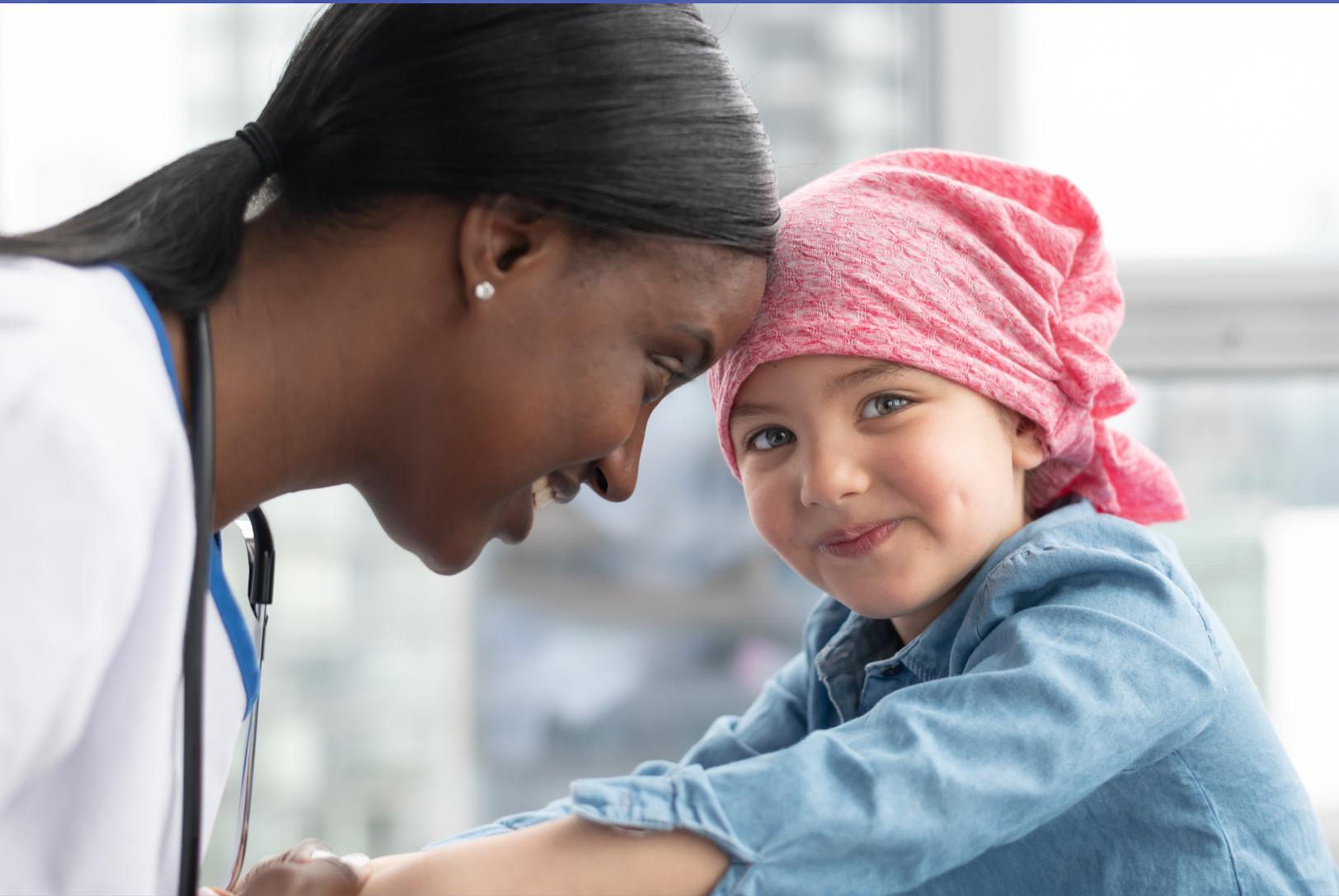


***Ethical Issues in Pediatric Palliative/Hospice Care***

ISSUE #59 | MAY 2020



# Pediatric E-Journal

**PEDIATRIC ADVISORY COUNCIL**

*Released in collaboration with the National Hospice and Palliative Care Organization*



**NHPCO**

National Hospice and Palliative  
Care Organization

# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

### Issue #59; May 2020

#### Issue Topic: Ethical Issues in Pediatric Palliative/Hospice Care

Welcome to the 59th issue of our Pediatric e-Journal.

This issue of the Pediatric e-Journal is focused on ethical issues in pediatric palliative and end-of-life care. Ethics is defined in its simplest form as a system of moral principles.<sup>1</sup> Bioethics is defined as “the ethical issues in healthcare, medicine, research, biotechnology, and the environment.”<sup>2</sup> Questions of justice, distributive justice, autonomy, beneficence, nonmaleficence, and truth telling have been highlighted repeatedly recently, especially in the media. At an organizational level, and especially in hospice and palliative care, these principles are at the heart of everything we do, not just during a pandemic.

This issue was planned a year ago and we could not have imagined the world in which we find ourselves now with the coronavirus pandemic. Although older adults have suffered the brunt of the infection, the challenges that this pandemic has created affect all of us. Not only have we had to create different ways of being, we have had to create different ways to provide care and services to all populations and for many, there have been significant disruptions.

We do not make light of the current situation and plan to revisit this topic, and the lessons learned from it, later in a way that is commensurate with its significance. In the meantime, while we offer you this issue’s collection of articles on ethical issues, we invite you to share some of the challenges and opportunities the pandemic has brought to your personal and/or professional life. If you would like to contribute to a future issue on the coronavirus pandemic, please contact either Christy Torkildson at [Christina.Torkildson@bannerhealth.com](mailto:Christina.Torkildson@bannerhealth.com) or Ann Fitzsimons at [ann@here4U.net](mailto:ann@here4U.net).

#### References

1. Retrieved from: [http://www.bbc.co.uk/ethics/introduction/intro\\_1.shtml](http://www.bbc.co.uk/ethics/introduction/intro_1.shtml)
2. <https://bioethicsarchive.georgetown.edu/bioethicsshowcase2015/what-is-bioethics/index.html>

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](http://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 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](mailto:Christina.Torkildson@bannerhealth.com) or Ann at [ann@here4U.net](mailto:ann@here4U.net).

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**Issue #59: Ethical Issues in Pediatric Palliative/Hospice Care**

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

***COVID-19: A Message from NHPCO President and CEO Edo Banach: The Role of Hospice during This National Emergency*** *p. 5*

**Edo Banach, JD**

On April 4, 2020, the President and CEO of the National Hospice and Palliative Care Organization shared this call to action arguing that hospice and community-based palliative care providers are going to be crucial resources to help treat and care for the hundreds of thousands or millions of Americans who are going to be impacted by COVID-19.

***Letting Go***

*p. 7*

**Christine Gharagozian, Levi's Mother**

In this article, Levi's mother describes the period between her last conversation with her son, his fall in a skiing accident the next day, her rush to get to the hospital in Reno where he was being

treated, and his death just under four months later at a children's hospice. At first, she writes, "Not surviving was not an option, in my mind, in those early days." But then, after Levi was stabilized and transferred to Children's Hospital Oakland, "there were lots of bumps on the road...I felt my awareness start to shift. I began to ask myself, 'How much more can my boy tolerate? When is enough enough?'" Here practical and ethical decisions that no parents wish to confront begin to appear. Similar challenges and ethical decisions emerged in the rehab unit when "My heart knew that full recovery was no longer in the realm of possibilities...For the time being, we weren't fighting for survival. We were fighting for quality of life." And as Levi's condition declined, "I had arrived at this point in my journey where I just wanted my boy to not suffer. I couldn't tolerate watching him suffer." Additional crisis points occurred in seeking to speak with the palliative care team, talking with a chaplain about quality of life, beginning to contemplate Levi's death, seeking online information about George Mark Children's House, and consulting with the hospital's Ethics Committee.

*"Good Ethics Starts with Good Facts"*

*p. 9*

**Suzanne Toce, MD, FAAP**

In this first of three articles for this issue, Dr. Toce notes that, "There are likely multiple ethically appropriate treatment choices available. The challenge is to determine which treatments best fit the goals of care of the individual child/adolescent and family. How does one get the factual information necessary to make the ethically appropriate decision? What makes a source reliable?" She then offers criteria for reliable resources for professionals, family members, and children/adolescents, plus a list of useful resources on these subjects.

*Uncertainty: Hope for the Best; Plan for the Worst*

*p. 12*

**Suzanne Toce, MD, FAAP**

This article argues that the palliative care framework is ideal for helping to address uncertainties that follow the diagnosis of a potentially life-limiting illness or condition. The article identifies potential sources of uncertainty and suggests how a care team can guide patients and families in becoming resilient.

*Allocation of Scarce Resources in Pandemics and Disasters*

*p. 16*

**Suzanne Toce, MD, FAAP**

This article focuses on issues of justice in managing scarce health resources, including "fair (not necessarily equal) distribution of scarce resources, respect for people's rights, and respect for laws." The article identifies typical resources in question and offers guidelines for addressing their allocation.

