

Nursing & Assisted Living Facility Professional

NOW IN OUR 11TH YEAR!

“NEWS AND VIEWS YOU CAN REALLY USE”

FEBRUARY 2021
ISSUE 2, VOLUME 11

SENT EACH MONTH TO YOU AS A MEMBER OF THE HEALTHCARE HEROES

THE ADELMAN ADVANTAGE by Rebecca Adelman

The Intersection of Long-Term Care and End-of-Life Care



I am grateful to Dr. BJ Miller and Sonya Dolan, co-founders of Mettle Health, for contributing to this article. Read on for their interviews.

No discussion about high-quality long-term care is complete without including the issue of end-of-life care. The COVID-19 pandemic shines a spotlight on the importance of advanced care planning in long-term care; an issue that has historically gone largely unaddressed. As the American Health Care Association/

National Center for Assisted Living (AHCA/NCAL) states in the *Guidance on the Role of Hospice Services in LTC Facilities During COVID-19 Pandemic*, “Long-term care facility residents and staff are experiencing a number of stressors and losses. LTC facility staff are experiencing challenges both personally and professionally. This has increased the need for hospice’s holistic, end-of-life care for patients and families as well as grief and bereavement support for residents, families and staff. It is critical that LTC and hospice staff partner together to ensure simple, clear and supportive communication, minimizing mixed messages.”

At this critical inflection point for long-term care providers, stakeholders must prioritize advanced care planning and hospice care for residents. The plans for “What’s Next” for long-term care and the evolution of healthcare for the elderly population include 1) identifying barriers to optimal supportive end-of-life care; and 2) creating and implementing solutions to overcoming these barriers.

Since 2001, I have been presenting “*Expectations Management and Collaborative End-of-Life Care Planning*” to raise awareness about and the need for quality end-of-life care including comprehensive palliative care. COVID-19 has highlighted the same themes that should be an explicit part of a national plan. Notably, the study entitled *International COVID-19 Palliative*

Care Guidance for Nursing Homes Leaves Key Themes Unaddressed, August 2020, identified, reviewed, and compared national and international COVID-19 guidance for nursing homes concerning palliative care, issued by government bodies and professional associations. The study found that several key aspects of palliative care, practical guidance, and broader structural and coordination considerations are largely absent from COVID-19 guidance documents concerning palliative or end-of-life care in nursing homes. Given rapid development of the pandemic and deficits in palliative and end-of-life care in nursing homes even before this pandemic, the study found the dearth of guidance is perhaps not surprising. However, important efforts are needed to fulfill the call for high-quality palliative care for the highly vulnerable population of nursing home residents.

To that end, I am proud to share that Adelman Law Firm and Mettle Health (www.mettlehealth.com), a healthcare service provider co-founded by Dr. BJ Miller and Sonya Dolan, have formed the *Adelman-Mettle Alliance For Optimal Supportive End-of-Life Care in Long-Term Care Communities*.

You may have heard of Dr. Miller. He is an established thought leader in the area of serious illness, end-of-life issues and death. He has been a physician for 19 years and speaks nationally, and internationally, on themes of terminal illness and dying. If you have not seen his compelling TED Talk, *What Really Matters at the End of Life*, I recommend it. Here is the link. https://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life?language=en

He also co-authored the book, *A Beginner’s Guide to the End: Practical Advice for Living Life and Facing Death*, published in 2019.

Sonya Dolan came to work in the field of hospice and palliative care after the death of her mother. This loss and the experience of being a caregiver greatly influenced her career trajectory and she left the world of event management for hospice administration. Her experience

Continued on page 2

at a non-profit hospice included working with teams of clinicians, patients, family members and outside vendors to provide care and services for hundreds of patients on a daily basis.

The *Adelman-Mettle Alliance* will focus on support and training for owners/operators, management and caregivers, industry education, quality standards, policy reform and other programs and services to raise awareness and improve care within the current system and support providers with the challenges ahead.

I'd like you to meet Dr. Miller and Ms. Dolan and Mettle Health:

Q.: Tell our long-term care communities about Mettle Health and its services.

