be too frightened*. *We can't talk about it with Mommy*, the children say. *She'll be too sad*. An all-too-common situation ensues, in which everyone is hurting, and no one says a thing.

It is unassailable that children notice and grieve the losses in their lives. Yet the myth that children do not grieve persists, likely fueled by a misunderstanding of what childhood grief actually looks like, the incorrect notion that children are unaffected by early events in their lives, and an adult-centric notion of what constitutes mourning. Given the right scaffolding and support, children are able, willing, and even eager to talk about death. They notice what is going on around them. They are keenly aware of adult emotions. They want to make sense of what happens, or at the very least be supported in their not-knowing. They have pointed, deep, and courageous questions after a person in their life dies. Their entire perspective of the world, their families, and their lives may be questioned or shaken, and they desperately need adults they can turn to. Death can feel insurmountably difficult to explain and comprehend (indeed, adults turn to everything from religion to self-help blogs in our attempts to do so), and children are often left alone in their grief and their questions when adults are unable to create a supportive environment in which they can openly express themselves.

Children Mourn Differently than Adults, but that Doesn't Mean that they Don't Grieve

Children manifest grief distinctly and in irregular ways, often leading adults to mistakenly assume that they are not grieving. Children's sadness is different from adults; it often appears cyclical and unpredictable as children step in and out of grief and display this in their patterns of mourning. Unlike adults who often remain in a state of devastation and grief for an extended period of time even as they carry on their daily functions, children may grieve acutely and exquisitely in one moment only to change the subject and begin laughing and playing the next. This does NOT indicate that a child's grief is any less genuine than an adult's, but rather that they are incapable of tolerating grief in high levels of acuity for extended periods. What may look like denial or a lack of understanding to an adult is in fact a mechanism of self-regulation that children often possess. They can face their grief head on, immerse themselves in it for a time, and then extract themselves when they've had enough. Though often confusing and concerning to adults, this is in fact a healthy and normal pattern of behavior.

Keeping the Truth from Children is Not Protection

While it's true that children are not "little adults," they are people who need and deserve to be told the truth about significant events in their lives, just as any adult would. Adults who believe that they are keeping the truth from children in order to protect them are more often than not protecting only themselves. Lies, half-truths, and sugar-coating, well intentioned as they may be, serve only to teach children that the adults in their lives will not answer their questions. Children need to understand what is going on in their world, and absent clear, loving, and honest truths from a trusted adult, children will create their own (often incorrect) explanations. Children need the protection that comes from having adults they can trust and the security of knowing they can talk openly about what is going on in their lives. Leaving children out of the conversation communicates the message that grief and death are not to be discussed, and forces children to cope with and sort out these immensely complicated topics on their own. They are not protected from the truth; they are left alone with it.

Talking about Death isn't Easy, but it's Necessary

Most children are very curious about death, especially when one occurs in their family. They want to and must make sense of their world, and as they do in all areas of life, they look to adults as sources of this information. Children also look to adults as the barometers of what is acceptable to talk about and feel and are masters of picking up social cues. When parents avoid discussions of death, whisper, and close doors when children are nearby, or pretend that nothing is wrong, children get the message that talking about death is bad or wrong. They may avoid voicing their grief or asking about what is happening out of fear that doing so will create more sadness, or because they simply do not have the language with which to face it.

When trying to talk with children about a death in the family, adults may place an inordinate amount of concern on finding the right words. However, what is needed to begin these conversations can often be quite simple. Sit with or hold a child in a quiet, calm environment. It can be helpful for some children to have a neutral or safe place for their eyes, so having coloring supplies or tactile items nearby is recommended. Start with a simple and honest statement, such as "I need to tell you something sad. Grandma died. Her body stopped working and she died," and then allow some time for the child to process this information and ask questions. Let them know that they can ask anything they want and that whatever they are feeling is ok.

Other Helpful Tips:

Ask children how much they already know and what they would like to know. Children frequently know more than you think and need different amounts of detail depending on their age. They will often guide these conversations through the questions that they ask.

One way to promote openness and ascertain what a child already knows is to respond to a question with a question. “That’s a great question and I’m glad you asked me. What do you think?” is one such possible response.

Use concrete language and answer questions in a way that the child can understand. Avoid euphemisms such as “passed away” and potentially frightening and confusing statements such as “she’s in a better place” and “he went to sleep.” Children may wonder why they can’t go to this better place to find their loved one or may fear sleeping themselves.

