

**Self-Care**

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# Pediatric E-Journal

**PEDIATRIC ADVISORY COUNCIL**

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**NHPCO**

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# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

### Issue #61; November 2020

#### Issue Topic: Self-Care

Welcome to the 61st issue of our Pediatric e-Journal.

This issue of the Pediatric e-Journal is focused on various aspects of self-care in the context of pediatric palliative and hospice care. Obviously, self-care is a huge and perennial topic of interest, so we can't claim to have addressed it in anything like an inclusive way, but we hope the articles in this issue will direct attention to its importance and spark further discussion.

Now, it is important to note here that this issue was planned over 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. 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 the next issue of this Pediatric e-Journal in a way that is commensurate with its significance. In the meantime, while we offer this issue's collection of articles on various aspects of self-care in connection with pediatric palliative, hospice, and end-of-life care, we also 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 [christytork@gmail.com](mailto:christytork@gmail.com) or Ann Fitzsimons at [ann@here4U.net](mailto:ann@here4U.net).

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 lessons learned from COVID-19, telehealth & hospice/palliative care, and racial inequities/social injustice for issues in 2021. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy at [christytork@gmail.com](mailto:christytork@gmail.com) or Ann at [ann@here4U.net](mailto:ann@here4U.net).

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## Issue #61: Self-Care

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

### *On Forgiveness*

*p. 5*

#### **Christine Gharagozian**

A little over two years after the death of her younger son, Levi’s mother reflects on what her bereavement has been like and what she has learned about self-care.

### *Going Home Checklist*

*p. 7*

This checklist from the National Health System in England offers six items to guide reflections looking backwards on one’s workday and looking forward to prepare for a transition to going home.

### *Putting on Your Own Oxygen Mask First*

*p. 8*

#### **Travis C. Overbeck, M.Div.**

Drawing on the familiar airline guidance that in the event of an emergency one should put on one’s own oxygen mask first before trying to help others, the author of this article reminds us that, “Often, we forget that in order to care for others, we must first put on our own oxygen mask.” That leads to reflections on self-care and a concrete interaction with a clinician who at first said, “I don’t have time for that.”

### *A Pause to Remember*

*p. 10*

#### **Peggy Bottenhorn, LMT, BCTMB, MA**

The author of this article offers 15 paragraphs that alternate between comments on her own personal experiences and quotations from seven referenced sources. The basic message appears in the first paragraph: “(The Gift of the) *Pause*...This simply profound action and word, has been one of my faithful companions through the years, conjuring all kinds of images and thoughts, offering gifts of comfort, silence, rest, peace, clarity, hope, inspiration, resilience, and imparting a deeper/richer/fuller way to seeing, knowing, and experiencing the many sides or aspects of any event.”

### *Caring for Us Is Caring for Others: Resilience, Emotional Intelligence, and Self-Care for Caregivers*

*p. 13*

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

This article begins by asking, “How do we not only survive, but actually thrive through challenging times?” The author’s answer addresses a variety of key topics: Self-Assessment; Resilience (Perceptions and Meaning-Making; an Internalized Locus of Control; Connection and Community; Adaptability, Flexibility, Coping; Self-Care; Gratitude and Hope); Emotional Intelligence; Mindfulness Practices to Build Resilience; and a Plan of Care.

### *The Limits and Power of Resilience*

*p. 23*

#### **Abby R. Rosenberg, MD, MS, MA, FAAP**

According to this author, “The work of pediatric palliative care was hard before. Now, for some, it seems impossible. Never before has there been a greater need for resilience.” She then

describes overlapping “phases” of resilience and ends with the following comments: “[P]eople have been navigating adversity for millennia. Although some seem to do it with more observable grace and skill than others, most keep going, despite their exhaustion. We have no choice but to be resilient...Resilience may not be sufficient—as in the only thing—we need to weather this time, but it is necessary. And, we all have it.”

*Promoting Well-Being for Pediatric Palliative and Hospice Care Professionals* p. 27

**Gina Geis, MD, MS**

In this article, the author notes that, “Stress is ubiquitous across all healthcare professions and this is not surprising. However, other pervasive elements include a sense of frustration as well as trouble with communication.” She adds that, “For healthcare providers, it is important to note that the drivers of burnout are multifactorial,” including both professional and personal stressors. To address such stressors, she recommends: a culture of wellness; efficiency of practice; and personal resilience.

*The Medicine Wheel as a Conceptual Model for Collaborative Patient Care and Practitioner Self-Care* p. 31

**Robyn Scherr, CMT, CST-D, and Staci Copses, OTR/L, CBIS, CST-D**

“In this article,” the authors write, “we present two circles that promote balance and wholeness, one currently being developed at UCSF Benioff Children’s Hospital Oakland (BCHO) as a systemic and ethical model of care, and one focused on practitioner self-care.” In the first model, a medicine wheel, “the circle represents a model of healthcare that embraces wholeness, balance, and change. It explicitly makes all resources knowable, facilitating communication and access.” The second model, “The Healing From the Core™ (HFC) method is the practice we use for ‘effective self-care’ as practitioners in private practice and in Staci’s work with patients in the NICU, PICU, oncology, and palliative care. This method is an invitation to move beyond the paradigm of ‘tips and tricks’ coping strategies into a regenerative self-awareness and therapeutic presence that extends, without depletion, to ourselves and others.” Two diagrams offer visual depictions to support the text.

*Developing Staff Debriefing Guidelines* p. 37

**Suzanne S. Toce, MD, FAAP**

Here, the author explains why we should facilitate staff debriefings, when there should be such debriefings, who should participate, who should conduct them, what should be the format and topics, when should they occur, what should be the expectations of attendees, what are some potential interventions and/or recommendations in response to grief, stress, moral distress, and compassion fatigue, what are the barriers to such debriefings, and what should be the follow-up.

*Self-Care Resources* p. 41

**Compiled by Ann Fitzsimons BS, MBA**

This article provides a list of seven organizations that offer resources for those seeking guidance or assistance in self-care. Note that many of these sites offer multiple subordinate resources.

## ON FORGIVENESS

**Christine Gharagozian**

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Grief is hard work. Staying connected with it and open to it requires trust in self. Sometimes it all feels like a cosmic prank. It has been just over two years since I lost my younger son and I still occasionally want to scream into the void...How can I trust the very same Life that handed me that which I feared most? The void screams back...Try the alternative on for a while and let me know how that feels. The early days felt like a sand storm, a white out, a brush fire, a burning down. I could not discern up from down. I developed an affinity for very dark humor and deeply empathetic human beings. Something deep inside of me knew that I would get through this season one way or another and it was grounding to be in connection with people who also sensed that. Sadly, there were not very many of them. Just enough to get my very human need of love and acceptance met.

These days, I am grateful to have access to the paradox, my emotional boundaries are growing as I deepen my connection to myself and I am able to sense our interconnectedness more and more. We give love; we receive love in return. My mind is clearer and my body is softening into my process. When the big waves come, I am more able to invite them in and watch them move through me. Letting go has been a slow, delicate process and healing from trauma has been very painful. I remind myself frequently that the only way is through. I am pondering what resurrecting JOY would feel like for me. I dream of writing a book one day and I am researching a career in freelance writing. I sense that would feel joyful. I also occasionally imagine working at a think tank with warm-hearted human beings who also feel that the earth would be a gentler place if folks just cried more often. We would all sit around an old solid oak table. We would craugh (cry-laugh) throughout the day and get paid to think about deep shit. It does feel miraculous to spend some time imagining this and it also feels far away. Both. The paradox of my present moment.

How did I discover this place that feels oh-so-much-more-peaceful than the alternative of being traumatized repeatedly? I forgave myself. Relentlessly. There is a voice in my head that tells me I am a failure. This voice tells me that good mothers successfully keep their children out of harm's way. I sat down for months and wept and got to know this voice inside of me. I attempted to meet this voice with curiosity and compassion because I quickly learned that shushing it only made it louder and made me even more miserable. Slowly, this voice started to simmer down. It had less of a hold on me. My curiosity grew.

I read all of Eckhart Tolle's books and began to sense that I understood what he was describing more and more. Yes, clearly, I am not this voice. I am not my thoughts. Well, then, what in the hell am I? Who am I? My curiosity grew.

As far as I can tell, I am Love. I always have been. I always will be. So are you. I am also quite skilled at getting in the way of that truest of truths, my humanness. I fear because I know that everyone I love will eventually die and I cannot know when. I have always known this. It is simply more stark now. I cannot avoid it. To cope, I forgive myself daily for not always leading with who I know myself to be. Love. I do my best with what I have been given and I trust that I will continue to grow. As I see it, Life is most assuredly both. It is wretched and it is glorious. Suffering is optional when we forgive ourselves in honor of our dead and those who continue to live.

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# Going home checklist

- ✓ Take a moment to think about today.
- ✓ Acknowledge one thing that was difficult during your working day - let it go.
- ✓ Consider three things that went well.
- ✓ Check on your colleagues before you leave - are they OK?
- ✓ Are you OK? Your senior team are here to support you.
- ✓ Now switch your attention to home - rest and recharge.