Sonya: BJ and I believe that palliative care is an incredibly wonderful form of healthcare that everyone should have access to when dealing with serious or chronic illness or end of life. But palliative care is difficult to find, depending on where you live, and most of the time it's hidden behind a referral wall, meaning that only a small percentage of the people who could benefit from it can actually use it in the way it was intended. I should probably stop here and define palliative care: Palliative care is specialized care for people living with a serious or chronic illness or caring for someone who is; its focus is on providing relief from the stress of illness or disabling condition of any sort, with the goal of improving quality of life for both the patient *and* their family and caregivers too. An important thing to note is that one does *not* need to be dying to receive palliative care and benefit from it.

So Mettle Health was created to provide palliative care services to anyone who wants them, anywhere in the U.S., without a doctor's referral. We address many of the issues that traditional healthcare wasn't set up to deal with: the emotional, practical, existential, communication and logistical issues that come up for patients and caregivers when navigating serious illness and the healthcare system. As the healthcare system has become more complicated, so too has the experience of being a patient or caregiver. People need guidance through medical decision making, communicating with their loved ones and doctors, understanding the services available to them or just coming to terms with this change in their lives. Mettle Health is a team of palliative care doctors, social workers, chaplains and nurses who understand that serious illness isn't just confined to a hospital.

Q. What barriers have you identified to optimal supportive end-of-life care in long-term care communities?

BJ: While the people who work in healthcare are there for wonderful reasons, generally to serve others, the system in which they work in was not really set up for *people*—it's set-up for diseases—and that causes a lot of issues and unnecessary suffering. Because death and illness are taboo topics, we tend to shy away from them, leaving

a very large blind spot where information is needed. Because healthcare has become so advanced, we expect that it can work miracles; keeping people alive longer, or curing intimidating diseases. Healthcare inaccurately presumes that people value quantity of life over quality, thereby sidestepping the vital issues of personal choice, values and subjectivity. In long-term care, and along the healthcare spectrum in general, families and patients don't have access to vetted knowledge about medical conditions and their trajectories, or about the realities of various treatment options. They may have unrealistic expectations, and, in healthcare, lack the support to make sound decisions for themselves. Professional care providers need symptom assessment tools, as well as palliative care knowledge, training and mentorship to provide holistic care to people in this period of life. So much of healthcare is about the body that we neglect the emotional and personal aspects of the body we are trying to keep alive.

Q. In what ways has the pandemic highlighted the need for quality supportive advanced care planning?

BJ: Death and the existential issues it provokes have always been there, but I think we're experiencing these issues en masse for the first time in our generation. COVID has exposed glaring blind spots in our healthcare, education and business sectors that have always been present, but now on a national scale we're forced to reckon with these just by reading the news. People who may not have thought about the end of their lives now understand that death is not a faraway concept, but something that lives just outside our door or even inside our home. Reading accounts of people on ventilators, in the ICU, alone, begs us to ask ourselves: "Would I want that?" The stark loneliness that patients in the ICU are experiencing brings up not only the medical aspects of care but the emotional toll that comes with loss. We are being forced to reckon not only with death, but with uncertainty and the grief that follows; all realities that we have given short shrift to in our society.

Q. Tell us about the palliative care model and the support it offers for operators, caregivers and residents?

BJ: One of the ways that palliative care is different is that it takes the entire care ecosystem into account, where the traditional medical system sees the disease, the body part that needs fixing. When there is no more "fixing" to be done, the healthcare system steps back, and this is one of the many places where palliative care can step in and be helpful. Palliative care is a team sport, and the idea is that we can treat someone's emotional, logistical, spiritual and existential suffering as relates to aging, illness or end of life. Caregivers need and deserve the same type of attention that patients do, and including them in the bigger picture of a "care plan" means that everyone can move forward together with an understanding of a path forward.

A palliative approach emphasizes optimal symptom control and the importance of family and friend involvement, as well as support for person-centered

medical decision-making based on the patient's wishes and values; often enough this means saying "no thanks" to that next invasive treatment or trip to the hospital that might prop-up our body at the expense of our soul (or our wallets, our relationships, purpose or dignity). Training and knowledge-base expansion for operators and caregivers supports multidisciplinary team collaboration.

Thank you for introducing us to Mettle Health. Adelman Law Firm is grateful for this alliance and important work in this area.

Please send me any question or comments about advanced care planning long-term care and your experiences. Stay tuned for more from this alliance.