When helping young children understand death, focus on these main aspects: All bodily and mental functioning stops at death (e.g., people cannot feel, think, or experience pain after death, nor do they continue to eat, drink, or sleep), death is permanent and irreversible (e.g., the person cannot and will not come back), and that the death was due to some physical cause (e.g., his heart stopped beating, her body got too sick, she was very hurt in the accident and the doctors couldn’t fix her.)

Promote routine as much as possible. Children thrive on the predictable and keeping a sense of normalcy during abnormal times can provide a sense of security.

Recognize that children often express themselves through modalities other than talking, and that they need opportunities to do so. Play, art, and storytelling are children’s natural means of expression and can help give them the words and emotional safety to begin processing difficult topics.

Involve children in the funeral process if they would like to be included, give them choices in this, and encourage memorialization and remembering. Rituals and memory making activities can be very therapeutic for children. For example, a child could be invited to choose photographs for the funeral program, items to be buried with their loved one, or a special song to be played.

Allow children to see your tears, difficult as this may be. Show them that mourning is a healthy response to sadness and emphasize that your sadness is not their fault. Making these feelings visible also grants permission for children to express their own. Children may be frightened of your grief and conclude that you won’t be able to take care of them as you used to if you are sad. This is not selfishness on their part, but rather self-preservation and an attempt to hold on to what matters to them. They may need reassurance that there will still be good times, that they are loved, and that they will always be cared for.

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**MYTH #9:
DISCLOSURE OF THE CHILD'S CONDITION/PROGNOSIS IS HARMFUL AS
IT TAKES AWAY HOPE**

**TRUTH #9:
DISCLOSURE SUPPORTS HOPE, EMOTIONAL ADJUSTMENT, FULL
PARTICIPATION IN DECISION-MAKING, AND ADVANCE CARE
PLANNING AND SHOULD, GENERALLY, BE THE STANDARD OF CARE**

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While disclosure may be stressful for the health care provider and team, child/adolescent, and the family, the process actually decreases the child's anxiety and enhances his or her sense of control. Disclosure supports hope in both the child and parents. Alternate hopes are developed. The child along with the family can fully participate in decision making and advanced care planning.

Children generally know when things are not going well, including when they are dying. At the same time, they may wish to protect their parents from distress. Imagine their conflicts, fear, and isolation when those that they love, and trust avoid pertinent conversations. Without disclosure of diagnosis/prognosis, children cannot fully participate in health care decisions and planning for their remaining time.

When faced with parental refusal of disclosing information to the child, the parents should be reminded of the duty of the health care professional to be honest. If it is absolutely necessary, the provider may reluctantly agree to a parent's request/demand not to voluntarily disclose poor prognosis or imminent death. However, the parents should be reminded that the professional should respond honestly to the child's direct question. In the unlikely event that the child/adolescent declines to engage in a conversation about poor prognosis, the provider should ensure that the child is not being coerced and fully comprehends the situation. The "door" should be left open for future conversations.

When children are informed and involved, the child can make the time remaining more meaningful. From the parents' viewpoint, a 2004 study showed that no parents regretted disclosing imminent death to their child/adolescent whereas almost half of the parents not disclosing regretted their decision. Receiving (and giving) bad news remains distressing, but it is better than the alternative.

Disclosure is more fully reviewed in the ChiPPS e-Journal Issue #44

https://www.nhpco.org/sites/default/files/public/ChiPPS/ChiPPS_e-journal_Issue-44.pdf.

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**MYTH #10:
YOU ARE A PEDIATRIC HOSPICE AND PALLIATIVE CARE
PROVIDER? YOU MUST BE SAD ALL THE TIME**

**TRUTH #10:
CARING FOR CHILDREN AND THEIR FAMILIES HAS GIVEN ME
SUCH A GREATER APPRECIATION FOR LIFE; I HAVE LEARNED
TO BE IN THE MOMENT, APPRECIATE THE PEOPLE AROUND ME,
AND CHERISH TIME WITH OTHERS**

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Last Saturday, I was at the salon, relaxing, enjoying my time, talking with other ladies and stylists, when the conversation turned to, “So Holly, what do you do for a living?”

We have all been there. You are at a gathering, mingling, meeting new people, or just standing in line at the grocery store and that question comes up...so, what do you do for a living?

When I hear that question, I immediately start thinking to myself, oh no, here we go, I am about to put a damper on this conversation.

I responded by saying, “I am a nurse.” Sometimes people will accept that response and keep the conversation moving forward but most of the time, there is a follow-up question, “Oh yeah, what type of nurse?” As soon as I say, “I am a pediatric hospice and palliative care nurse,” the look on their face and body language change. “That has to be so sad,” “You must be sad all the time,” “Oh, that is so hard,” “How can you do that,” “Oh my heart aches just to think about that,” “You must be a special person to do that.” In my mind, I am already strategizing my response to all these follow up questions.