*Withdrawing Treatment in Neonates: The Roles of Time, Culture, and Gestalt*

*p. 21*

**Thomas D. Harter, PhD, and Jennifer C. Peterson, MD**

This article takes its point of departure from a case study of "an hours-old newborn girl with multiple congenital abnormalities, a malformed frame, and who is already ventilator-dependent." Her parents, who are Amish, wish to withdraw the ventilator anticipating that she will die; the professionals agree that her death is likely if the ventilator is withdrawn and acknowledge that her death is likely despite medical intervention. So, the issue is "what paths forward are best or, at least, the most supportable" from an ethical and moral standpoint? The

authors write: “This article does not attempt to answer these questions. It merely highlights what many neonatal and pediatric providers likely already know: unlike end-of-life care in adult populations, where decisions are primarily the result of acting on a patient’s known treatment preferences, end-of-life decision-making in neonatal and pediatric cases always has more potentially confounding variables since babies and young children typically do not have established treatment preferences and rely on parents or other adults to make those decisions for them. Time, culture, and treatment gestalt are just three such variables that providers should be aware of when engaging in neonatal or pediatric end-of-life situations and discussions...it is frequent, clear, transparent communication that is most likely to help identify and address those variables to begin with and potentially avoid conflict altogether.”

*Ethics Case: Disclosure, Truth Telling, Veracity*

*p. 25*

**Deborah Fisher, PhD, RN, PPCNP-BC, CHPPN**

In this article, the author examines a case example of a 12-year-old girl who has Ewing’s Sarcoma of the pelvis with recurrence and metastases. Among the issues considered are: Should care providers honor the parents’ wishes to withhold information from their daughter?; Is honesty the best policy?; If the girl is to be told the truth about her situation, how should that best be done?

*Ethical Emotional Boundaries for Health Care*

*p. 29*

**Carla Cheatham, MA, MDiv, PhD, TRT**

This article focuses on three questions that can guide professional care providers in maintaining ethical emotional boundaries in caring for children and adolescents: Who is the hero?; Whom do I trust?; and How am I meeting my needs? The author concludes: “When we remember the ethics that guide our caregiving, trusting even the young to live their own lives and practice their own self-determination, trust the results of our care into other hands, and care for ourselves well, everyone will benefit and be protected from unintentional harm. Caring within bounds is the most compassionate thing we can do for everyone involved.”

*The Ethics of Organ Transplantation in Minors*

*p. 35*

**Marilyn A. Fisher, MD, MS**

Here the author examines “the ethical issues involving procuring tissue or organs from minors.” The two central issues considered are determination of brain death and organ procurement from the anencephalic infant. The author concludes that “extreme caution must be exercised in the mechanism by which recovering of the organs is justified.”

## COVID-19: A MESSAGE FROM NHPCO PRESIDENT AND CEO EDO BANACH THE ROLE OF HOSPICE DURING THIS NATIONAL EMERGENCY

**Edo Banach, JD**

President & CEO, National Hospice and Palliative Care Organization  
Alexandria, VA

We are amid a global pandemic that challenges and strains all of us, our institutions, and the entire fabric of our economy and democracy. It is disorienting for all and paralyzing for many, but those in our community must engage and respond. **There has never been a more important time to be ambassadors of the kind of person-centered, serious illness care that our country is going to need.**

Indeed, hospice and community-based palliative care providers are going to be crucial resources to help treat and care for the hundreds of thousands or millions of Americans who are going to be impacted by COVID-19. It is also a crucial time for all of us to execute or review our [advance directives](#). We must make sure that folks get the care they want, and do not get the care they don't want.

It is important to remember that we as a professional community have been here before. HIV and COVID-19 are very different viruses, but both are contagious diseases that were not fully understood at the time. Fear ruled, and the government and traditional health care system at first shied away. Hospice was then in its infancy in the United States, and yet our community—hospice pioneers—leaned in to help.

Although many of us are sheltered in place, and concerned about hospital capacity, we will soon be inundated by community need for care. In hotspots like New York City, this is already happening. This can be pre-hospital, post-hospital, or instead-of hospital care. Most of this care will not be end-of-life hospice care, but almost all of it will require the skills and talents of a community-based interdisciplinary team that is skilled at providing serious illness care in the community.

### **Provider Community Call to Action**

So, here's my ask of the hospice and palliative care provider community—and my call and promise to the nation—during these uncertain times:

- **Lean in.** Ask what you can do to help, and help. Focus on care and compassion.
- **Stay safe!** Although our commitment is to care for all those who need our services, we must protect our hospice and palliative care staff. We are working with government and industry to provide the protective equipment we need to make visits to our patients.
- **We are all in this together.** This is an all hands on-deck moment, and we need to rise to the challenge. Go big, get magnanimous, and there's no room for any of us to be small and petty.

- **Practice self-care.** You cannot care for others unless you are well yourself. Eat right, exercise, do yoga, dance, or do anything else that helps you recharge.

This crisis is horrible. And yet, it is also our time as professionals to show our mettle. We as a field have been arguing that we need flexibilities in hospice to achieve our fullest potential. We are about to get flexibilities new to us.

I thank all those in the hospice and palliative care community for your work and commitment to the people we care for. NHPCO promises to be right there alongside you as we lead person-centered care. It is our time to step up, to lean in, and to be as large as this moment.

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## LETTING GO

**Christine Gharagozian**

Levi's Mother

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April 22, 2018 started out as a very normal day. My older son and I were home in Oakland getting ready for his baseball game. My younger son, Levi, and his dad were having a weekend skiing. I spoke with Levi the evening prior and it sounded like they had had a great Saturday. He spoke excitedly about all the jumps and bumps. He sounded so alive. He was so alive. That would be the last verbal communication I would have with him.

I got the call from my husband while I was doing field prep for my older son's baseball game. He told me that Levi had experienced a terrible fall and was airlifted off the mountain. I remember feeling an enormous rage move through me in that moment. I imagine I went into shock, too. I don't really know. And, then, I got clear. I needed to grab my older kid and get to Reno as quickly as I could, with some measure of safety. I remember that I was able to think. I was not frozen in non-thinking. I was thinking.

We arrived at the hospital...an act of grace. Levi had already had surgery to remove a bone flap to relieve the pressure on his brain. I walked into his room in the PICU and immediately felt a huge wave of grief and love for my child. My child who was now hooked up to a ventilator, unconscious, and fighting for his life. My baby boy. The first few days were critical. His injury was severe, and the intensivists were not certain he would survive. Not surviving was not an option, in my mind, in those early days. He must live, I told myself. He must go back to being the wildly full-of-life human being that filled my heart with so much joy. That's where I was. Every cell in my body needed my boy to get healthy.

One week after Levi's injury, he stabilized enough to be airlifted to Children's Hospital Oakland (CHO). We were heading home. Hope. Levi spent five weeks in the PICU at CHO, continuing his fight to get stable. We hit lots of bumps along the road. A collapsed lung, the need for a tracheostomy due to weak airway, diabetes insipidus, to name a few. I dealt with this stress and struggle by crying (endlessly) and connecting (with anyone who would listen to my story). I also did laps around the PICU hallways and gave other grieving parents hugs. I read short Buddhist prayers and I wrote updates on our Caring Bridge site. I felt my awareness start to shift. I began to ask myself "How much more can my boy tolerate? When is enough enough?"

My husband was a warrior. His expressed love for his son came in the form of being present with the doctors doing rounds, getting to intimately know all of the medications and dosages that were being administered, and holding ground during some of Levi's most difficult moments, including the night of Levi's lung collapse. We were both sitting next to Levi's bed and his oxygen started to drop quickly. The nurse sounded an alarm and Levi's room was flooded with medical staff. I took this as my cue to exit. In my mind, my emotions were simply too big and would have further intensified the chaos. My husband stayed. He calmly stood at the foot of Levi's bed, knowing full well how serious this was. I bow in gratitude.

Levi survived the bumps in the PICU and was moved to in-patient rehabilitation. I remember feeling a cautious hope. By this point, I was coming to terms with the severity of his injury and grieving the loss of the boy he was. My heart knew that full recovery was no longer in the realm of possibilities. The rehab floor had a much different feel. For the time being, we weren't fighting for survival. We were fighting for quality of life. There were small moments when my mind really wanted to attach to noticeable progress, but these moments were rare. I mostly saw and felt no change. In some ways, his medical condition was declining. The drugs that we were trying to wean him off were only going up in dosage. He seemed so uncomfortable which tortured me. I had arrived at this point in my journey where I just wanted my boy to not suffer. I couldn't tolerate watching him suffer. I was done.

I began to make requests to speak with the palliative care team. I talked to the chaplain about quality of life. I discovered the George Mark Children's House online. I needed to know that we had options. Death had entered my consciousness. I started to think about death differently. I started to believe that Levi would never want to live like this. He was too big and too bright. I had landed. I was clear.