Important Update on PREP Act California Ruling: Recall in last month's Adelman Advantage, we discussed the PREP Act and liability immunities for senior living providers. On Wednesday February 10, the U.S. District Court, Central District of California granted a motion from Sunrise Senior Living and Welltower to dismiss claims from the Plaintiffs of elder abuse and neglect, wrongful death and intentional infliction of emotional distress for failing to keep residents safe, and for not following Centers for Disease Control and Prevention (CDC), state and local public health guidance to prevent the spread of Covid-19 in Sunrise Villa Bradford, an assisted living community in Placentia, California. The court, relying on two Department of Health and Human Services Office of General Counsel opinions (see Adelman Advantage October 2020 and January 2021) and, ruled that Sunrise and Welltower's actions were covered by the PREP Act and, therefore, qualified for complete immunity.

Stay tuned for Episode #4 of Deny Everything coming soon! Stay well.



Rebecca Adelman is an entrepreneur, influencer, thought leader and founder of Adelman Law Firm and Claims Management, a Women's Business Enterprise National Council (WBENC) certified Women Business Enterprise (WBE) established in 2001. For nearly 30 years, Rebecca

has concentrated her practice in insurance defense and business litigation. The firm's practice extends through the Tri-States of Arkansas, Mississippi and Tennessee. Rebecca's insurance defense practice includes representation of insurance companies and long-term care providers and their insurers, both regionally and nationally. She also provides consulting services and educational programming to healthcare professionals and business associates. She has active practices in the areas of general liability, professional liability, premises, and employment law. She is a listed mediator serving all areas of business and healthcare litigation. Contact Rebecca at rebecca@adelmanfirm.com and visit www.adelmanfirm.com.



Mettle Health www.mettlehealth.com

Mettle Health was co-founded by BJ Miller, MD and Sonya Dolan, who have worked together since 2016 promoting discussions in our culture about serious illness and educating the public about palliative care. Between them, they have decades of experience caring for patients and caregivers dealing with aging, serious illness and the end of life.

BJ and Sonya understand the positive effects that candid and loving conversations can have for patients and caregivers alike. They are passionate about palliative care and making it more readily available to the public.

BJ Miller, MD

BJ is an established thought leader in the area of serious illness, end-of-life issues and death. He has been a physician for 19 years and has counseled over 1,000 patients and family members. This vast experience has led him to understand what people really need when dealing with difficult health situations.

BJ has given over 100 talks, both nationally, and internationally, on themes of serious illness and dying, and has given over 100 media interviews, including podcasts, radio and print. His TED Talk, [What Really Matters at the End of Life](#) has been viewed over 12 million times. He also co-authored the book, *A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death*, which was published in 2019.

Sonya Dolan

Sonya came to work in the field of hospice and palliative care after the death of her mother. This loss and the experience of being a caregiver greatly influenced her career trajectory and she left the world of event management for hospice administration. Her experience at a non-profit hospice included working with teams of clinicians, patients, family members and outside vendors to provide care and services for hundreds of patients on a daily basis.

Her work with hospice, coupled with caregiving for her mother and being a breast cancer survivor has given her a keen awareness of what the healthcare system provides and where it is lacking.

Survivor Guilt



We are approaching the one year anniversary of the American invasion of COVID-19. Many would agree this has been one of the most tragic, exhausting, and frightening experiences of our lives. And, it's still going. Over the past year, we've experienced and witnessed heart-wrenching tragedies,

death, and suffering in our facilities, communities, and families. The physical signs, symptoms and repercussions of COVID-19 are well-documented and will continue to be studied. Also needing parity is the mental health effects of COVID-19 - the signs, symptoms and repercussions that affect one's emotional well-being. That includes survivor guilt.

Before we discuss survivor guilt, let's start with plain old guilt. This word is bandied around in our society and has become a 'catch-all' for an array of feelings. By definition, guilt implies responsibility for a wrongdoing, synonyms include blameworthy and at fault. *I feel guilty that I'm not doing more. I feel guilty that I can't spend more time with each resident. I feel*

guilty that she died. Think of the last time you used this word, did you actually do something wrong or is something else going on for which you aren't sure of the feeling?

Survivor guilt was first identified in 1942 in a study of the survivors of the Coconut Grove fire in Boston where 492 people died and hundreds more were injured. Survivors suffered emotional repercussions as they struggled to understand why they lived when others died. (1) Survivor guilt around COVID-19 may sound like this: *I feel guilty that I haven't gotten sick.*



I feel guilty that I got well. Why did I live, and others died? Like survivors of any tragedy, people may struggle for meaning and understanding. (2) Further complicating survivor guilt is that the survivor's family may not understand these feelings, they may even express anger or disbelief that someone could feel guilty for having lived. The survivor may then feel even more isolated, placing them more at risk of depression.