The truth is, I love the work that I do. Honestly, I do not feel like it is “work” at all. It is a calling and blessing to me. I feel honored and privilege to have the opportunity to work with so many children and families. I have learned so much more from the children and families I have cared for about love, life, gratitude, value, importance of family, appreciation, and the list could go on and on.

Caring for children is not sad. It is the opposite. Children want to be happy. They want to play. They want to laugh and have fun. They have this drive and spirit for love and happiness. This is, for a child, their quality of life. Just go to any pediatric hospital, walk thru the hall ways, you will see it yourself. The joy, laughter, and cheer. The bright colors on the walls and décor. Then walk thru the hallways of an adult unit. You will see and feel the contrast in the environment.

While I understand that sad and tragic situations happen to children and their families, I also know that the underlying spirit of a child, that drive for love and happiness, what they define as quality of life, will come thru.

I'd like to share with you one such example that always comes to mind.

I was asked to consult on an 8-month-old baby girl, who I will call Bella. Bella had a neurologic condition that was causing her to be irritable, along with some other distressing symptoms. Bella had not slept in weeks for more than a couple hours at time. The parents were rotating shifts to care for her. Bella only would calm down if she was being held by the parents while they were walking and bouncing her. Bella also had three older brothers, who were being cared for by family members because the parents needed to provide care to Bella. The family was spread between multiple homes.

When I entered Bella's room, the mother was pacing back and forth. She began sharing Bella's journey and the family's journey with me. I asked to hold Bella, so that the mother could sit for a moment. The mother gently placed Bella into my arms and sat down on the couch. With tears in her eyes, she said with a trembling voice, "When will this be over? I know this sounds horrible, but we haven't slept in weeks. Bella is miserable. This sounds horrible, but when will this be over?"

Hearing those comments, my heart broke for this mother, the family, and Bella. We had to find a way to provide comfort and rest for Bella so that the family could be a family again, enjoy their time with her, and have quality of life.

We made some adjustments to her medications and care over the next couple of days. A few days later, I got a call from the father. I can still hear him saying to me, "I thought Bella died last night." I just paused for a moment. He then said, "Bella slept all night. We (the parents) didn't, because we kept getting up to check on her. But she was sleeping and slept all night. Thank you!"

Over the next couple of weeks, Bella's symptoms were managed well. The family was able to enjoy friends over at their house. They went for ice cream. Bella loved tasting ice cream. The parents would call and share with me all the experiences they were having with Bella and as a family. The joy and happiness were palpable.

The day Bella died, the family was at a family gathering. The mother shared with me that she felt Bella knew this would be her last day. Bella peacefully died with both of her parents, her

brothers, aunts, uncles, and many other family members by her side, supporting her parents and loving her.

While sad, the spirit of love shines. Bella and her family experienced quality of life as they defined it.

Caring for children and their families has given me such a greater appreciation for life. I have learned to be in the moment, appreciate the people around me, and cherish the time with others.

I love to laugh, have fun, and I strive for love and happiness. This is quality of life. I am not a downer.

People who work in pediatric hospice and palliative care share in this drive to provide quality of life for all our patients and families.

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ITEMS OF INTEREST

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

1. **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

2. **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** 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*
 - *'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*

3. Trends in Pediatric Palliative Care Research

Every month PedPalASCNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#).

[View the New Citation List in their Library](#)

4. Pediatric Hospice and Palliative Care Training:

- **Upcoming 2019-2020 Webinars provided by the Pediatric Care Coalition:**
 - **November 21:**
Compatible with Life: Rethinking Care of Children with Trisomy 18
Presenter: Nicole Hahnlen & Deanna Deeter
 - **January 23:**
Decoding Decision-Making with Families with Janet Duncan
- The 2020 NHPCO Leadership and Advocacy Conference is where hospice and palliative care leaders gather to exchange ideas, strategies, and solutions. This year we will focus on strengthening your organization and connecting with other leaders in the field.

The conference will offer peer-to-peer educational sessions that will address these specific topic areas:

- Advocacy
- Clinical and Operations Management
- Emerging Markets and Partnership Opportunities
- Engagement and Marketing
- Finance
- Fund Development
- Leadership
- Palliative Care
- Quality
- Regulatory
- Staff Development

- ### 5. Subjects and Contributors for Future Issues of This E-Journal.
- For upcoming E-Journal issues, we plan to address issues related to 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 Ann Fitzsimons at ann@here4U.net. We will work with you!

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