My husband came to the same conclusion in his own way, two weeks later. I cannot deny the fact that our relationship suffered deep wounds during our decision-making process. He needed time to talk with doctors and to read journal articles and I only put pressure on his psyche. I was insistent. I was terrified that our boy would be trapped. In the midst of a great deal of suffering, we came to a mutual decision.

The Ethics Committee at CHO is a multi-disciplinary group of individuals and volunteers who provide insight into assisting medical staff and parents in times of difficult decision-making. A meeting was convened to discuss transitioning Levi's care to palliative. The morning of the meeting, I threw up and then I pulled on a relatively nice-looking outfit that no longer fit after 20 pounds of weight loss. My husband and I drove to CHO and sat together over a cup of coffee in the cafeteria. I felt connected to him in that moment. Life was asking us to make this excruciating decision and we had come together. When we walked into the conference room and I was confronted with a room full of people, I quickly ran to the closet and hid for a moment. I was so very overwhelmed and so very traumatized. It was the only thing I could think to do. With the support of the Chaplain, I found my seat at the table. I had no idea what to expect but I was afraid. When we were asked to talk about Levi, I felt the fear fade and my heart open. I vaguely remember mentioning that I was of the belief that his spirit animal was a spider monkey. I mostly just bled griefy love everywhere. My husband also had a chance to share his love for his son. And, then, I felt something powerful enter the room. Compassion. I really don't remember what any of Levi's care team said, I just remember how I felt in listening. I felt their full support and I felt held. I felt brave.

Levi died on August 5, 2018 at the George Mark Children's House, full of peace and love.

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## “GOOD ETHICS STARTS WITH GOOD FACTS”

**Suzanne Toce, MD, FAAP**

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Whenever I am challenged to make a difficult decision that is ethically valid, I am reminded of the above phrase frequently used by Dr. Norman Fost, Professor Emeritus of Pediatrics and Bioethics at the University of Wisconsin. In this day of social media, parent support groups, and “fake news,” finding the “facts” necessary can be particularly challenging for both health care professionals, patients, and families dealing with the seemingly constant decisions involved with the child/adolescent with complex medical conditions.

The Vermont Ethics Network uses this operational definition of ethics: “Health care ethics (a.k.a. “medical ethics”) is the application of the core principles of bioethics (autonomy, beneficence, nonmaleficence, justice) to medical and health care decisions. It is a multidisciplinary lens through which to view complex issues and make recommendations regarding a course of action.” There are likely multiple ethically appropriate treatment choices available. The challenge is to determine which treatments best fit the goals of care of the individual child/adolescent and family. How does one get the factual information necessary to make the ethically appropriate decision? What makes a source reliable?

Reliable resources are comprehensive, fact based, up to date, non-biased, and multidimensional addressing professional, family and child/adolescent concerns.

Some criteria for reliability of websites and other sources of information:

- Information is clear, presented in a professional way, and is easy to understand by non-professionals.
- The source is sponsored by a reputable leader such as a governmental, or respected professional organization (such as the CDC and American Academy of Pediatrics)
- Academic websites
- Sponsored by a reliable healthcare organization
- Not for profit; not selling a product or service; few advertisements – this may be a conflict of interests
- Responsible authors with contact information are included
- **The information is credible**
  - The information is recent with dates of posting and updating
  - There is evidence if available (beyond expert opinion) to support the advice
  - The information is “peer reviewed,” i.e., reviewed by experts in the specific field with such review stated. Without such review, the unproved claims may indeed be “too good to be true.”
  - The source of the information, such as references in the medical literature, studies, or articles, is included.

- If personal information is collected, the privacy policy should state the use of such information.

What about parent support resources? Some groups and websites are very evidence based, supported by professionals, and helpful, such as the Courageous Parents Network. Their stated purpose is “to be a destination created by parents, for parents, to support, guide and strengthen families as they care for a seriously ill child. Here you will find wisdom from fellow parents and pediatric care providers to help you be the best parent you can be to your child and children—and get through each moment.” They have “Guided Pathways” that discuss specific topics such as a discussion of the sibling experience and examples of working with the medical team to establish goals of treatments. Their section on decision making is very clear.

Other parent support groups may offer support and hope but seem to be based more on anecdote or case reports than facts gathered from many similar children. Web based resources may provide parents with parent-to-parent support, information and experience sharing, and understanding of the condition that may be hard to find for rare pediatric conditions. But, remember “the plural of anecdote is NOT data.” (Parenthetically, this is a misquote, but in this case seems appropriate. <http://blog.danwin.com/don-t-forget-the-plural-of-anecdote-is-data/>) The outcome of a single child’s disease or condition is not necessarily predictive of the outcome of another child with the same condition and treatment until the treatment is well studied.

Parents and the child/adolescent may desire to engage in a dialogue with their child’s health care professionals concerning information gained from parent-to-parent support resources and/or the Internet. Providers should understand and accept that in the current environment, substantial information is obtained from sources other than the health care providers. The health care team should inform and guide patients and their families in acquiring factual information that will guide them in their quest to determine the best ethically appropriate choice that meets their goals.

## Resources

American Academy of Pediatrics [www.aap.org](http://www.aap.org) and Healthy Children <https://www.healthychildren.org/English/Pages/default.aspx>

The Canadian Pediatric Society: Caring for Kids. **Very helpful guide of reliability of website information.** [https://www.caringforkids.cps.ca/handouts/health information on the internet](https://www.caringforkids.cps.ca/handouts/health%20information%20on%20the%20internet)

Centers for Disease Control and Prevention: [www.cdc.gov](http://www.cdc.gov). Includes information on multiple topics such as congenital heart disease <https://www.cdc.gov/ncbddd/heartdefects/links.html>

Children’s Health MedlinePlus <https://medlineplus.gov/childrenshealth.html>

Courageous Parents Network <https://courageousparentsnetwork.org/about/our-story/>

Mayo Clinic: <https://www.mayoclinic.org/patient-care-and-health-information>

Nemours Children's Health System - Kids Health <https://kidshealth.org>

Nicholl H, Tracey C, Begley T, King C, Lynch A. Internet Use by Parents of Children with Rare Conditions: Findings from a Study on Parents' Web Information Needs. *J Med Internet Res* 2017;19(2):e51

Pehora C, Gajaria N, Matava C et al. Are Parents Getting It Right? A Survey of Parents' Internet Use for Children's Health Care Information. *Interact J Med Res*. 2015; 4(2):e12.

US Food and Drug Administration [www.fda.gov](http://www.fda.gov)

Vermont Ethics Network:

Health care ethics: <https://vtethicsnetwork.org/medical-ethics>

Pediatric Decision Making. <https://vtethicsnetwork.org/medical-decision-making/more-topics-in-medical-decision-making/pediatric-decision-making>

WebMD <https://www.webmd.com>

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## UNCERTAINTY: HOPE FOR THE BEST; PLAN FOR THE WORST

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Ethics can help us choose between ethically acceptable choices, but what if the facts or goals are unclear? After a diagnosis of a potentially life-limiting illness or condition, the world can seem full of uncertainty to the child/adolescent and family. Not addressing these uncertainties can lead to fear and the sense that their world is an unpredictable place. The palliative care framework is ideal to address these uncertainties and “What ifs.”

In what areas might there be uncertainty?

- Diagnosis
- Prognosis – especially challenging with rare diseases and conditions

**“An uncertain prognosis should serve as a signal to initiate palliative care, rather than to avoid it, even when it is not yet appropriate to begin EOL care.”**

Davies, 2008

- Disease trajectory
- Best treatment course
- Quality of life including pain and symptom burden of both disease/condition and treatment
- How to best communicate with the child/adolescent, family, community
- How much information to disclose to parents and the child/adolescent
- Impact on the family and community
- Cost effectiveness