## PUTTING ON YOUR OWN OXYGEN MASK FIRST

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I had heard those words a thousand times, but never had they caused such contemplation...It was early one April morning and my wife, myself, and our 4-month-old son had boarded a plane to fly to the East Coast to spend time with extended family. This was our first flight with our son. We had settled into our seats, our son was in my wife's lap, when the announcement began. "Good morning ladies and gentlemen, as we prepare to take off, please focus your attention on the crew as they do their safety demonstration." These words were so familiar, that they blurred into the background until the phrase, "in the event of a sudden change in cabin pressure, oxygen masks may fall from the ceiling directly in front of you. If you are traveling with a child, please put your own mask on first." I paused. I became anxious. Words so familiar were jarring. How am I supposed to put on my own mask before putting on my child's?

These past few months have been extraordinarily challenging on just about every front imaginable. Nearly everything that was once familiar has become to some degree, foreign. As stress levels rise, as anxieties are heightened, as patient care and family support have become in many ways more demanding and complex, the question becomes, in the midst of it all, how are we caring for ourselves?

We talk about self-care, we encourage our patients and their families to practice it, we even make suggestions and recommendations for how one might go about doing it, yet so often we forget to actually practice what we teach for ourselves. Often, we forget that in order to care for others, we must first put on our own oxygen mask.

So, what is self-care? At its most simple level, self-care is being intentional about caring for yourself. Self-care is the practice of setting time aside to invest in oneself and one's wellbeing. While this is not always easy, it is entirely essential, especially for healthcare workers, particularly during these challenging times.

Recently I was talking with a clinician and as we talked, I could tell that something just didn't seem right, but I was having a difficult time figuring it out. She seemed "off." She was someone who was always well put together yet now somewhat disheveled, someone who nearly always had a positive attitude, yet was now frustrated all the time with things that never would have bothered her. She shared that one of her patient's families had even asked her how she was doing. Admittedly, she too was having a hard time understanding what was going on. She was frustrated as she knew this wasn't her norm. Finally, after further conversation I asked, "How

are you taking care of yourself?" She looked at me perplexed. I clarified, "When was the last time you did something purely for you? When was the last time you were not a clinician? A mom? A wife? When was the last time you stopped and cared for you?" Her response was so brutally honest, and I think her response is probably where many of us are today, "I don't have time for that." I looked at her and gently said, "I wonder what would happen if you made time." She had been giving her all on behalf of so many others, not just in work, but also in family – which is not a bad thing, but along the way, she had ceased to care for herself.

We began to talk about some of the benefits of self-care, things like increased immunity, improved mood, lower stress levels, better patient care, reduced risk for burnout and compassion fatigue, and even longer life-expectancy. The clinician shared with me, "I've heard of the benefits, I know it's good for me, I know it's important, but it just seems so hard to actually commit to doing it." So, we discussed some practical ways to work self-care into her normal day. Self-care when practiced doesn't have to be complicated or complex. Self-care can be as simple as doing some mindful breathing between patient visits, parking an extra block away from a patient so that you have to go for a walk, downloading a mindfulness app, practicing guided imagery, taking PTO that isn't necessarily for vacation, but rather a day set aside for YOU, carving out time that is set aside purely for you.

The reality is that every one of us, in order to be the best person, the best clinician, the best self that we can be, we must first pause from the busy-ness and clamor of our lives to care for ourselves. In caring for ourselves, may we find the strength and energy to go about our daily happenings in ways that are healthy, in ways that are refueling rather than draining. I hope especially during these times, these times that are unprecedented in every way imaginable, that we would pause to first put on our own oxygen mask.

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## A PAUSE TO REMEMBER

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(The Gift of the) *Pause*...This simply profound action and word has been one of my faithful companions through the years, conjuring all kinds of images and thoughts, offering gifts of comfort, silence, rest, peace, clarity, hope, inspiration, resilience, and imparting a deeper/richer/fuller way to seeing, knowing, and experiencing the many sides or aspects of any event.

***As a matter of fact, if my experiences have taught me anything it's that it's when I do simply pause with a breath or two to just be, whether with myself or with another in pain, grief, or anguish—love, compassion, honor, and respect abundantly pour in and gently radiate. <sup>(1)</sup>***

Within my role as a Holistic Health Specialist for a hospital sponsored Home-Based Palliative Hospice Care Program for Children, Adolescents, Young Adults, and Perinatal Moms, remembering to pause and take a breath has brought greater awareness and clarity to the (*many*) expected or unexpected moments of my days. It has been a life-changing/life-giving experience, affording me the luxury to walk with and learn from this gifted companion, and nurturing me with much solace in these uncertain times we're in.

***The suffering of each of us affects others. The more we learn about the art of suffering well, the less suffering there will be in the world. Mindfulness is the best way to be with our suffering without being overwhelmed by it. <sup>(2)</sup>***

Yet setting the course for this awareness to simply stop, ever so briefly, throughout the day, will be a lifelong practice for me. As I grow in greater appreciation for its value, I also recognize it will continue to enrich my level of insight. Looking back, I've learned that this practice of a *pause*, a breath, a **still point** in my day began with a desire deep within, a willingness to actively listen to the whispers of my heart, a desire to become more present, more intentional in the present. Practicing this *pause* supplies me with the courage to step into the unfamiliar and allow all else to fade while the silence, the breath, the stillness restore and faithfully open doors to an even greater focus, understanding, appreciation, acknowledgement, insight.

***You may have heard the story about some Westerners who hired a few bushmen guides to help them travel through the Kalahari Desert. Not being used to moving at the pace their employers were expecting, the bushmen suddenly sat down to rest. No amount of persuasion could induce them to continue the journey until they were ready. The bushmen explained,***

***“They had to wait for their souls to catch up.” This ancient knowing they call “the tapping of the heart.” (3)***

Make no mistake about it though, this is a practice and not without its own set of frustrations; learning to tune out the noise, turn off the “chatter,” change the channel type of distractions, however...this *pause*...whether you call it meditation, mindfulness, silence, prayer, reflection, contemplation, humbug, or something else...this simple practice that is within (any/everyone’s) grasp, has the capacity to sharpen concentration, lower blood pressure, ease anxiety/pain, increase connectedness, refine or shape the contours of our interior, **anchor** us. It has been shown to strengthen neurons (Neuroplasticity: neurons that fire together, wire together), unite body, mind, and soul, reframe thoughts/attitudes/perspectives, and all while honoring the moment...without questioning, fixing, depleting, judging.

***“But it does more than simply train your attention—it strengthens the part of your brain that’s responsible for making more considered decisions. So, in your “eyes open” life, you can pause before responding instead of simply reacting.” (4)***

This simple yet profound practice of pausing to breathe in and out or to just simply notice your breathing can bring you into the present moment—to be aware right here and now, to be in greater touch, greater depth with yourself, and then with others.

***A Pause “immediately sends signals to your brain that everything is okay and rather than moving into the part of the nervous system responsible for our flight or fight reactivity, we activate the part of our nervous system coined “rest and digest” or the place in us that is more grounded, centered, and relaxed. “Restoration happens in the moment of the pause.” (5)***

In fact, I have found it becomes one of the best ways to **cradle** or be with my own or another’s grief, pain, suffering, frustrations without being overwhelmed, without trying to fix or say the right/best thing, without judging. This *genuine* way of sitting with that unknown, scary, or risky arena of grief, pain, and suffering creates space for an abundance of freedom, energy, acceptance, resilience. It has empowered me to be(come) more fully present with a patient or family without the burden of what to do or say. Pausing offers the gift to **be** more authentically at home with ourselves and with others.

***“Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.” (6)***

As we become more aware of and at home with ourselves or **grounded**, we lay a unique foundation to more authentically communicate with others, supplying strength, courage, and often times space to address the challenges, the suffering, the uncertainties, the transitions, the loss. When we can sit with, *even rest with*, the uncertainties and frustrations, creative options arise that will elevate qualities of resilience. And when we embody these qualities, whether in our professional or personal lives, there is a ripple effect.

***“We don’t think ourselves into new ways of living. We live ourselves into new ways of thinking.” (7)***

The *Pause*...such a profound self-care tool! Costing nothing but a brief moment in your day. Carried with you wherever you are, adaptable no matter what you are doing, practiced before getting out of bed, as you are making or drinking your coffee, while driving, before or after answering the phone, or going into a Hospice visit, the Doctor’s or better yet the Dentist’s office, during Zoom or Teams meetings, while preparing supper, gardening, walking, while lounging on the back porch, washing the dishes, or as you prepare yourself to rest at bedtime. This practice can become one of the most versatile and valuable tools we possess to move forward in health of body, mind, and soul!

## **Resources**

1. Coleman, L. Meditation Expert and Founder. Be. Modern Meditation. March 11, 2020 [www.thriveglobal.com](http://www.thriveglobal.com).
2. Nhat Hanh, T. 5 practices for Nurturing Happiness. August 25, 2020 Lions Roar. [www.lionsroar.com](http://www.lionsroar.com).
3. Wiederkehr, M. *Seven Sacred Pauses: Living Mindfully Through the Hours of the Day*, 2008, Sorin Books, p. 22.
4. The Power of the Pause. August 5, 2019. [www.goyogausa.com](http://www.goyogausa.com).
5. David, S. Emotional Agility. Online Seminar, Schwartz Center Rounds, May 20, 2020. [www.theschwartzcenter.org](http://www.theschwartzcenter.org).
6. Frankl, V. *Man’s Search for Meaning*, 1946.
7. Rohr, R. Center for Action and Contemplation. Journey to the Center. [www.cac.org](http://www.cac.org)

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## CARING FOR US IS CARING FOR OTHERS: RESILIENCE, EMOTIONAL INTELLIGENCE, AND SELF-CARE FOR CAREGIVERS

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### **Introduction**

How do we not only survive, but actually thrive through challenging times? A century ago, researchers began seeking the answer to this question as they observed kids encountering similar circumstances but with different outcomes—some would excel afterward while others faced lifelong struggles.