As leaders and staff in nursing homes, what can we do?

Perhaps you feel overwhelmed and worry that once you open this Pandora's box of emotions, you may not be able to handle what is released. That is understandable but remember, just like with trauma-informed care, we do not have to be therapists to be therapeutic. There are things we can do to make a difference.

Create a safe place for staff to talk about feelings. A psychologically safe workplace supports staff emotionally, especially when they are struggling with tender issues like survivor guilt. To normalize the feelings, you could say, "I can hear the pain in your voice (see it on your face). Thank you for talking with me about these difficult feelings." Then, name it.

Survivor Guilt. Often when people have a name for something they're struggling with, it becomes more manageable. The boogeyman has been pulled out from under the bed and we can see it. A-ha, you have a name! Let staff know that if they are experiencing survivor guilt, they are not alone. Validating these feelings as normal and understandable is important.

As stated before, guilt implies wrongdoing. Accurately naming the experience as something other than guilt can be powerful. Approach with curiosity and invitation, e.g., "I'm wondering if you would be

willing to consider reframing the feelings (of guilt) as sadness, anger, or helplessness?" So, instead of *I feel guilty that...*, it becomes *I feel sad that I can't take away the pain. I feel helpless that there is so much suffering around me. I feel angry about what is happening.* Then, allow for compassionate silence as the other person digests this perspective.

Here are a few other ideas to consider implementing in your facility. Commit to becoming a trauma-informed culture that upholds principles of safety, trust, and empowerment. Trauma-informed care is so much more than doing a trauma screening for residents. Normalize talking about feelings, even the distressing ones. Provide a couple brief articles on the topic of survivor guilt, include information on the topic in your facility communications. Create a list of questions/topics and dedicate a reasonable amount of time on meeting agendas for staff to share their feelings and experiences. Find ways to connect with staff who do not attend the meetings. See if staff want to organize peer support groups. Partner with a mental health provider in your community to lead discussion groups with staff (with residents, too!). Implement a process for staff to have access to mental health care. Be alert for staff who might be suffering but who will not readily ask for help. Offer it. Offer the quiet presence to listen and reflect their feelings, to validate, and to normalize them. Post resources (free!) from organizations like The Suicide Hotline (<https://suicidepreventionlifeline.org/media-resources/>) and the Substance Abuse and Mental Health Services Administration (https://store.samhsa.gov/?search_api_fulltext=covid&sort_bef_combine=search_api_relevance_DESC).

And most importantly, remember you do not have to be a therapist to be therapeutic.

Maxwell R, Aldredge-Clanton J. Survivor Guilt in Cancer Patients: A Pastoral Perspective. *The Journal of Pastoral Care*. 1994; 48(1): 25-31.

The Covid-19 Symptoms No One Talks About by Elad Simchayoff, September 20, 2020, <https://elemental.medium.com/the-covid-19-symptoms-no-one-talks-about-ffdfa8895acb>.

Contact Paige at 520-955-3387
or at paige@paigeahead.com
Discover more about her at
www.paigeahead.com

CYBER ATTACK!

How to Protect Your Residents' and Facility's Private Information in These Challenging Times

You hear and read about it with alarming frequency-sensitive, classified data has been stolen and with it peoples' lives are turned upside down! It's happened in government, in banking ... and in healthcare - here it could be resident identity theft, facility financial information stolen, or some other horror!

At this very moment, how safe is your nursing or assisted living facility's stored data? Is residents' personal medical information, social security numbers, financial information, and other critically important data at risk? Do you accept credit card payments for services - how secure are payers' stored credit card numbers in your system?

FYI: your facility will be sued if a resident's identity is stolen, or a family's credit card number falls prey to a hacker because your building's negligence. What about the facility's information on file (i.e. bank account numbers, other classified data); is it vulnerable to today's ultra-sophisticated and savvy hackers?



Extended Care Products, the leader in nursing and assisted living discovery education, presents a power-packed program for the times we live! You may have IT help; however how well versed are they

safeguarding classified data within your system? You may have firewalls, but is this enough?

FOR MORE INFORMATION

CALL TOLL-FREE

1-800-807-4553