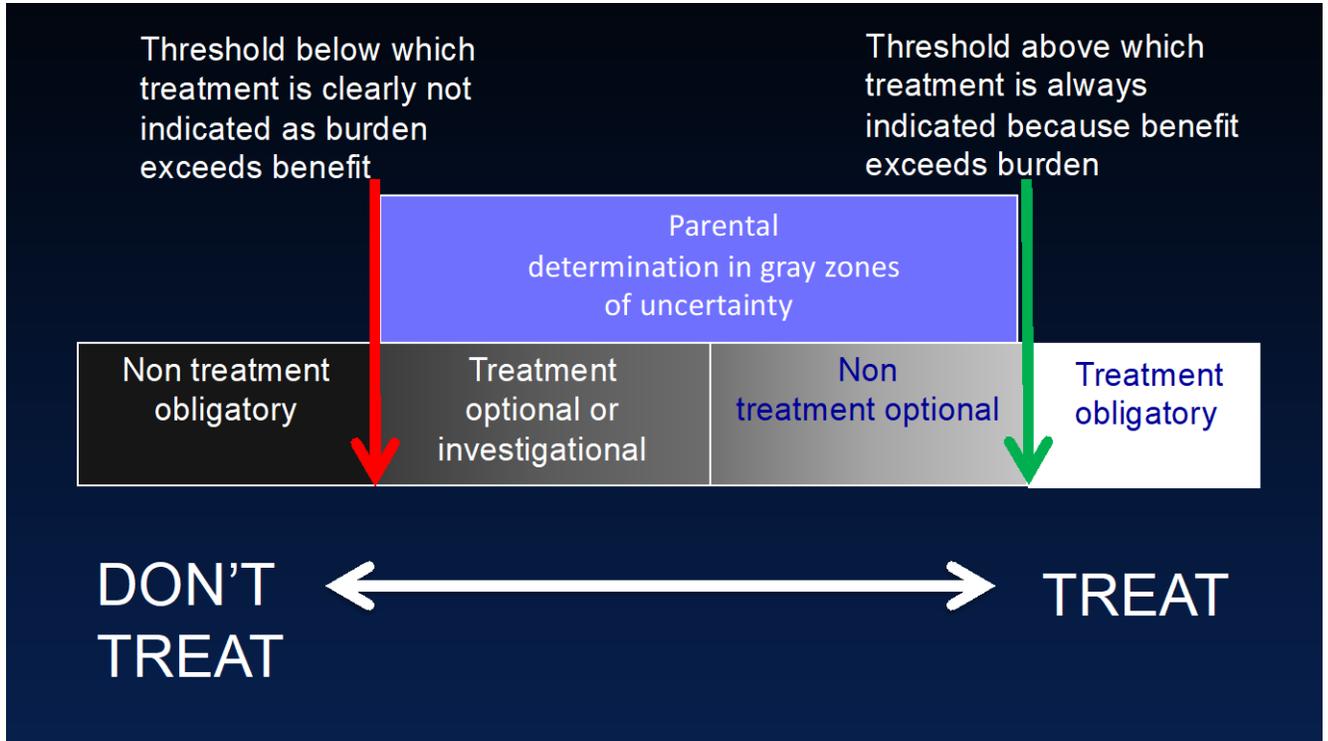
How can the team guide the patient and family in becoming resilient? How can we support patients and families in the face of these uncertainties? These “What if?” conversations are best held during times of stability rather than crisis, so don’t delay!

- Inquire! Learn from the patient and families what they most fear and worry about as well as what they hope for.
- Words matter! For instance, presenting outcome data in terms of survival vs. mortality sounds very different to patients and families. The Snaman, Levetown, and Feudtner articles [listed among the Resources at the end of this article] give excellent examples of supportive communications.
- Be open about the extent and range of uncertainties.

**“Teach thyself to say, ‘I don’t know’ and thou shalt progress.”**

Maimonides, 12<sup>th</sup> Century

- Be comfortable saying “I don’t know.” Be clear about what you do know and what you do not know.
- Explore worries and fears – the “what ifs” such as:
  - “What if the cancer comes back?”
  - “What if the treatment causes heart failure?”
  - “What if my hair falls out?”
  - “What if the treatment doesn’t work?”
  - “What if I can’t go home from the hospital?”
- Support the child/adolescent and family in learning about and accommodating to the new uncertain reality. Include ranges of outcomes such as survival, long term disability, anticipated clinical course.
- Be honest and unbiased.
- Review all ethically appropriate options where benefit MIGHT outweigh burden, not just those that you recommend.
- Do not offer unacceptable options.
- Establish new contingency plans – “Hope for the best; plan for the worst.”
- Frequently reassess hopes and goals. As appropriate, explore smaller, more attainable hopes.
- Parents and child/adolescent with capacity are determinative in cases of uncertainty. Even younger children benefit from being included in the conversations.



The medical team is not obligated to do what the child/adolescent and/or parents ask:

- If you refuse treatment, you must have valid moral/ethical/medical justification.

- There is a threshold beyond which the child/adolescent has a right to treatment.

Even introduction of pediatric palliative care can be fraught with uncertainty. Hill et al. identified seven uncertainties in proposing palliative care:

- Prognostic uncertainty: What are the possible outcomes reviewed with the patient? What is the degree of prognosis certainty?
- Informational uncertainty: How complete (vs. insufficient) will the information such as diagnosis or treatment options be that is given to the patient? Consultation to the palliative care service would address this uncertainty.
- Individual uncertainty: How clear (vs. ambivalent) will the information be that the provider gives? Professional values should be clarified.
- Communication uncertainty: How clearly and confidently (vs. insecurely) can the provider introduce the topic? Communication training is beneficial.

Once the topic of palliative care is introduced:

- Relational uncertainty
  - How accepting (vs. distraught) will the family react? The provider can train for difficult conversations.
  - How collaboratively (vs. antagonistically) will this impact the family–provider relationship? The provider should accept the possibility of a negative family reaction.
- Collegial uncertainty: How will colleagues support (vs. question) the provider? Team values should be reviewed, and goals regularly reviewed and updated as needed.
- Inter-institutional uncertainty: How will other medical centers agree (or recommend alternatives)? Communication and relationship plans with other organizations should be developed and reinforced.

Introduction of palliative care early in the course of the disease or condition may overcome many of these challenges.

Not addressing these uncertainties, worries, and fears can lead to a feeling of isolation and lack of control. Ethics provides a boundary or framework. As information and goals evolve or change, it will be natural to expect that hopes, decisions, and choices would change. The palliative care model is uniquely suited in supporting the child/adolescent through these uncertainties.

### Resources

Carter B. Discomfort with uncertainty and the double-edged sword of a diagnosis. *American Academy of Pediatrics Hospice and Palliative Medicine Newsletter*. June 2014.

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## ALLOCATION OF SCARCE RESOURCES IN PANDEMICS AND DISASTERS

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When we address ethical principles, we are usually focused on autonomy, beneficence, and nonmaleficence. We rarely have the occasion to invoke justice. However, in this time of the SARS-CoV-2/COVID-19 pandemic, the issue of justice has become prominent. The application of justice includes fair (not necessarily equal) distribution of scarce resources, respect for people's rights, and respect for laws. In this review, I will be focusing primarily on managing scarce health care resources.

What resources might be included?

- Ventilators
- Intensive care beds
- Oxygen
- Medications
- Blood products
- Renal dialysis
- Surgery
- Personal protective equipment
- Skilled (healthy) health care providers and support staff
- First responders
- Home care providers

How do we as a society establish guidelines to support these difficult decisions?

- Ideally the process would occur **in advance** of the public health emergency and would involve all stakeholders including health care providers, ethicists, the public, and lawmakers. Members of the public will live with the consequences of these decisions. Involvement of the public helps ensure a fair process of decision making and may enhance trust. Public input has proven to be useful in guidelines for allocation of influenza vaccine and organs for transplantation. However, in the case of public health emergencies such as with the current pandemic, there has been little advance public involvement.
- Be transparent
- Determine who makes the decision
  - While the patient (with capacity) and family in concert with the medical team generally make this decision, scarcity mandates a different approach.
  - Separating a triage role from a clinical role is one approach to enhance objectivity, avoid conflicts of responsibilities, and minimize the moral distress of clinicians. A multidisciplinary triage team including health care providers, clergy,

and community members may fulfill this role. Either the triage team or the bedside team could communicate with the family.

- Regardless of the decision makers, anticipate tension, moral distress, and need for support of yourself and the staff as the focus shifts from acting in the patient's best interest to acting to make the best use of the available resources for the good of the most people. It will likely be necessary to deny ventilators (and other resources) to patients who might otherwise survive because no ventilator is available.
- An ethics committee consultation should be sought as needed.
- Determine the principles guiding allocation. Consider the following possible strategies:
  - First come, first served – routine clinical circumstances. Clearly, not fair when resources are scarce.
  - Lottery – also not fair.
  - Treat those most likely to survive in the short term, for instance until hospital discharge – this is similar to triage during war time and could be done using validated scoring systems. There are a variety of validated scoring systems for both adult and pediatric patients. Focusing solely on survival to discharge is ethically inadequate but could be incorporated into a broader approach.
  - Save the most life years – a healthy 70-year-old would have priority over a 70-year-old with congestive heart failure.
  - Invoking the life-cycle principle – priority is given to younger people with a goal of giving all individuals the opportunity for a normal life span. With this strategy, the pediatric population would be given some preference.
  - Value to others – health care providers and first responders as well as pregnant women may be given priority.
  - Determine exclusion criteria – these usually relate to pre-existing conditions related to documented very high mortality risk.
  - Multiple principles have been incorporated into allocation strategies. While more cumbersome, this approach seems more balanced and avoids excluding large groups of patients. It also allows for patients to remain “eligible” as availability of ventilators or other resources changes.
  - Morally irrelevant considerations such as race/ethnicity, intellectual or other disability, sex or gender identity, insurance coverage, poverty/wealth, social status, politics, or social connections should not influence allocation.
- Determine when to invoke the guideline
  - **Do not limit ventilators or other resources prematurely.** There is a danger in limiting resources because there might be a shortage in the near future. That would clearly be unfair and might lead to denying potentially beneficial treatment.
    - Don't let fear and finances contribute to decisions.
    - Until resources are limited and triaging is in effect, the patient's best interest determines the treatment.
    - Transparency and anticipatory guidance are appropriate. Prepare to address withdrawing the ventilator or other resource if the patient initially meets criteria but subsequently does not. Reallocating a ventilator can be emotionally challenging for all involved.