What they found was a cluster of skills that can be taught, practiced, and developed to support our resilience, our ability to bounce back after hardships. Continued research has found we can not only recover to previous levels of functioning, but also flourish through and beyond them, developing greater emotional intelligence and achieving something now known as post-traumatic growth.

Nothing can completely alleviate the stress of caring for a child, adolescent, or young adult facing serious illness. Practicing these skills—which do not require extra time, energy, or money—can improve our quality of life, protect our health, and enhance our ability to provide quality care for the sake of all involved.

### **The Struggle**

For both professional and family caregivers, no matter how gladly we do the work, there are various risks we face:

*Burnout*—experiencing perceived work overload, lack of control, lack of reward, lack of community, lack of fairness, and a values conflict between what we honor and what others around us value (see Maslach et al., 2001).

*Compassion Fatigue*—a state of extreme deficits in our bodies, minds, and emotions resulting from giving more care outward than is coming in to replenish our internal resources (see Figley, 1995).

*Grief*—profound sadness from loss of abilities, resources, hopes and dreams, relationships, etc.

*Ambiguous Grief/Loss*—emotion we can't quite put our finger on stemming from a loss that has no real closure, with a resulting lack of understanding that can leave our grief on-going and unresolved (see the work of Pauline Boss at <https://www.ambiguousloss.com/>).

*Trauma*—“An event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life-threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being” (SAMHSA <https://www.integration.samhsa.gov/clinical-practice/trauma>).

*Vicarious/secondary trauma*—suffering resulting from the impact of witnessing the trauma and/or trauma symptoms of others (see Pearlman & Saakvitne, 1995).

The symptoms we experience from each of these may involve struggles in various aspects of our lives including but not limited to:

- emotional—anger, apathy, sadness, cynicism, low self-esteem, guilt
- mental—depression, confusion, lack of focus, intrusive thoughts, helplessness
- social and relational—displaced anger, isolation, dependence
- behavioral—chronic lateness, decreased effectiveness, workaholism, perfectionism
- spiritual—existential struggles, disillusionment, loss of hope and meaning
- physical—exhaustion, gastrointestinal issues, pain, sleep disturbance, eating disturbance

We are more highly at risk for such struggles when we have experienced previous trauma, have poor boundaries or coping strategies, have high self-expectations, or inadequate support from our social circles and/or workplace. Family caregivers are particularly vulnerable to depression, anxiety, autoimmune diseases, and accelerated aging of immune system (Bennett et al., 2013) with an up to 63% increased mortality rate if they experience caregiving as a strain (Schulz & Beach, 1999).

For family caregivers, research shows that ways of thinking known as psychological appraisals that may protect against these risks include optimism (not false positivity), perceived autonomy, sense of purpose, perceived levels of social inclusion, and resilience (Maguire et al., 2019).

### **Self-Assessment**

Those wanting to assess their current levels of well-being may be helped by completing self-assessments such as the three free tests provided by the Compassion Fatigue Awareness Project (<http://www.compassionfatigue.org/pages/selftest.html>). They may also find benefit from considering questions from the Family Caregiver Screening Tool that evaluates mental health, social support, resources, behavioral management, and coping (Mockus et al., 2000).

These questions include:

Do you feel that you are currently under a lot of stress?  
What aspects of your day are the most stressful?  
Have you been feeling down or blue lately?  
Have you been feeling more anxious and irritable lately?  
Do your family and friends visit often?  
Do they telephone often?  
Do your friends and family watch your relative for you so that you have time for yourself?  
Do you have any outside help?  
Is your relative having any behaviors, such as wandering, that are difficult to manage?  
What do you do to relieve your stress and tension?

Once we have an idea of the areas that may need more attention, we can focus the interventions we put into place to care for ourselves, so we can show up well for those whom we seek to care.

### **Resilience Research**

As described previously, resilience occurs when a person is able to evolve beyond adversity to an increased level of practice wisdom, while experiencing a continual or expanding capacity for compassion (Kapoulitsas & Corcoran, 2015). One particularly helpful article that reviews the history and present understandings from resilience research is “How People Learn to Become Resilient” by Maria Konnikova from *The New Yorker* (February 11, 2016, <http://www.newyorker.com/science/maria-konnikova/the-secret-formula-for-resilience>).

An insightful quote from *The New Yorker* article that summarizes a resilient mindset is by one of the preeminent researchers in resilience, George Bonanno:

Frame adversity as a challenge, and you become more flexible and able to deal with it, move on, learn from it, and grow. Focus on it, frame it as a threat, and a potentially traumatic event becomes an enduring problem; you become more inflexible, and more likely to be negatively affected. (Bonanno, 2016 in *The New Yorker*)

We often believe building our overall health and well-being takes resources of time, energy, money, and effort we do not feel, or may not actually have. However, resilience, emotional intelligence, and post-traumatic growth stem much more from our own thinking and our practices of mindful self-awareness. Even these may seem challenging to build, but there are simple techniques in which we can engage that can make a profound difference in our lives. They also allow us to care for others for the long-term marathon rather than flaming out in a full-on sprint.

### **What Resilience Involves**



We do not yet have one definitive model of what comprises resilience, but research consistently identifies the following:

### *Perceptions & Meaning-Making*

As Bonanno stated in the previous quote, events are only potentially traumatic based upon the stories we tell ourselves about them. Our minds need things to make sense, so much so that in the absence of meaning we will create a story to try to understand our circumstances and therefore feel more in control of them. Unfortunately, the stories we tell ourselves all too often are negative and less than helpful.

These stories are called our explanatory styles, how we make sense of what we are experiencing. We can choose to see things are permanent or that things will change in time. We can see things as pervasive and all-consuming or can we see that our circumstance is only one part of our lives and there are things in our lives that are good, despite how bad things may seem. We can see our circumstance as personal, as if the universe hates and has abandoned us or can we accept that it is not about us, that sometimes life is just life-y and people often act in ways that are not their best selves, despite our best efforts (see Seligman, 2006 for more).

If we are not mindful of them, our stories often induce learned helplessness, the belief that we can do nothing to change our circumstance. This is the opposite of learned optimism, which is different from false positivity that denies the reality we face and calls us to merely putting on a happy face. Instead, learned optimism is about acknowledging and even grieving our reality, while also accepting it. Then, we may focus on the possibilities and opportunities that exist around us.

### *Internalized Locus of Control*

To practice such learned optimism, we can maintain our internalized locus of control rather than externalize it by wanting everyone and everything else to change so we can feel OK. It is about focusing on what we *can* do rather than continuing to rail and fight against what we cannot. It is about acknowledging that, while we may be powerless to change people and circumstances, we are not helpless to take action on our own behalf.

One key to maintaining our internalized locus of control is to get past the seduction of what I call the Blame Game. It feels so much easier and tempting to make everyone else responsible for our feelings, circumstances, and well-being. That is handing over our power to another, which rarely goes well for us.

When we search out what our part is in a situation, getting clear about what there is that we can change, and focusing our energy and efforts there, we will fare far better in the long-run. This does not mean we never name behavior that is not acceptable to us. It means that we ask for what we need and name our boundaries, while also being willing to take action whether the other person responds constructively or not.

## *Connection & Community*

Decades of research into social support tells us that the more, close, positive connections we have, the safer we feel and more protected we are from life's struggles (for an overview, see <https://www.nytimes.com/2017/06/12/well/live/having-friends-is-good-for-you.html>). Healthy support alters our neurochemistry, bolstering our immune system and releasing feel-good chemicals in our brains and bodies that help give us energy and protect us from the impact of stress.

Knowing that others have our backs, that we are not alone, that others care for us and will be there for us allows us to draw on their strength, even when we feel ours is failing. We trust that we will not be completely destroyed or cast down by what we face and feel, because we have the reassurance that others will come alongside us, reminding us of the good in the world, and in ourselves.

## *Adaptability, Flexibility, Coping*

Such connection and sense of safety can allow us to be more adaptive and flexible in our coping, which are key to our resilience. Continuing to rely on defense mechanisms or ways of coping that can be less than helpful gets us nowhere new. Finding new ways to cope, opening ourselves to new ideas that think outside of the boxes we often feel we are in, requires creativity.

Creativity, however, involves risk because it involves doing something different and new. The safer we feel and the most trusting we are that such risks will not leave us totally destroyed or judged by others, the more we will be willing to try new ways of coping with whatever we face.

The safer we feel, the less likely our internal systems will be hijacked and distracted by being in survival mode, and the more possibilities we can see as the rational portions of our brain are more available to us. Survival instincts and reactions are designed to help us in the short-term; they are not a helpful way to live on a continual basis. Finding safety within ourselves, and with our tribe of support, can only serve to help us be more adaptive in our coping.

## *Self-Care*

Most have heard the airline instruction to “put your own oxygen mask on first.” We use it in everyday language to encourage self-care, especially for those seeking to care for others. It is a reminder to tend to our own needs first so we can survive long enough to support others well.