- Contingency planning in advance of a possible scarcity might include
  - Clear communication of the possibility of scarcity and need for triaging with the patient and family.
  - Safeguarding supplies and equipment. There have been reports of people in emergency departments walking out with masks.
  - Ensure efficient and appropriate current use of resources at risk of scarcity. A good philosophy is that a hospital would not go into triage mode before all the hospitals in the region or state go into triage mode.
  - Expand capacity
    - Alternate care space
    - Altered staffing models
    - Conservation and/or use of alternate meds
    - Repurposing and or reusing critical care equipment
    - Accessing emergency stockpiles
    - Collaboration amongst organizations
    - Transfer patients and/or equipment
    - Alternate treatments
  - Reduce unnecessary exposure to the disease
    - Limit exposure of trainees and nonessential family members to infected individuals
    - Consider telemedicine to address some of the health care needs of uninfected individuals
    - Delay nonessential procedures
- Build in a process to verify that the guidelines meet the intended goals

Once the guideline is in place, it needs to be operationalized. Triage is the process by which people are categorized based on their needs for urgent care vs. their chance of benefiting from such care. It is generally only necessary during wartime, and during pandemics or natural disasters when the need exceeds the available resources. As with the current crisis, the situations frequently evolve and change over time. Compassionate communication by trusted health care authorities and top political figures can help direct the public opinion and reaction. If expectations are clear prior to triage, the difficult conversations may go more smoothly. Once triaging is in effect, ensure that the process is unbiased and that guidelines are applied equally. Anticipatory guidance and expert communication, i.e., phrasing the use of the ventilator as a “trial of ventilation” can help manage expectation in case of reallocation of the ventilator.

- All cases should be reviewed.
- Refer to the ethics committee as needed.
- Verify that there is no discrimination.

Luckily, except for infants, COVID-19 seems to cause a milder illness in children, therefore it is less likely that resources would be severely limited. However, there may be challenges with availability of intensive care rooms, ventilators, and medications that can also be used for adults. It is also possible that health care personnel may be reassigned from pediatric to adult care.

In an effort to be fair to everyone and to do the greatest good for the most people, the focus would need to shift from what is in the person's best interest (beneficence) to making the best use of the scarce resource for the most people (justice). Clearly, planning ahead would be of benefit so that policies, processes, and practices can be developed. Expert palliative and hospice care are critical to help ensure that, regardless of the resources available, the patient and family have the best care available including emotional, psychosocial, and spiritual support.

### **Resources (no scarcity!)**

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## WITHDRAWING TREATMENT IN NEONATES: THE ROLES OF TIME, CULTURE, AND GESTALT

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It is nine o'clock on a Friday morning. Outside a fifth-floor conference room window of the hospital, the sun shines off a nearby river, creating a warm, blinding, glimmering effect. Only a few wispy clouds are hovering in an otherwise blue sky. However, we are in the NICU and on the other side of conference room door, the scene is not as idyllic. Concern mounts for the newest patient, an hours-old newborn girl with multiple congenital abnormalities, a malformed frame, and who is already ventilator-dependent. Just before she was born, her mother—36 weeks pregnant—was emergently transported to the hospital after experiencing vaginal bleeding at home. Had this birth occurred at the parents' home or a less capable hospital, it is likely this baby would have died by now.

A year before, this baby had a sibling born under similar circumstances who lived only a few hours. Her parents expected the same result this time. Not wanting to fight God's Will or subject this baby to a quality-compromised life, her parents, who are Amish, ask to withdraw the ventilator, anticipating she too will die. Her physicians agree that withdrawing treatment at this point would result in her death. They acknowledge that she may not survive despite medical intervention. If she survives, it is uncertain for how long; it is predictable, though, that she will have permanent physical and cognitive disabilities. What is unknown is whether her death is *inevitable* should treatment continue. Those involved with this baby's care are now faced with the uneasy and tense task of trying to figure what next steps should be taken.

Cases like this are emotionally taxing for both families and medical providers. They also raise several ethical and moral issues about what paths forward are best or, at least, the most supportable.<sup>7,10</sup> Of note in this case, there is not significant disagreement about the criticality of the patient; both her physicians and parents concur that there is a high probability of death or a life of profound disability for this baby. Where disagreement emerges is in a clash between time, culture, and treatment gestalt about what to do next after the parents' request treatment be withdrawn.

While physicians may sympathize with the parents' request, there is a worry that stopping ventilatory support the moment it is requested without first having more diagnostic and prognostic information is premature. Particularly, before agreeing to the parents' request, the attending physician is wanting an ultrasound and an echocardiogram (ECG) to determine the extent of damage to the baby's brain and heart. The baby's parents, especially given the difference in cultural perspectives, believe a delay in honoring their request usurps their parental authority and is tantamount to unfair discrimination.<sup>1,5</sup>

Both perspectives are valid. What level of diagnostic information is necessary to prognosticate and make a treatment recommendation is largely left to the treatment gestalt of the attending physician. This is a function of multiple variables, including the physicians' medical training and knowledge, their practice environment, and their personal preferences for how they practice.<sup>9</sup> In this case, for example, some physicians may be comfortable with the information about the baby's current physiological status and family history to make the decision to honor the parents' request to withdraw without obtaining an ultrasound or ECG. Given the stakes of this case, however, other physicians may agree with wanting more certainty about prognosis before agreeing to withdraw ventilator support, and some may never be comfortable with the decision to withdraw until the baby is clearly declining regardless of what additional diagnostic information may show. For physicians comfortable with withdrawing without further diagnostic information, it is likely there would be little to no disagreement or ethical conflict between the physician and parents in deciding to withdraw ventilatory support soon after the request is made by the parents. But this does not mean that physicians who wish to pause on agreeing to withdraw ventilatory support are, by contrast, acting unethically. Mutual agreement does not necessarily make for sound ethical practice and vice versa; just because a physician and the parents might agree to withdraw ventilatory support, it is still possible the action may be ethically unsound if it were the case that the baby's condition was not life-threatening and that the child could live for a prolonged, indefinite period of time, albeit, with disability.<sup>2,4</sup> Yet, in this case, pausing to obtain more diagnostic information—thereby delaying a decision to honor and facilitate treatment withdrawal—is what causes ethical conflict rather than helping to avoid or ameliorate it.

Apart from the issue of treatment gestalt and its influence, cultural differences between the family and medical providers also matter in this case. Medical providers are beholden to practice standards and laws that govern the societies in which they live and practice.<sup>3,8</sup> The Amish, however, do not abide by these laws, and intentionally remain aloof from cultural practices outside of their own.<sup>1</sup> Not aware or concerned with various regulatory standards and practices, it should not be considered surprising or unreasonable that the parents in this case would question the delay in honoring their request and believe they are being treated unfairly. For many parents, and the Amish in particular, it seems odd to think that they would not have the right to make treatment decisions for their children in some environments or circumstances but not others—after all, parents in United States are typically permitted broad authority in how they raise their children, ranging from the foods they eat to the cultural beliefs and practices they teach and instill. It is of little consolation in a case this like to ensure parents that they *do have* a right to make *some* treatment decisions, but not all types of decisions in all circumstances, and that some treatment decisions necessarily require a higher level of scrutiny before acting on them. By virtue of delaying acting on the parents' request to withdraw

treatment that will assuredly result in the baby's death, medical providers may be acting appropriately in securitizing the request—especially if they are practicing in a state with governing laws about withdrawing treatment in children—but they still risk being accused of cultural incompetence if either they fail to account for the cultural differences between families and providers or if families simply disagree with the laws or practices medical providers are using to justify the delay.<sup>1,6</sup>

Sadly, this case concluded as tragically as it began. The physicians did not immediately honor the parents' request, opting instead to obtain the desired ultrasound and ECG against the parents' wishes. Later in the day, while awaiting neurological and cardiological assessment of the tests, the baby's respiratory drive worsened, and she was unable to maintain good oxygenation despite ventilatory support. With head hung low, the baby's attending physician came out of her room with the news there was nothing he could do to reverse her decline.

A decision was made not to escalate treatment, to discontinue medical interventions, and to offer the baby's parents the opportunity to hold her before she died. An exhausted mother and father looked grateful to hold their child. The door was then closed, the blinds were drawn, and a purple and green leaf was placed on the door as part of the institution's grief protocol to indicate the loss of life and the family's need for privacy. After a day's worth of hurt and anguish, there was finally some relief. Yet dissatisfaction and questioning persisted. Where the parents treated unfairly despite the concerns about withdrawing treatment too soon without greater prognostic information? Was it wrong to delay treatment withdrawal and not initiate comfort only care upon the parents' request? When is it appropriate for a neonatologist or pediatric intensivist to offer palliative care in cases when death is probable but not certain?

This article does not attempt to answer these questions. It merely highlights what many neonatal and pediatric providers likely already know: unlike end-of-life care in adult populations, where decisions are primarily the result of acting on a patient's known treatment preferences, end-of-life decision-making in neonatal and pediatric cases always has more potentially confounding variables since babies and young children typically do not have established treatment preferences and rely on parents or other adults to make those decisions for them. Time, culture, and treatment gestalt are just three such variables that providers should be aware of when engaging in neonatal or pediatric end-of-life situations and discussions. While health care ethics experts can help identify paths forward when these potentially confounding variables result in *bona fide* conflict, it is frequent, clear, transparent communication that is most likely to help identify and address those variables to begin with and potentially avoid conflict altogether.

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## ETHICS CASE: DISCLOSURE, TRUTH TELLING, VERACITY

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### Case

Bethany is a 12-year-old girl with Ewing's Sarcoma of the pelvis originally diagnosed two years ago at age 10. She completed standard therapy and on routine follow up was found to show recurrence. Further evaluation revealed metastases. Her family was told this devastating news and have asked you not to tell her. Their fear is that this will interfere with her will to live and will exacerbate her underlying depression and anxiety. There is an open study for children with relapsed metastatic disease, and the parents are interested, but don't want to tell Bethany before signing consent.

### **Ethical Question: Should you honor Bethany's parents' wish to withhold information from Bethany?**

In order to answer that question, we need to look at the historical viewpoint regarding veracity in medicine. Before the advent of modern technology and medicines, the prevailing practice was to avoid disclosing bad news. This benevolent practice was believed to protect the patient by avoiding dashing their hopes and damaging their spirit. This misguided altruism prevailed into the beginnings of modern medicine until the late 20<sup>th</sup> century, when patients' rights and ethical principles moved to the forefront of medical practice and disclosure became routine.<sup>1</sup>

Paternalistic viewpoints of the past, where the doctors felt that they may do harm by telling the patient upsetting news, are not dissimilar to the literal paternalistic desire to protect the child. Fast forward to present day healthcare,

Children are inherently a vulnerable population and it is our duty as pediatric providers to advocate for the patient's rights.<sup>2</sup> From a legal standpoint in the US, the age of majority is at 18 years of age. Ultimately, the parents have the legal right to make medical decisions for their child within reason.

### **So, we should honor her parents' wishes to not tell her the truth?**

Not necessarily, as one might ask, how is a child incompetent up until the age of 18 then magically becomes competent and fully able to make important decisions? The quick answer is that this is a fallacy. There is a reason that in pediatric research, assent is solicited from the patient. Children can make decisions for themselves before the age of 18. The age of competence is dependent on a variety of factors including maturity, insight, and understanding of their disease. Hence, involving children in the decision-making process is important and the

right thing to do. Children who are involved in decision making are more adherent to the treatment and generally more satisfied with their care.<sup>3</sup>

### **Speaking of the right thing to do, is honesty the best policy?**

#### **Beneficence**

Do the right thing. Treat people as you wish to be treated. Each of these statements alludes to beneficence, where your intent is to do good, in this case, by providing the truth. There are many benefits to truth telling including the beneficence of respecting the person's right to know.<sup>1</sup> *For Bethany, she has the right to know what is happening to her body and to participate in decision making.*

#### **Respect for Autonomy**

Part of respect for persons is to tell the truth and to avoid confabulation which in most instances would be a degradation of the standard of care.

#### **What about Avoidance of the Truth?**

Our modern-day goal of transparency is to be clear and complete in our communication with our patients and their family so that they will have the necessary information for decision making, planning achievement of goals, and even legacy building. *If Bethany does not want to hear the information, her wish should be respected as forcing her to hear the information can be damaging and traumatic.*

#### **Why would Bethany's parents not want to tell her?**

By soliciting fears from the family, you have a foundation to begin the discussion. Until these are addressed, the family will most likely be resistant to changing their mind about what is best for the child. Again, use the ask, tell, ask format in soliciting fears or worries. *In the case of Bethany, her parents are worried that the news will be so deflating that her depression will be all consuming. They do not want to harm her, nor do they want to burden her with the weight of this news.* Since it is not uncommon to hear parents wish that they could switch places with their child, to take the pain, to suffer instead of their beloved child, this comment is not surprising.

#### **So how do we tell Bethany?**

The same rules for sharing information with adults: to be honest, share a clear message, listen, and respect the response are applicable here. **As with any difficult conversation, start from a grounded place. Avoid distractions by finding a quiet setting, where everyone can sit together in privacy. Turn off pagers and cell phones.**

#### **Be Honest**

In healthcare, we have an obligation to tell the truth. Honest disclosure enhances relationship building and fosters trust. Most adolescents and their parents prefer the truth. Avoidance of the truth is confining and can lead to further avoidance or even confabulation to maintain the

altered or incomplete truth. Keep in mind that children as young as three years of age know that something is going on with their bodies and depending on the stage of the trajectory, know when they are dying. By not talking about the proverbial elephant in the room, the message sent is one of non-communication. By not providing the information to the child, distrust, a sense of betrayal, and poor decision making is fostered. Further, noncommunication of the bad news between parent and child interferes with the potential intimate, precious conversations that may be treasured by the parent for years to come.

*Bethany's parents didn't realize that their intent to protect their daughter might contribute to her suffering. Since Bethany has been asking what's going on, you proceed to ask Bethany what she wants to know and how much detail she prefers.*

### **Share a Clear Message**

Use developmentally appropriate, clear, concise language. Children can understand the subject matter if explained using familiar vocabulary. Provide incremental building blocks to the full intended message. Begin with the current understanding. Provide clarification and correct misconceptions.

### **Listen and Respect the Response**

You may have an intended target or goal for the conversation but allowing for silence and respect for emotion will further build the trusting relationship. Ask for permission to tell more or to regroup later if the patient and or the family is unable to process more currently. Timing will depend on the need for a quick decision.

Prognostic information relayed in a kind, compassionate manner allows the child and family to prepare for the unalterable or possible event. In this case, *Bethany and her parents both have the right to honest, clear and complete information regarding her health.* For children who are cognitively able to communicate, developmentally appropriate information should be shared, as desired by the patient. Partnership with the patient and family is important to maintain a trusting relationship. Conflicts between the parents and the child can be processed with inclusion of trusted team members such as Social Work, Chaplaincy, Child Life Specialists, Psychologists, or Expressive Arts Therapists. The expertise of Child Life Specialists can be exceedingly helpful in promoting developmentally appropriate communication.

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## ETHICAL EMOTIONAL BOUNDARIES FOR HEALTH CARE

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Maintaining healthy emotional boundaries can be challenging enough. It can be that much more difficult when caring for children, adolescents, and young adults. Professionals, parents, or other loved ones involved in pediatric palliative care know this all too well.

These boundaries protect others from our well-intentioned overstepping and us from the compassion fatigue that can leave us ineffective. As we strive to practice them, we can ask ourselves perhaps no greater questions than these:

Who is the hero of this young one's journey?

To whom do I trust the life of this child?

How am I meeting my own personal needs?

It is hard-wired into our DNA to feel responsible, and even sacrifice ourselves, for the sake of the young. It is an adaptive response that is hard to deny. Sit at any social gathering where children are playing and watch the meerkat impersonation all the adults do, heads popping up to attention, when one begins to cry. As helpful as that instinct is, it can lead us to over-function in unhelpful ways.

Certain ethical principles such as **beneficence** (to do good), **nonmaleficence** (to avoid harm), and **justice** (to treat fairly) guide our caregiving. These apply universally in ways that are typically easy to grasp.

Our ethics also include respect for patient **autonomy** (self-governance) and **dignity** (honor and worth), which can be a bit more difficult for us to follow, perhaps because they call us to let go of our control and trust another to find their own way that may differ from what we want for them.

A helpful conceptualization of such boundaries comes from a brochure called, "A Nurse's Guide to Professional Boundaries," published by the National Council of State Boards of Nursing, Inc. (Chicago, Ill; <https://www.ncsbn.org/3757.htm>):

Professional boundaries are the spaces between the nurse's power and the patient's vulnerability...Nurses should make every effort to respect the power imbalance and ensure a patient-centered relationship... the therapeutic nurse–

patient relationship protects the patient's dignity, autonomy and privacy and allows for the development of trust and respect.

As care providers, we must constantly monitor to protect care recipients from unintentional coercion and usurping of their autonomy, dishonoring their dignity by taking over their lives in a way that denies them of their rights as an independent person.

I teach professional and informal (meaning unpaid) caregivers regularly about our ethics, boundaries, and the healthy practices to help us maintain the balance between our wants and patients' needs. But how are we to apply these ideals in the much more gray areas of caring for the young?