While everyone agrees this is a good idea, most of us do not regularly put it into practice. Professional and family caregivers often report feeling guilty about taking time away from their responsibilities to engage in self-care. Selfishness is when I do something at your expense. Self-care is when I care well for myself so I can show up well for you. That means self-care is not

only a good idea, it is our first and greatest responsibility in order to care well for others for the long-term.

Self-care includes setting boundaries. We can monitor what we allow to enter into our field of influence, protecting ourselves from anything that destroys rather than build us up. Remembering that “No” is a complete sentence may be helpful, as may the practice of allowing others the dignity of coping with their own reactions to what we determine is, and is not, best care for us.

Guilt and manipulation are not loving. Dishonoring boundaries is not caring. Building a tribe of those who encourage and support us in caring for ourselves is a tremendous act of exquisite self-care. Letting go of perfectionism, people-pleasing, and trying to live up to others’ expectations can be one of the greatest gifts we can give to ourselves.

This self-care, again, need not take extra time, money, or energy. It can be as simple as practicing mindfulness awareness, as will be described later in this article.

### *Gratitude & Hope*

We think of gratitude and hope as feelings, but they are not. They are cognitive-behavioral constructs we develop through practice. We practice gratitude by recalling good things in our world. As a result, we come to feel grateful. More will be written about this in the next section.

We build hope by facing challenging circumstances, having people around us who believe in our ability to find our way through. Then, once we have made our way through, we have built hope, confidence if you will, that the next time we face a challenge we will be able to handle it, because we now have the lived experience that we already have before.

### **Emotional Intelligence**

It is also helpful as we consider ways to build our resilience to turn to the literature on emotional intelligence, which includes:

*self-awareness* (the most important of the 4)—intentional insight into our own behavior, emotions, and feelings

*managing disruptive emotions*—the ability to self-soothe and keep perspective without going to extremes that may harm us and others

*empathy*—for ourselves and also for others as we practice perspective-taking—considering another’s experience or point of view

*constructively handling relationships*—artfully navigating conflict, offering and allowing ourselves to receive supportive presence, and reciprocally tending to the needs of both parties

Some may be familiar with the work of Jon Kabat-Zinn on mindfulness, which he calls moment to moment non-judgmental awareness and paying attention on purpose in the present moment. Practicing our ability to be more mindfully self-aware is key to building our emotional intelligence and subsequent resilience.

### **Mindfulness Practices to Build Resilience**

All the research, all the techniques, may sound good but it can feel quite overwhelming to know how to actually implement them. In my writings, training, and coaching, I work to break these things down into simple and practical techniques so they may feel more accessible to us in our daily lives.

As we practice doing things we already do in a more intentional, aware way we learn to be in the moment and to notice what is going on in our minds, bodies, and behavior. In a previous article for this publication called “Ethical Emotional Boundaries for Health Care” ([www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics); Pediatric E-Journal, Issue #59), I wrote of some of these mindfulness practices that can help bolster our care for ourselves, improve our emotional intelligence, and deepen our resilience.

These included:

*Pausing before walking through a door to go care for another to breathe and center.*

*Imagining 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 to offload our stresses and worries rather than allow them to build up throughout the day.*

*As we wash our 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 work day 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.*

In addition to these practices, we may incorporate other techniques, such as:

*mindful eating*—try noticing everything about an orange and the sights, sounds, tastes, smells, feelings as you experience eating it for 5 minutes. This helps to bring you into the present moment and notice with gratitude each part of the experience.

*mindful walking*—slow down on at least one walk a day, even to the point of spending 3 minutes taking 3 steps by noticing the shifting of your weight, lifting of your foot, the feel of the ground underneath you, the slow movement of the foot sliding forward, the shifting of weight forward as you put your foot down, etc. This slowing down, getting back into one's body, grows our ability to notice what is going on within us.

*mindful breathing*—practice taking in air while expanding your belly, filling it up first before then filling up your chest for the count of 4. Hold that breath for 7 counts, then slowly exhale for the count of 8. This can be done at a stoplight, while cooking, in the bathroom, or before sleep to calm the body and mind and bring you back into the present moment.

*mindful noticing*—when feeling panicked, name the 5 colors you see in the room, 5 sounds you hear, 5 textures you feel on and under your body. This can ground us back into the present moment and what is real, pulling us out of the past and future which is where our angst and fears often lie.

*gratitude*—write a short list of things for which you are grateful (one of the key tenets of resilience). When I most need to practice gratitude is when I often feel the least grateful, so I name something for each letter of the alphabet for which I am grateful. This helps us to balance out the negativity that often permeates our thinking and can shift our perspective.

*mindful our stories*—we need to vent and name our frustrations, fears, and struggles, but if we do so exclusively, we merely wear the neural network of negativity more deeply into our brains. When we allow ourselves to vent and then also name the things that we *can* do it helps us to shift our perspective, find new meaning, and re-establish our internalized locus of control. We can ask for what we need, say how we feel, ask for support, set boundaries, and take action on our own behalf, all of which help maintain our power and build learned optimism.

*noticing and befriending our thoughts*—we all have a committee in our head that regularly talks to us. Noticing those thoughts without judgement (remember that mindfulness is

about non-judgmental awareness) allows us to be aware of the stories we are telling ourselves and then to shift them to more resilient perspectives (another key to resilience).

*reclaiming our first love*—psychologist Ken Pargament (Pargament et al., 2014) found that trauma workers can protect themselves from vicarious trauma that could arise from hearing trauma after trauma from others by noticing what he calls “sacred moments.” These are those moments when we know that we know we have made a difference. Ask yourself why you first began caring for another. Then ask yourself why you continue to care. This can build what is known as compassion satisfaction, which is the antithesis of compassion fatigue.

*overcoming toxic shame*—guilt is adaptive because it tells us we have done something, a behavior, that does not align with our values and how we want to be in this world and moves us to make amends and improve our behavior. Shame is toxic because it says not that we have done something wrong or bad but that we, in and of ourselves, are wrong or bad or defective. We can change our behavior; we cannot escape who we are. It leads us to isolation, fear of disconnection, and leaves us feeling worthless. Noticing shame and considering what behavior we may need to change can help prevent our falling into a dangerous and incredibly unhelpful place.

*build self-compassion*—caring for ourselves enough to engage in self-care can seem tricky, and it is not something we will build overnight, but it can be developed. Turn to authors that promote self-compassion such as Mark Nepo, Anne Lamott, Elizabeth Gilbert, Maya Angelou, Brene Brown, Pema Chodron, Rachel Naomi Remen, Melody Beattie, Oriah Mountain Dreamer, or whomever speaks to you can be invaluable for this process.

The work of Kristen Neff on building self-compassion may be particularly helpful (<https://self-compassion.org/>). You may also find comfort and guidance in the words of Brene Brown in her “Wholehearted Parenting Manifesto” (<http://brenebrown.com/downloads-badges/>). Whether or not you are a parent, the world could only be better if we all cared for ourselves and each other in this way.

## **Plan of Care**

We who care for others develop plans of care for others on a regular basis. Rarely, however, do we create them for ourselves. Don Miguel Ruiz of *The Four Agreements* writes, “You can have many great ideas in your head, but what makes the difference is the action. Without action upon an idea, there will be no manifestation, no results, and no reward” (Ruiz, 1997).

What is your plan? What in this article has spoken to you and feels like something you can see yourself implementing? Write these things down. Share them with others. Ask them to join you. Start with one or two things you will do for 7 days. Then check in and see how well they are working for you, how they may need to be adjusted to serve you better, adapt as needed, and then celebrate the successes you have gained.

You, and the ones for whom you seek to care, are most definitely worth it.

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## THE LIMITS AND POWER OF RESILIENCE

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2020 has challenged our pediatric palliative care community in unimaginable ways. The COVID-19 global pandemic has pushed us to work from home, balance child-care and professional responsibilities, weather financial hardship, and navigate fears of being infected and infecting others. It has demanded that we change our standards of care delivery. We share difficult news through facemasks and video-screens, unable to hold a person's hand. We watch children die with too few loved ones beside them. We debate which services and personnel are "essential." We postpone funerals. The Black Lives Matter movement (although not new in 2020) reminds us that systemic racism translates to perpetual health disparities and societal inequities. We have marched, felt the urgent need for change, and continued to watch with anguish when progress is too slow. The tension and animosity associated with the U.S. Presidential Election is palpable and profoundly polarizing. We are in a serious economic recession with no clear end in sight. We are beset with natural disasters—hurricanes, wildfires, and derechos, so far—and it is only August.

The work of pediatric palliative care was hard before. Now, for some, it seems impossible. Never before has there been a greater need for resilience.

Before I talk about the power of resilience, allow me first to talk about its limits. Resilience is not a panacea. In fact, a recent commentary in *The New York Times* suggested "resilience is overrated."<sup>1</sup> After the author correctly stated that resilience can be learned, she questioned its sufficiency. "People are exhausted," she wrote. Two days before that, another author wrote in *Forbes* that "all the mindfulness and yoga in the world will not fix our heightened distress."<sup>2</sup> Both suggested it was unfair to place the burden of being resilient on individuals and instead called for changes to the system.

Neither author is wrong. Eighty percent of the factors of burnout come from workplace and professional systems rather than individual characteristics or personal practices.<sup>3</sup> If we want to "fix" burnout, distress, and all the rest of our stressors, our organizations must help. Neither author (in my opinion) is completely right, either. While resilience and self-care are not sufficient to fix any of these problems, both are *necessary* to navigate them.

I have been studying resilience for over a decade. When I started, the predominant resilience theories were hotly debated; clinicians and investigators wondered if resilience was an immutable trait, a flexible process, or a dichotomous outcome.<sup>4</sup> Over time, the field coalesced



to its now more commonly accepted conceptualization: resilience is the process of harnessing resources to sustain well-being in the face of adversity.<sup>4</sup>

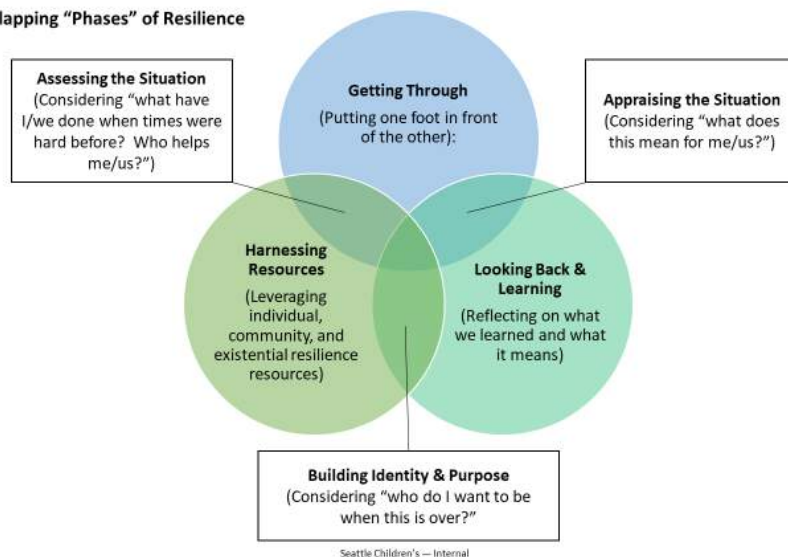
Those “resilience resources” tend to be the same in adversities as variable as natural disaster, poverty, or pandemics. They include three categories: individual resources (personal characteristics and skills), community resources (social support networks and communities), and existential resources (the quest for meaning and purpose). Which resources work best for whom and in which circumstances is also variable, although once people identify their preferences, they tend to return to the same resources over and over again.

2020 taught me to consider the *evolution* of resilience more than I had before.<sup>5</sup> For example, to suggest that people who feel exhausted are not resilient seems wrong. People who are exhausted are the very epitome of resilience: they keep going. Indeed, I have come to consider “getting through” (that time where we get out of bed and put one foot in front of the other), to be the first, critical phase of resilience. Feeling exhausted is part of that phase, and it is normal. So are experiences like stress, worry about if and how it will ever get better, and the unmanageable sense of uncertainty and change.

The second phase of resilience is when we begin to do the sometimes new and always deliberate work of “harnessing resources.” Here, we acknowledge the hard, recognize what is in our control (and what is not), and lean into change. More, it is when we bolster and hone our resources.

The last phase of resilience is when we “look back and learn.” It is when we reflect, crystallize what we did and recognize who we have become.

Figure: Overlapping “Phases” of Resilience



I should say here that the word “phase” is a bit misleading. Resilience is not linear; it is more like a Ven diagram (**Figure**). We constantly flow between the three phases like water. While we

are exhausted and “getting through,” we may also start “harnessing resources” by considering what we have done in tough times before. We may also begin to consider how this adversity will change us. While we are deliberately “harnessing resources,” we may start to identify new purpose by “looking back and learning.”

The power of resilience is in its perpetual motion. Moving through and around these phases buffers us from the next adversity, whether we know it or not. It is a skill that can be refined and strengthened. Think of it this way: telling loving parents that their child will die is always hard, no matter how much training we have. However, telling parents their child will die *does* become more *familiar* with experience. We start to anticipate grief—both the parents’ and our own. We start to know which words will work better than others. We start to know what needs to come next—be it professional responsibilities or personal reflection. Resilience is similar. As we strengthen our metaphorical resilience muscle, we come to better understand ourselves, our limitations, our flow through the phases, and our opportunities for growth.

What does this mean for us now, in the middle of 2020? I often start by asking people (and myself) three sets of questions for the three categories of resilience resources. To explore individual resilience resources, I ask, “What have you (I) done when times were tough before?” A similar question might be, “From where to you (I) draw strength?” To explore community resilience resources, I ask, “Who helps you (me)?” And last, to explore existential resilience resources, I ask, “Who do you (I) want to be when this is over?” And then, I pay close attention to the answers. Which questions bring lots of ideas and which are followed by silence? I champion the resources identified, and I brainstorm how to bolster the ones that seem to be comparatively sparse.

Common responses—either spontaneously noticed or identified via brainstorming—include: (1) Individual resources such as grit, hardiness, optimism, sense of humor, patience, and perseverance, and skills such as stress-management, goal-setting, and self-care (including yoga, mindfulness, meditation, self-compassion, and exercise); (2) Community resources such as connecting with family, peers, loved ones, colleagues, religious communities, and anyone else who will support us. Sometimes this one involves deliberately building new connections and friendships; (3) Existential resources such as skills in cognitive re-appraisal (turning negative self-talk to manageable self-talk), meaning-making, gratitude-finding, and reliance on faith and prayer.

Again, it is important to remember that each person will have their own go-to resources. Any and all of these are okay; the trick is that we find the ones that work for us. After the brainstorm, it is important to name the resources the same way we might name emotion in our palliative care communication practices. Write your resilience resources down. Decide which one to bolster, develop, and try anew. Commit to building resilience just as you would any other skill. Hold yourself accountable.

I will close with one last observation: people have been navigating adversity for millennia. Although some seem to do it with more observable grace and skill than others, most keep

going, despite their exhaustion. We have no choice but to be resilient. Today, two-thirds through a year that has changed the world, I have confidence and hope. Resilience may not be sufficient—as in the only thing—we need to weather this time, but it is necessary. And, we all have it.

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## PROMOTING WELL-BEING FOR PEDIATRIC PALLIATIVE AND HOSPICE CARE PROFESSIONALS

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The healthcare landscape is rapidly evolving, and clinicians are facing both familiar and novel challenges. Pediatric palliative and hospice care providers are accustomed to the hardships that death, dying, pain, grief, and loss can bring. They are also motivated to alleviate these hardships for patients and their families, and they find profound satisfaction in doing so. However, it can sometimes feel as if the external pressures, regulations, and logistical barriers amplify these innate challenges which may ultimately contribute to dissatisfaction, disempowerment, burnout, and a loss of professional fulfillment. The nature of the work in pediatric palliative and hospice care is challenging and weighs on the minds of professionals every day; and so, it should. At its core, these professionals are welcomed into the lives of sick children and their loved ones at some of the most difficult periods in their lives. It is a privilege to be invited in and these professionals take their responsibilities very seriously. Their roles require emotional, physical, and spiritual prowess as the work is extremely challenging in its own right. So, what can be done to support these professionals to sustain and thrive in their care for patients?

As a bioethicist and neonatologist, I first became interested in the concept of clinician burnout years ago when I would round with the various residency programs in my role as Chair of the Hospital Ethics Committee. It was in these informal, round-table discussions that I would learn of the distress that providers were experiencing, commonplace across all disciplines in medicine. They would use the term “burnout” frequently when discussing ethical dilemmas, communication breakdowns, unexpected critical incidents, medical mistakes, and death and dying. With the frequent use of this term, I became motivated to learn more about clinician burnout. Surely there must be some evidence-based literature on this important topic that could explain this variation in key-drivers.

Indeed, burnout has been a well described phenomena in healthcare for decades. Dr. Christina Maslach has conducted much of the foundational work in this area across multiple professions, and for healthcare providers. She describes burnout as a combination of three key components: emotional exhaustion, depersonalization, and a lack of personal accomplishment.<sup>1</sup> The emotional exhaustion (EE) subscale assesses feelings of emotional depletion and work-related exhaustion, whereas the depersonalization (DP) subscale measures an individual’s detachment or the degree to which one treats patients with an impersonal response. The personal

accomplishment (PA) subscale assesses feelings of competence and achievement towards one's work. Maslach proposed that burnout is indicated by high subscale scores for EE and DP, along with a low subscale score for PA.