### **Who is the Hero?**

When I was trained in psychology, my classmates and I would ask our instructors how we could know when we were over-stepping and over-functioning with a client. They consistently responded, "When you do for the client what they could do for themselves."

That can be hard enough to follow for well-meaning, compassionate caregivers when adults are struggling. Where do we draw these lines when it's the young who are suffering?

Long before the phrase "helicopter parenting" was coined, developmental psychology taught us that children need to accomplish tasks such as learning autonomy, initiative, industry, and identity in order to become healthy and secure adults. In short, they need to learn to trust themselves to become the heroes of their own journey.

They need grownups in their lives to be just close enough to comfort, guide, and protect, but far enough away so they have room to become their own persons as they learn to self-regulate, self-soothe, problem-solve, fall down and eventually to get back up.

When the young are ill, the need to learn these things does not simply go away. Their need for us to provide care may be greater and their ability to do for themselves may be lessened in some ways. This means it is even more important to support their autonomy, dignity, and access to at least some control over their lives in whatever ways we can.

It feels wonderful to know we have made a difference and to receive adoration and appreciation for scaring away the monsters or making something that hurts feel better. Offering comfort does help kids build trust in those around them. We never want to do so, however, at the expense of them learning to also trust in themselves.

In every care interaction, we can ask ourselves whether we are taking on what the child could do for themselves. Are we empowering and equipping them to become their own heroes or are

we handicapping them further than illness may be already by communicating to them by our actions that we do not trust them to do their own lives?

We offer as much choice as reasonably possible and developmentally appropriate in both seemingly small and large decisions. Do they want the light on or off, the bed up or down, the IV in the left or right arm, treatment before or after the school dance, or do they want to continue the treatment at all?

We listen to their values, goals, needs, and desires. What is important to them? What does the wisdom inside of them have to say about the plan of care we believe is the best option? What do they have to tell us about what is going on with their bodies that we may be missing?

As we take off our super-hero capes and help them learn to put on their own, young ones can feel more included, confident, trustworthy, and strong. This honors their developmental needs, their autonomy, and dignity, decreases the risks of our over-stepping and imposing too much of ourselves onto their situation, and also protects us from compassion fatigue that can occur when we take on too much.

### **Whom Do I Trust?**

In November of 2012, Brene Brown was being interviewed by Krista Tippett for the podcast “On Being” about the courage required to be vulnerable. As they spoke, the conversation turned toward helicopter parenting and Brene reminded us that we think we help our children when we smooth out all of life’s rough spots for them. We actually hurt them, however, by robbing them of the opportunity to fall down and learn to trust that they can get back up.

She went on to describe the work of C. R. Snyder, whose research was about hope. According to Brene, Snyder’s research found hope is not a feeling but instead a cognitive-behavioral construct we develop when we face challenging circumstances and have people around us who believe in our ability to find our way through. When we do find our way, we now have built hope that the next time we face a challenge we will be able to handle it.

[\(https://onbeing.org/programs/brene-brown-the-courage-to-be-vulnerable-jan2015/\)](https://onbeing.org/programs/brene-brown-the-courage-to-be-vulnerable-jan2015/)

We caregivers often think we have to give hope to those for whom we care, but we don’t, and we actually can’t. What we can do is be the ones around them who believe in their ability to find their way and reassure them that, while they do, they will not be alone.

When we do need to step away from them either briefly during the normal ebb and flow of our day or more long-term due to changes in our lives, it can be helpful to get clear about our own views of suffering—why it happens, how we are to cope, how we make sense of or find meaning in it (if at all), where we find hope, etc. Some answer such existential questions by

turning to the teachings of a formal religion or spiritual path, while still others turn to the sciences, arts, or the greater human consciousness.

Getting clear about our own answers to questions of theodicy—a fancy theological term for the question of where the heck is divine good when bad things happen—can help us keep a solid footing. Without such guidance, reassurance, and comfort, we are more likely to get so hooked by the story unfolding in front of us that we feel the need to fix things that may not be fixable, or that are not ours to take on.

That means that when we step away from a care situation, we hand the person over into other hands—of a deity, the universe, their other caregivers, their own—and do not carry worries about them with us. We learn to care for and even hurt with them, but not to pick up their struggle as our own.

Granted, this can be far easier for professionals to do than loved ones. I do not presume to suggest that parents and family members should not carry the young in their heart or that letting go of feeling completely responsible for them is by any means an easy task.

We hope to eventually send them to school the first time, to ride a bike with no training wheels, to a sleepover with friends, to get their hearts both lifted and broken by love, go out into the world of work and college, and to have a family of their own. We expect these transitions and risks, but not the struggles and risks involved in living with a serious illness.

I have my own ways of making meaning during times of worry and heartache. You likely already have or will someday find your own. Our views change over time, especially in the face of challenges and suffering. Whatever answers you find, may you find some sense of peace that will help you hold steady as you face the unknown.

We can practice this trust, this boundary of remembering that we own neither the young one nor their process, with simple practices:

- Pause before walking through a door to see them, with a hand on the handle for a moment, to breathe and center.
- Imagine a waterfall coming down from the doorway, allowing it to wash off negative energy and worries of the day while walking through it to a care situation, and again when leaving while trusting them into other hands.
- When washing hands multiple times a day, take the 20 seconds to relax the belly and breathe, find your feet on the floor, relax your shoulders away from your earlobes where they tend to creep throughout the day, say a mantra or prayer or recite a

meaningful poem, or do anything else that brings you back into the present moment, your body, and helps you center.

- End your workday by removing your badge and placing it some place consistent and special. Make a commitment to yourself and your loved ones to put the worries of work down with it until it is time for your next shift. That means that, unless you are on-call, you do not worry about, check up on, or obsess over patients.
- Loved ones may do something similar by having a certain piece of jewelry or clothing you wear or a river stone you carry in your pocket when you consider yourself primarily responsible for the young one. When others are taking care of them or they are out in the world in some other way, and you are practicing your own self-care, remove that necklace, scarf, or stone and hand it over to its special place as a tangible reminder that you are off duty.

### **How Am I Meeting My Needs?**

Research consistently finds that practicing self-care is important for mental, emotional, and physical health. We serve best when we care for our own needs first and come to care interactions full with something to give from the overflow of our resources rather than pulling from the dregs at the bottom of our internal barrel.

We may already feel guilty about taking time away for self-care, but there is nothing selfish about it. Selfishness is when I do something for me at your expense. Self-care is when I take good care of me so that I **can** show up well for you. There is a subtle but significant difference between the two.

Self-care is also vital to our holding healthy boundaries. If I come to my work full—of my own hobbies and interests, relationships with people who love me on both my best and worst days, my own rest and other needs met—then I can simply allow my caregiving to be fulfilling.

If I come to work empty, I risk looking to my care interactions to fill me up and make me feel good about myself. That increases the risk I will overstep my boundaries and taking on far more of others' experiences than is healthy for us both.

Again, it feels good to be of service and research demonstrates Compassion Satisfaction can help protect us from Compassion Fatigue, but if I **need** the care interaction to go a certain way so I can feel whole, I set myself up for constant disappointment, disillusionment, and the breaking of boundaries in various ways. The more I fill myself up outside of my caregiving experiences, the less likely I or those for whom I care will be harmed.

One helpful resource is from the Compassion Fatigue Awareness Project (<http://www.compassionfatigue.org/pages/selftest.html>) where you can take and score tests that assess your compassion fatigue, compassion satisfaction, and life-stress. After taking these tests, develop your own plan of care to tend to your needs outside of your time with care recipients.

When we remember the ethics that guide our caregiving, trusting even the young to live their own lives and practice their own self-determination, trust the results of our care into other hands, and care for ourselves well, everyone will benefit and be protected from unintentional harm. Caring within bounds is the most compassionate thing we can do for everyone involved.

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## THE ETHICS OF ORGAN TRANSPLANTATION IN MINORS

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Children may experience failure of their vital organs, just as adults may. Organ failure leading to death in a child is even more tragic than when it occurs in an adult, especially when one considers the number of years of potential life lost.

In a case of severe chronic organ failure in a child, without the availability of organ transplantation, if the child does not die and is able to accomplish marginal survival, the psychosocial, neurodevelopmental, and growth effects of the child's illness pervade every aspect of his or her life. Although there may be no guarantee that organ transplantation will suddenly cure a child's illness, there is a chance that organ transplantation may improve the child's quality of life. There do not seem to be many ethical concerns regarding having minors *receive* a needed organ compared to the concerns surrounding the donation of organs *by* minors. Considerable attention has been devoted to the ethics of procurement of vital organs *from* minors<sup>1</sup>.

Why would minors be needed for organ donation? Logistically, a small patient would need a small organ. Generally, an adult-sized organ would simply not fit into a child. Additionally, an adult-sized organ requires adult amounts of blood flow in order to keep the organ viable. A small heart with a child's small circulating blood volume would not be able to provide adequate perfusion to an adult-sized organ to keep it viable.

In this article, we examine the ethical issues involving procuring tissue or organs from minors.

**Brain Death.** At first glance, it would seem unethical to remove vital organs (heart, lung, etc.) from a living individual. Until relatively recently, death had been determined to occur exclusively when all bodily functions, especially the heartbeat and respiratory efforts, had ceased. With the advent of life-sustaining technology in the past half-century, a patient's circulation, respiration, and nourishment may be artificially continued, even if a patient has no mentation, no spontaneous respiratory effort, no ability to take in nutrition on his or her own. In 1981, the Uniform Determination of Death Act<sup>2</sup> recognized that there were actually *two* means of assessing death: (1) the long-standing assessment of irreversible cessation of circulatory and respiratory function; and (2) the new assessment of irreversible cessation of all functions of the entire brain. Thus, in a person declared brain dead, the heart continues to beat, the various organs continue to function, and the person is even able to reproduce.

Legally, vital organs from a patient may be procured for organ donation only once death of the donor has occurred. Death may now be declared by virtue of cardiac death or brain death.

With regards to children, there are specific examinations and ancillary tests that must be performed in order to declare a child brain dead, which are different from those exams and tests for adults.<sup>1</sup>

The Task Force on Brain Death in Children<sup>3</sup> has stated that, in order for death of a child to be determined, the child must have sustained: (1) irreversible cessation of circulatory and respiratory functions; or (2) irreversible cessation of all functions of the entire brain, **including the brainstem.**

Neonates less than 37 weeks gestation are not eligible for the brain death determination due to insufficient data in this age group<sup>4</sup>. However, the law allows for recovering vital organs with the intention for transplant, from older children with irreversible cessation of all functions of the entire brain, including the brainstem.

**Organ Procurement from the Anencephalic Infant.** Anencephalic infants have a developmental brain defect in which the cerebral cortex, the part of the brain used for thought, never developed. There is a large skull defect so that the brainstem remnant and the spinal cord are exposed to the environment. The patient is permanently unconscious, and has never been capable of consciousness, even as a fetus. Some rudimentary mid- and hind-brain/brainstem structures may be present, giving the patient the ability to exhibit primitive reflexes, such as the spinal cord reflex of withdrawal of an extremity to painful stimuli, and breathing. Babies with anencephaly usually die within several days of birth from overwhelming central nervous system infection, cessation of spontaneous breathing, fluid and electrolyte abnormalities, hormone abnormalities, low blood pressure, low body temperature, and aspiration pneumonitis. Since the cerebral cortex is absent, even though the spinal reflex causes a withdrawal movement in response to pain, the anencephalic infant probably does not *experience* pain. Even if an anencephalic infant is placed on a ventilator to breathe for that infant (because that infant is not capable of remembering to breathe regularly) and the amount of time that the infant's heart beats and that its organs are perfused with oxygen are prolonged, the infant will continue to be unconscious.

Because anencephalic patients have a completely hopeless prognosis, and, aside from their abnormal central nervous system, generally have no organ abnormalities, organs derived from these patients would seem to be perfect organs to transplant into a child recipient. It has been also argued by various organizations (the Uniform Determination of Death Act, New Jersey Assembly Bill No. 3367 of 1987, Uniform Anatomical Gift Act of 1987) that: the demand for neonatal organs exceeds supply; that, while his heart is still beating, the anencephalic infant's organs are the ideal organs for donation; that the ultimate outcome of an anencephalic infant, unfortunately, is that it will certainly die, whether or not the infant donates its organs; that the parents of an anencephalic infant may derive some emotional benefit in donating organs from their infant, realizing that some good can come of the tragic situation; that donation of an anencephalic infant's organs is an altruistic act to benefit society; and that, having always been unconscious, the anencephalic infant does not have its own interests to protect. All these factors might contribute to the argument favoring removal of vital organs from anencephalic babies for organ donation. Notwithstanding these arguments, the anencephalic infant cannot be considered to be "brain dead" because it still exhibits some primitive, brainstem neurologic

function, such as breathing and primitive withdrawal to painful stimuli.<sup>5</sup> Ancillary tests looking for blood flow to any part of the brain will show arterial flow to the hindbrain. Therefore, just as the clinical exam does not diagnose brain death, the brain blood flow study does not diagnose brain death.

If a breathing, heart-beating anencephalic infant's organs are considered to be fair game for organ donation because of its permanent state of unconsciousness, its lack of personal interest in the past, present, and future, and its progression toward inevitable death, the next logical step would be the evaluation of other classes of brain-damaged individuals for their acceptability for organ donation. Thus begins the so-called "slippery slope" argument.<sup>6</sup> Should unconscious, breathing, heart-beating infants with severe congenital brain malformations, who will apparently contribute nothing to society, be considered brain-damaged enough to donate organs, even though they, too, do not technically meet the criteria for brain death? Should unconscious, breathing, heart-beating individuals with stroke, progressive neurologic dysfunction, Alzheimer's disease, and sequelae of head trauma be considered brain-damaged enough to donate vital organs, even though they do not technically meet the criteria for cardiac death nor for brain death? Because these brain lesions are acquired, some of these patients may have had an opportunity to let their personal interests be known before the onset of their neurologic dysfunction. After they become brain-damaged, are their previously-stated personal interests valid any longer? If the brain damage is potentially reversible, for instance, following head trauma, even though certain individuals may never have voiced their own personal interests previously, someday in the future, they may theoretically be neurologically competent enough to make their interests in their own welfare known.

**Summary.** In summary, the donation of organs is a much-needed act, accomplishing a desirable end. Parents who choose to offer their infant's organs have made a difficult and altruistic decision. However, extreme caution must be exercised in the mechanism by which recovering of the organs is justified. The definition of death should not be relaxed in order to accomplish this deed, as this may have far-reaching negative implications on the moral and ethical foundations of society. The bending and distorting of the law in order to justify the killing of anencephalic infants, or other brain-damaged individuals, by removal of their vital organs should be forbidden. In order to protect society's high moral and ethical structure, recovering donor organs from live anencephalic infants should be prohibited.

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## ITEMS OF INTEREST

In each issue of our Pediatric E-journal, 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](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://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](http://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 2020 Webinars](#) provided by the Pediatric Care Coalition:**
  - **May 21, 2020** – Guiding Families to Mindfulness Supports Decision Making for Adults and Children – with David Steinhorn, Children’s National Medical Center and Jana Din, Tao Center for Healing
  - **June 16, 2020** – Ethical Questions in Pediatric Palliative Care – with Sabrina Derrington, Ann & Robert H Lurie Children’s Hospital
  - **July 21, 2020** – Beyond Fairytale Endings: Using Storybooks and Other Therapeutic Tools to Explain the Death of a Child – with Lori Weiner, National Cancer Institute and Meaghann Shaw Weaver, Omaha Children’s Hospital
  - **August 20, 2020** – Pediatric Concurrent Care – with Lisa Lindley, University of Tennessee
  - **September 22, 2020** – Explaining Pain: Pain Education and Mind-Body Tools for Pediatric Chronic Pain – with Rachel Zoffness, American Association of Pain Psychology
  - **October 22, 2020** – Through the Eyes of a Grieving Child – with Viki Jay, NAGC – National Alliance for Grieving Children
  - **November 17, 2020** – Partnering with Funeral Professionals to Support Families Following the Death of a Child – with Kristin James, Greater Illinois Pediatric Palliative Care Coalition and Kelly Manion, Funeral Service Foundation
- The [2020 Interdisciplinary Conference](#) is going to be a virtual offering this year. While we look forward to a time when we can re-convene the NHPCO community face-to-face, the NHPCO staff is exercising its creativity and imagination to deliver a virtual event different from anything we have done before!

The Virtual Interdisciplinary Conference will take place over the span of three weeks, October 12-30, 2020. The conference will include live and on-demand content; there will be more than 60 hours of content, falling within 7 learning tracks, as well as opportunities to network and connect with your colleagues from across the country and NHPCO staff, and download resources that you can view off-line.

5. **A new storybook resource for families.** We are so grateful to also introduce you to Gerbert, a brave little gosling who helps children and their families process and discuss illness. Gerbert's egg hatched due to the need for bibliotherapy resources:

<https://www.ncbi.nlm.nih.gov/pubmed/28346862>

“Gerbert the gosling is strong and brave and has fun times with his family and friends but knows that, one day soon, he won't be able to keep up with them anymore. As Gerbert prepares for his final migration, he finds a way to show his flock that he will always be with them. Includes a one-page Note to Readers and an online Note with additional information useful for parents, caregivers, grandparents, siblings, and teachers.”

<https://www.amazon.com/Gift-Gerberts-Feathers-Meaghann-Weaver/dp/143383023X>  
<https://seattlebookreview.com/product/the-gift-of-gerberts-feathers/>

6. **Subjects and Contributors for Future Issues of This E-Journal.** We are currently discussing topics such as 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](mailto:Christina.Torkildson@bannerhealth.com) or Ann at [ann@here4U.net](mailto:ann@here4U.net).

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