In my discussions with various healthcare providers on this topic, some common themes emerge. Stress is ubiquitous across all healthcare professions and this is not surprising. However, other pervasive elements include a sense of frustration as well as trouble with communication. It is also clear that a single critical event of significance could have a lasting impact on the well-being of providers, but also that even less noteworthy events compiled over months to years can have lasting and compounding influence. We know that burnout impacts our work, our personal relationships, and can lead to feelings of isolation. Burnout has been shown to be higher in physicians than in the general population. It seems to have a bimodal distribution, peaking early on during training and again in mid-career. It has been linked to various physical stresses including impaired immune function, inflammation, elevation of cardiovascular risk factors, and depression, and has also been shown to have negative effects on patient care and on the overall healthcare system.<sup>2</sup>

For healthcare providers, it is important to note that the drivers of burnout are multifactorial. Research has shown that both professional and personal stressors contribute to burnout. Examples of professional stressors include: expectations of unrealistic endurance, increased clinical demands, time pressure, excessive work hours, decreased autonomy, increased regulatory issues, threat of malpractice suits, inefficiency and intrusion of the electronic health record, difficult patients, coping with death, unprocessed grief, sleep deprivation, and unsupportive environments. Personal stressors include financial worries, limited free time, feelings of isolation, and uncertainty in a variety of settings including the practice of medicine, the dynamic and often times dysfunctional healthcare system, and even one's own job security. Personal stressors also include a "culture of silence" which can lead to feelings of isolation, as well as a lack of effective personal management skills.<sup>3</sup> Burnout is often accompanied by depression or anxiety, and suicidal ideation as well as completed suicides are not uncommon. It is estimated that 300-400 physicians commit suicide annually in the US and women are at highest risk with a RR of 2.7 in relation to the general female population. This is particularly concerning in pediatrics where women make up the majority of trainees.<sup>2</sup> Burnout is also associated with increased medical errors, increased turnover, and lower patient satisfaction score metrics. Ultimately, it is clear to see that burnout has a profoundly negative impact on providers, their friends/family, patients, their organizations, and the medical community at large.

With such a pervasive problem and nearly 50% of the physician population experiencing burnout,<sup>4</sup> it is imperative that we develop solutions and strategies that are appropriately scaled for this epidemic. But is eliminating burnout enough? Is this the highest-order goal we can hope for as medical professionals? Do we aspire to a state of simply avoiding burnout? It is for these reasons that leaders in the field such as Stanford Medicine and Mayo Clinic have developed a model aimed to achieve *professional fulfillment*. Dr. Tait Shanafelt, the Chief Wellness Officer for Stanford Medicine, states that "well-being goes beyond the absence of distress and includes

being challenged, thriving, and achieving success in various aspects of personal and professional life.” More representative of this state of well-being would be to achieve professional fulfillment which has been defined as “happiness or meaningfulness, self-worth, self-efficacy, and satisfaction at work.” The Stanford WellMD model for professional fulfillment outlines three key domains: 1. **Culture of Wellness**, defined as organizational values, behaviors, and leadership that prioritize personal and professional growth, community, and compassion for self and others; 2. **Efficiency of Practice**, defined as workplace systems, processes, and practices that promote safety, quality, effectiveness, positive patient and colleague interactions, and work-life balance; and 3. **Personal Resilience**, defined as individual skills, behaviors, and attitudes that contribute to physical, emotional, and professional well-being.<sup>5</sup> In this model of reciprocity, the organization takes primary responsibility in supporting and establishing the culture of wellness and efficiency of practice, whereas individual providers take responsibility for developing and fostering their personal resilience.

Pediatric palliative and hospice care providers face many of the personal and professional stressors that drive burnout. They also have the opportunity to build relationships, alleviate suffering, and work in unique environments that can have provide significant benefit to the patient and family, which can promote professional satisfaction and fulfillment. This work is essential to the community and invaluable to the individual patient and his or her family. To best support these providers, we must balance our efforts and initiatives across all three domains. Some examples include:

1. **Culture of Wellness:** e.g., Leadership support, commitment, and accountability for wellness efforts, regular measurement of well-being and professional fulfillment, recognition and appreciation for the efforts and work performed, fairness and inclusiveness, values alignment and transparency of the organization, occupational and peer-support, etc. In essence, promoting the culture of wellness is to remove barriers that stand in the way of achieving well-being, thus allowing providers to reconnect to the meaning of their work.
2. **Efficiency of Practice:** e.g., Identification and redesign of inefficient work, teamwork models of practice, design of workspace to promote interpersonal proximity and improved communication, designing roles to allow all team members to practice at the top of licensure, realistic staffing and scheduling, etc. The palliative care provider offers a unique value to the patient and family that should be both honored and supported. Efficiency of practice is a strategy to maximize that value delivered, thereby allowing the provider to do what she or he does best.
3. **Personal Resilience:** e.g., Self-care assessments and support systems, safety nets for crisis interventions, encouragement of peer support, systems to support healthy nutrition, exercise and sleep hygiene, life-needs support mechanisms such as child and elder-care programs, mindfulness practices, gratitude practices, etc. Personal resilience is the area most often associated with well-being. For decades, promoting well-being was aimed solely at the individual level which created a culture of blame and

resentment instead of support and healing. Promoting personal resilience is critical to this mission and the model of reciprocity, but to be effective must be met with even greater effort by healthcare organizations, leadership, and legislative bodies to create impact. Self-care is critically important and is increasingly addressed in the medical literature as an effective strategy. In 2019, The Oath to Self-Care and Well-Being was established, emphasizing the shared duty of well-being between the clinician and the system, with greater responsibility resting in the hands of the system.<sup>6</sup>

In conclusion, the work of pediatric palliative and hospice care clinicians is both daunting and rewarding for these dedicated professionals. Thus, it is imperative that our healthcare landscape evolve to support them in their critical mission. Understanding the multitude of key drivers and the costs of untreated burnout presents opportunities abound. It is time to place caring-for-the-caregiver in the capable hands of both the individual and the healthcare system.

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## THE MEDICINE WHEEL AS A CONCEPTUAL MODEL FOR COLLABORATIVE PATIENT CARE AND PRACTITIONER SELF-CARE

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Working with patients in hospice and palliative care is absorbing and demanding, with complex dynamics and often unresolvable issues. No matter how well we care for ourselves, we all face circumstances that leave us feeling overburdened, alone, and depleted. No matter how committed we are to our patients' care, our time and resources are limited, treatments fail, patients and families struggle, and grief is a near constant companion.

An antidote to the burnout and compassion fatigue that is alarmingly prevalent (Harrison et al., 2017) in our current system is to recognize the support that is available for both our patients and ourselves, and to access that support in ways that are effective for each of us.

That sounds so simple, doesn't it? Just access resources and put them to use. Yet accessing resources for patients can be a challenge within medical systems that don't have an appreciation for diverse modalities or structures to facilitate communication among practitioners (Maizes et al., 2009). We then can't know the full breadth of what's available or possible for our patients. This can result in team leaders bringing in modalities without a deep understanding of how and when they are useful to a particular patient or patient group, and some modalities being sidelined altogether. Success can be scattershot and unpredictable.

For practitioners, the practices we identify as self-care are often actually coping strategies rather than prevention (Mills et al., 2018). They're rituals that are useful to get us through a challenging moment, that "patch us up and get us back into the game," but don't necessarily nourish or replenish us. Coping strategies are vital! We need them when we are depleted and must continue caring for our patients. But coping strategies are not self-care, as defined by Mills and colleagues as "a proactive, holistic, and personalised (sic) approach to the promotion of health and wellbeing."



When we are depleted and habitually using coping strategies to get us through our shifts, we are less able to think creatively, be therapeutically present, or consult with our colleagues. Our focus narrows and our risk of medical errors increases (West et al., 2006). We're less attuned to our patients and our colleagues, because our energy and focus is required to employ our coping strategy. Our ability to truly see and be with our patients and their families is diminished. We become more alone in our work.

Compartmentalization is not good for patient care and it doesn't make for good self-care, either. The circle, with its nonlinear, nonhierarchical configuration is a helpful conceptual framework to combat compartmentalization. When composed of elements that encompass the breadth of care—a medicine wheel—the circle represents a model of healthcare that embraces wholeness, balance, and change. It explicitly makes all resources knowable, facilitating communication and access.

In this article we present two circles that promote balance and wholeness, one currently being developed at UCSF Benioff Children's Hospital Oakland (BCHO) as a systemic and ethical model of care, and one focused on practitioner self-care.

"By its simple shape, circle includes everyone without distinction, welcomes and invites all to participate, and creates equality among those gathered...If you want to include diverse colleagues and think well together, use the circle." (Baldwin & Linnea, 2010).

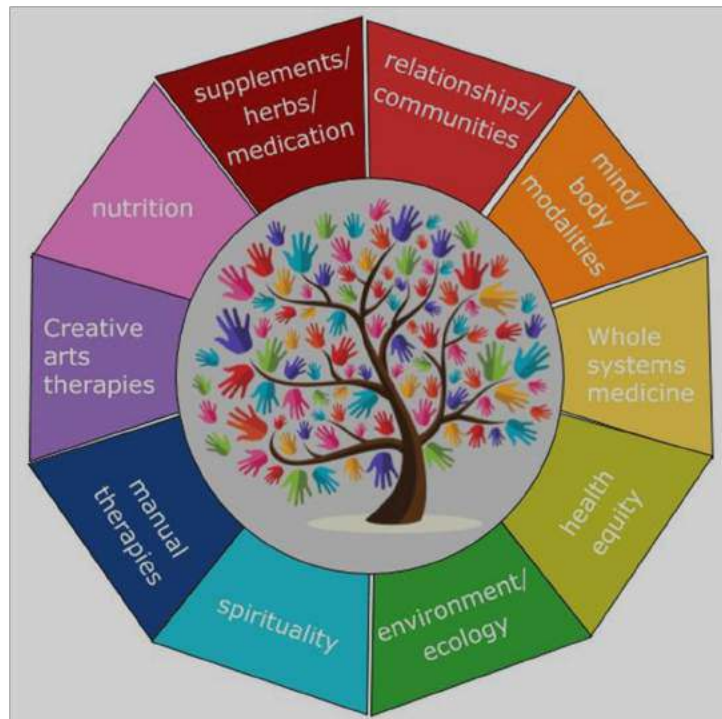


Figure 1. The Benioff Children's Hospital Oakland Integrative Medicine Staff Committee's "Collaborative Medicine Wheel" (a work in progress)

The Integrative Medicine Staff Committee at BCHO is crafting a collaborative medicine wheel (Fig 1., a work in progress) to acknowledge and value the many modalities—prevention and intervention—that contribute to patient wellbeing. This wheel is adapted from the Integrative Medicine Wheel<sup>sm</sup> (William Collinge, PhD), which is itself an adaptation of indigenous concepts of medicine and health.

The collaborative medicine wheel is an invitation to see the breadth and depth of medicine and healthcare within the BCHO system. It serves as a potent reminder that we are never alone when providing care to our patients—that they, and we, have resources to call in as needed. The skilled work of medical providers and lay practitioners, modalities patients employ themselves, the nurturing support of family and community, and environmental and institutional influences all have their places on the wheel.

No one approach or provider is favored. This framework encourages collaboration and participation among all parties; since we all sit together on this circle, we're more able to learn about everyone's strengths and needs. This allows the right resources to be employed at the right time and in the right dose. Given the needs and circumstances of the patient and the availability and skills of the providers, any one or combination of modalities may be most prominent or take the lead, until once again the balance shifts and the wheel turns to what's needed in this current moment.

You'll notice the center of the wheel, the patient, is not represented by a single figure. We recognize that each person is woven uniquely within their family and community. Notice, too, that the center image's hands reach in all directions. We view the patient and their family as not only *in* the circle but *on* it: they are full and equal participants in their care.

The wheel also acknowledges that while our patients receive care and help from us, we too receive from them. We develop and refine our professional skills as we care for them. Their experiences and responses to treatment contribute to thought and research, and influence future practice. While we maintain healthy professional boundaries and are steadfast in our mission to serve, it's undeniable that we form relationships with our patients and are affected by their strengths and their struggles. We grow in consultation and conversation with them, by sharing our humanity.

"The biggest hindrance to self-care is organisational (sic) culture," states a participant in the research of Mills and colleagues. As an antidote, the BCHO collaborative medicine wheel promotes a culture that encourages self-care in its very structure. It explicitly values the relationships inherent to our work and recognizes that the wellbeing of each of us is tied to the wellbeing of all of us. Rather than the organizational structure holding just the patient, the BCHO wheel holds the whole, including practitioners.

When practitioners are nourished and resourced, we can bring our full selves to our patient encounters. We're more likely to give excellent and attuned care, avoid errors, and feel less depleted at the end of our shifts. However, just as hierarchical structures are the norm in

medicine, resulting in some modalities and providers being overused or underused, we practitioners tend to operate from just a fraction of our full selves (generally our hearts and heads).

Relying on fragments of ourselves—no matter how talented or skilled those parts of us may be—is a recipe for depletion. Our responsibility to ourselves and those we care for is to attend to ourselves. We need to know ourselves deeply so we can understand our unique needs, both in the moment and over time, and cultivate support systems that meet them. When we consider the whole of ourselves and integrate the wisdom in our brains and the compassion in our hearts with the unique informing available from all the tissues of our bodies, we have a collaborative approach to self-care.

The Healing From the Core™ (HFC) method is the practice we use for “effective self-care” (Miller et al., 2018) as practitioners in private practice and in Staci’s work with patients in the NICU, PICU, oncology, and palliative care. This method is an invitation to move beyond the paradigm of “tips and tricks” coping strategies into a regenerative self-awareness and therapeutic presence that extends, without depletion, to ourselves and others.

When we don’t leave any part of ourselves behind, we develop what the HFC method calls Full Body Presence. This is defined as “the ability to feel all parts of your body with a good flow of healthy energy moving through you. It also includes a connection to your inner and outer resources for health and a good sense of personal boundaries” (Scurlock-Durana, 2010). It builds capacity and resilience, both in the moment and over time. Building our capacity and resilience allows us to show up for ourselves, our patients, and our colleagues with a presence that is clear, unbiased, and supportive.

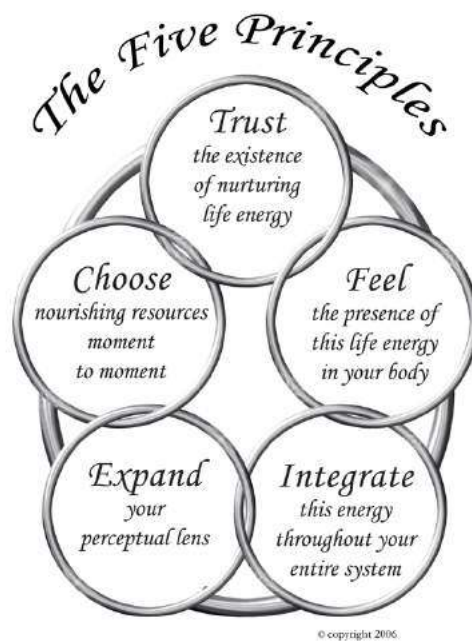


Figure 2. The Healing From the Core's Five Principles of Full Body Presence (Scurlock-Durana, 2010)

Like the BCHO model of collaborative medicine, the HFC model is represented by a wheel. Each component is equally important. They're interconnected and interdependent; each one influences and is affected by the others. The wheel structure allows for movement: at any given time, one component may be more relevant than the others, calling for our focus until the wheel turns again. In other words, we need all of the principles and they all work together.

We work with the HFC principles to develop our capacity and resilience by engaging with a practice, the “ground and fill,” that we experience as both relaxing and rejuvenating. The practice can be done as a deep exploration and, after gaining some familiarity, can also be done in short moments (as few as five breaths). This allows us to bring in nourishing sensation that buoys and sustains us throughout the day and guides us toward choosing healthy resources moment to moment. We have included a link to both written and audio versions of the [ground and fill practice](#).

By working with these principles to develop our Full Body Presence, we are able to understand and make use of the valuable cues our bodies give us. This allows us to provide excellent, attuned patient care while remaining resourced ourselves. At the end of the day we may be physically tired, because our work is challenging and does require effort, but we can feel energetically full and connected, ready to be in relationship with ourselves and our loved ones, relishing activities we enjoy, and able to rest deeply.

We believe collaboration is the key to all good care: care of our patients, care of family and community, care of our teams, and care of self. The structure of the wheel reminds us of the resources and support available to us and to our patients. Availing ourselves of different forms of support—those we tailor to our unique needs as we develop Full Body Presence and the professional support available within our organizations—allows us to fill ourselves up from within and grow both personally and professionally.

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## DEVELOPING STAFF DEBRIEFING GUIDELINES

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Adverse events such as the death of a child and severe, unexpected complications are common in children with medical complexity, especially those who are receiving pediatric palliative care. Staff members caring for the child and family are frequently significantly affected. Anticipatory guidance and support through health care team debriefing may decrease the impact of these events.

Consider this possible scenario:

Ava was born prematurely at 24 weeks. Three months later, she has had surgery to close a patent ductus arteriosus and remains in the neonatal ICU on the ventilator for severe chronic lung disease. She has required resuscitation three times in the past two weeks. The medical team feels that she has a very low chance of survival. Parents visit infrequently and do not seem to accept that she is dying regardless of optimal treatment. Many of the nurses are stressed as they feel that the treatment is prolonging Ava's suffering. At a family conference, many of the nurses are able to attend. The parents do not agree to stopping what the team feels is non-beneficial ventilation. They do agree to a 1-week trial of treatment. Three days later, Ava has a cardiac arrest. Parents cannot be reached for several hours. Ava does not respond to resuscitation. One of the nurses holds Ava as she dies.

**Why** should we facilitate staff debriefing? Exposure to adverse events including death, emotional families, staff conflicts, and decisional challenges is very stressful. Unaddressed staff grief, emotional distress, anxiety, depression, compassion fatigue, and moral distress may lead to suboptimal team dynamics, feelings of isolation, burnout, and loss of staff. While the mechanics of resuscitation and other procedures are more frequently reviewed, need for staff emotional support is less frequently addressed via team debriefings following a death or adverse event. The goals of staff debriefing include providing emotional support and promoting resilience.

**When** should there be a staff debriefing? For consistency, it is helpful to have standard triggers for a staff debriefing. A nurse manager or primary health care coordinator would be in an ideal position to ensure that a debriefing is scheduled when there is one of the qualifying triggers. In addition, any of the staff participating in the care should feel free to recommend a debriefing. Depending on the setting, these triggers may include:

- Death of the child/adolescent patient

- Resuscitation
- Significant unexpected adverse or untoward event
- Significant “near miss” event
- Conflict of opinions, disputes with co-workers
- Staff expressions of stress, conflict, grief, moral distress
- Anticipation of any of the above

**Who** should participate? All staff and trainees participating in the care of the child/adolescent should be invited to participate.

**Who** should facilitate the debriefing? It is optimal to have a facilitator trained in post death facilitation. A chaplain, social worker, or palliative care professional frequently has the training for this type of facilitation. This person should encourage participation by all attending, direct or coach the discussion when necessary, de-escalate conflict or severe emotions, and manage the tone of the debriefing.

**What** should be the format and topics? While in some settings, there is a standard format, in most cases the facilitator elicits thoughts and concerns of the participants and facilitates support of the health care providers. The focus will generally be on experiences and emotional reaction rather than on treatment details. Consider these topics:

- Were the goals of care of the child/adolescent clearly identified? Was the treatment consistent with the goals?
- Were there differences of opinion about the goals of treatment or best treatments? Were your opinions sought and listened to?
- What could have been done better?
- What could have avoided?
- Were resources adequate? What resources would have helped the patient, family, and/or the team?
- Were team members coordinated and cooperative?
- Was communication optimal? What would have helped?
- What were stressors? What could have decreased stress?
- Was leadership of the care optimal? What could have improved leadership?
- Did you feel adequately supported by your team members? Did you feel adequately supported by the organization?
- At the end of the session, ask “Was this a safe forum to discuss your feelings?” “Did you feel supported?” “What other resources might be beneficial after a death or significant adverse event?” “How would you deal with a similar event in the future?”

**When** should the debriefing occur? This likely depends on the situation. Ideally, it should happen within 48 hours of a death or other significant event.

**What** should be the expectations of the attendees?

- To be heard

- To have one's emotions be validated
- To be supported
- To be cared for
- To have stress ameliorated
- To improve teamwork

**What** are some potential interventions and/or recommendations in response to grief, stress, moral distress, and compassion fatigue? Depending on the specific stressor, consider the following:

- Exercise
- Reflective writing
- Spiritual practice
- Yoga, mindfulness practice
- Outdoor activities
- Support via sharing experience with co-workers
- Time off from work
- Art or music therapy
- Bereavement support
- Meeting with a counselor or therapist
- Writing condolence letters to the family
- Honoring the memory of the child by attending the funeral or memorial

**What** are some of the barriers to debriefing?

- Time constraints
- Timing—when is the optimal time?
- Scheduling—different staff are available at different times
- Location—is there an available place and setting optimal for this activity?
- Discomfort—not everyone is comfortable sharing their concerns or experiences
- Participant buy-in
- Leadership buy-in
- Organization buy-in

**What** should be the follow up? This is likely very case specific. Issues may arise that need to be dealt with such as inadequate solicitation and inclusion of staff opinions, poor communication, or suboptimal teamwork. If so, consider organizing a small interdisciplinary group to address these issues and work on a plan to resolve them.

Debriefing is a form of staff support has been referred to as “emotional first aid” (Graham 2019). While it is difficult to prove efficacy in terms of measurable improvements in stress and anxiety, staff retention, team dynamics, and morale, participants in this type of team support found debriefing helpful, describe feeling cared for, and recommend continued team debriefing following death and significant adverse events.



## Resources

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## SELF-CARE RESOURCES

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In an e-Journal issue dedicated to self-care, we would be remiss to not include some additional resources to tap into to help support YOU when you need to care for yourself—body, mind, and spirit. While several of these resources have been compiled by the organizations listed in response to helping frontline workers take care of themselves through this COVID-19 pandemic, they have application for enhanced self-care of you any time.

Please note that each of these organizations listed provide other resources within their sites, resulting in a good cross-section of what you need for yourself, or your staff, in terms of enhanced self-care.

We thank you for how much you give and sacrifice of yourself to care for your patients and their families, and hope that this issue, and these resources, are something you can lean into when you need to take better care of you, through this pandemic, and afterwards.

### **Self-Care Resources by the American Academy of Nursing**

- Academy Fellows who have expertise on the subject of self-care discuss the importance of nurses practicing self-care especially during the coronavirus pandemic. This resource includes three videos by:
  - **Bernadette Melnyk**, PhD, APRN-CNP, FAANP, FNAP, FAAN, Vice President for Health Promotion, University Chief Wellness Officer, Dean and Professor, College of Nursing, Professor of Pediatrics & Psychiatry, College of Medicine, The Ohio State University
  - **Cynda H. Rushton**, PhD, RN, FAAN, Anne and George Bunting Professor of Clinical Ethics, Berman Institute of Bioethics, Professor of Nursing and Pediatrics, Johns Hopkins University School of Nursing
  - **Judy E. Davidson**, DNP, RN, FCCM, FAAN, Nurse Scientist, University of California San Diego Health Sciences

<https://www.aannet.org/yearofthenurse>

### **Self-Care Resources for Healthcare Professionals by the American Psychological Association**

- A list of resources including free pdf downloads of posters on topics like 5 science-based Tips for Managing Your Stress, How to Calm/Focus/Ground/Relax/Celebrate Yourself, self-care videos on the same topics, and more.

<https://pages.apa.org/healthcare-worker-covid-19-resources/>

### **Resources for Healthcare Worker Well-being and Resiliency by CAPC**

- A curated list of articles, presentations, and toolkits representative of leading organizations that focus on well-being and resiliency for healthcare workers impacted by COVID-19. Some of these resources include: How to Deal with Stress in a Health Care Setting, 59 Mental Health Resources for Health Care Providers, Resiliency Tools for Health Care Professionals, Emotional Coping Strategies, and more.

<https://www.capc.org/covid-19/resources-health-care-worker-well-being-and-resiliency/>

### **Self-Care Resources During COVID-19 by Health Leads USA**

- Some resources suggested here are things you and your staff can easily implement including Reflection Logs, a Tool for Creating Your Self Care Plan, Practical Solutions to Properly Supervise and Care for Frontline Staff, a link to Headspace which is offering free online meditation services to U.S. Healthcare Professionals, and more.

<https://healthleadsusa.org/resources/self-care-resources-during-covid-19/>

### **Resources to Help Enhance Self-Care and Stress Management Techniques for Nurses by Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN)**

- AWHONN recognizes the significant psychological, emotional, and physical impacts on nurses who provide patient/family care during and after COVID-19. The resources include screening tools, apps, tips and strategy guides, handouts about specific health topics like Managing Workplace Fatigue, Wellness Tips and Tricks, Mental Health Toolkit, etc.

<https://awhonn.org/novel-coronavirus-covid-19/covid-19-self-care-resources/>

### **NAMI Frontline Wellness Initiative by National Alliance on Mental Illness**

- NAMI has joined the [#FirstRespondersFirst](#) initiative to support frontline health care and public safety professionals facing the adverse mental health effects of the COVID-19 pandemic. This website includes information and resources for frontline workers on the topics of Confidential and Professional Support, Peer Support, Techniques to Build Resilience, Support for Family Members, and Information on How to Identify Signs of a Potential Mental Health Emergency, among others.

<https://www.nami.org/Your-Journey/Frontline-Professionals>

### **Mental Health/Therapeutic Resources for Healthcare Professionals**

- **Headspace**, an app committed to advancing the field of mindfulness meditation through clinically-validated research, is offering all U.S. healthcare professionals who work in public health settings free access to Headspace Plus through 2020. If you are a

healthcare professional, you can redeem your subscription using your National Provider Identifier (NPI) and email address. If you are a nurse and you don't have an NPI, you can provide your organization information to verify your credentials.

<https://www.headspace.com/health-covid-19>

- **TalkSpace** is offering free online therapy for healthcare professionals who register with a work badge and/or NPI after downloading the app ([Google Play](#) or [App Store](#)). Once certified, healthcare professionals gain access to a free month of the Unlimited Messaging Plus plan.

<https://www.talkspace.com/>

- **For the Frontlines Crisis Hotline:** text FRONTLINE to 741741 for immediate chat support and free crisis counseling for health care professionals and essential workers. Offers support to deal with anxiety, fear, isolation, or other difficult emotions you may be experiencing during the COVID-19 pandemic.

<https://www.forthefrontlines.org/>

The following organizations also have lists of resources created during the pandemic but focused on self-care (these are links):

- [AMDA-The Society for Post-Acute and Long-Term Care Medicine](#)
- [American Nurses Association \(ANA\)](#)
- [Center to Advance Palliative Care \(CAPC\) toolkit](#)
- [ELNEC Support for Nurses During COVID-19](#)
- [Hospice & Palliative Nursing Association \(HPNA\)](#)
- [National Academy of Medicine \(NAM\)](#)
- [National Comprehensive Cancer Network \(NCCN\)](#)
- [National Hospice and Palliative Care Organization \(NHPCO\)](#)
- [Nurses Improving Care for Healthsystem Elders \(NICHE\)](#)
- [Oncology Nursing Society \(ONS\)](#)
- [VitalTalk](#)

Note: This list is not exhaustive, nor should inclusion be construed as a direct endorsement by NHPCO of any particular product or service.

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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 Webinars](#) provided by the Pediatric Care Coalition:**
  - **January 19, 2021** – The Use of Telemedicine in Pediatric Palliative Care
  - **February 16, 2021** – Together in the Sandbox: Palliative Care and Complex Care Partnerships in the Medical Neighborhood

### 5. NEW Pediatric Resource on Medication Coverage:

In an effort to standardize the medication coverage process for children receiving concurrent care, the National Hospice and Palliative Care Organization (NHPCO) Pediatric Advisory Council developed a new resource for providers titled [Determination of Hospice Medication Coverage in CHILDREN](#).

### 6. Subjects and Contributors for Future Issues of This E-Journal.

We are currently discussing topics such as lessons learned from COVID-19, telehealth & hospice/palliative care, and racial inequities/social injustice for issues in 2021. 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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