



MNHPC ALERT

July 8, 2020
Monthly eNewsletter

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Health Equity and COVID-19

MNHPC is proud to present "Health Equity and COVID-19" a webinar with Dr. Miguel Ruiz on Tuesday, July 14th at 12:00 PM.

Data is increasingly showing that the coronavirus is having a disproportionate effect on people of color, both in rates of infection and numbers of deaths. Disparities in health care and health outcomes among members of different racial and socioeconomic communities are not new, but they are becoming even more striking against the backdrop of the COVID-19 pandemic.

Dr. Miguel Ruiz, medical director for HealthPartners Hospice and Community-Based Palliative Care and member of the palliative care team at Regions Hospital, will present a one hour webinar focused on these disparities and how we in hospice and palliative care can play a role in challenging injustice, disparities, and power imbalances.

Dr. Ruiz was a closing speaker at the 2019 MNHPC Annual Conference and is a member of the MNHPC Board of Directors. He is a leading voice in promoting health equity and cultural humility.

We hope you will join us for this continuing education opportunity on Tuesday, July 14th. The cost is \$20 for MNHPC members and \$30 for non-members. A portion of the proceeds will be used to support scholarships to future MNHPC events. Scholarships will be given to members of communities that are underrepresented in hospice and palliative care.

Special thanks to Corner Home Medical, St. Croix Hospice, and the LaClare Group for making this event possible.

CEU's are available. If you are not able to attend the live webinar, you can still register and we will send you a link to a recording of it. [Click here to learn more and to register.](#)

And for more information about health equity and COVID-19, check out this month's Resource of the Month, an extensive post from CAPC highlighting some data and resources focused on inequalities in health care.

Join us (virtually) to celebrate and support MNHPC!



MNHPC invites you to join us for a virtual celebration and fundraiser on Thursday, July 23rd at 7:00 PM.

This year marks the 40th anniversary of MNHPC's inception. This milestone is an opportunity to celebrate how far hospice and palliative care have come in Minnesota since 1980 and to look ahead at how our organization can continue to play a vital role in ensuring that all Minnesotans can receive the best possible care when they face a serious illness or the end of life.

This year has also presented our organization and its members with a unique set of challenges. The COVID-19 pandemic has required that we adapt how we support health care providers, patients, and families and how we can continue to educate about and advocate for hospice and palliative care in Minnesota.

Now more than ever MNHPC is committed to our mission: We strive to ensure that everyone has the help they need to live and die according to their wishes. But we need your help. Like many organizations, MNHPC is experiencing financial effects as a result of the COVID-19 pandemic and the need to adapt our work.

MNHPC depends on \$90,000 a year in contributions from supporters to help us carry out our mission and support our members that are providing hospice and palliative care to all Minnesotans and others in communities that border Minnesota. Like most small non-profits we cannot hold our usual in person events for our supporters and contributors. Specifically we could not hold a major public event this last April and will not have any in person events for the rest of 2020. So we invite you to join us virtually and make a gift whether you are a new donor or a long time friend and supporter.

We hope you'll join us on July 23rd. After a brief update from Executive Director Jess Hausauer, we'll hear from Lores Vlaminck about how hospice and palliative care have grown and changed over the years and how MNHPC has been at the forefront of that growth. Lores will also share her personal experience as a caregiver being on the receiving side of hospice for her loved ones.



And then Dr. Vic Sandler, MNHPC Physician's Committee chair and frequent presenter at the annual conference, will talk about his journey to becoming a hospice and palliative medicine doctor as well as the current state of hospice and palliative care, especially against the backdrop of the COVID-19 pandemic.



For 40 years MNHPC has been made up of a dedicated community of health care providers, volunteers, and caring individuals who understand the value of providing the best care possible for individuals and families at life's most difficult times. We could not do the work we do without the support of this community, and we are looking forward to celebrating all that this community has accomplished and looking ahead to continuing to do this important work.

Please join us, Thursday, July 23rd at 7:00 PM. You'll be able to access the event through the MNHPC website or on our Facebook page. And invite friends, family, neighbors, and colleagues to join as well.

PEDIATRIC PALLIATIVE CARE COALITION OF MINNESOTA

A Safe Haven During the Pandemic

Crescent Cove Respite & Hospice Home for Kids is a vibrant and joyful home-away-from home for kids with life-threatening conditions, where each moment is embraced and celebrated. It is located in Brooklyn Center, MN and provides 24/7 nursing care and integrative therapies for children 0-21 years of age. The following article outlines the conservative, cautious, and creative approach Crescent Cove has taken during the coronavirus crisis. Thank you to Kathryn Koehne, RN for submitting this for the Alert.



Kathryn Koehne, RN, Director of Nursing & Operations, Crescent Cove

In the last weeks of 2019, a virus made its appearance in a city 7000 miles away from Minnesota. Although the unique and virulent characteristics of this virus were worthy of attention, it seemed worlds away from Brooklyn Center and the comfort of Crescent Cove. However, by early January news swept across the world that this virus was spreading rapidly and leaving many victims in its path.

The virus became more threatening when the first case was diagnosed in the US and by mid-March the virus had infected people across the country. Leaders and staff at Crescent Cove vigilantly observed the data and followed guidance from public health experts and governmental leaders at the state and national level. Careful investigation, deliberation and discernment led the leadership and board of directors to make the decision to keep the doors open and continue to serve our children and families.

As a healthcare facility that cares for medically fragile children, Crescent Cove already has strict infection control standards in place. A decision was made to have only essential staff on the premise. This decision led

to a cascade of other decisions. All in-home volunteers would be on an indefinite hiatus. Some integrative therapies would be on a pause and music therapy would be offered virtually. The leadership staff would telework. The nursing assistants, nurses and house manger would remain as a core staff to ensure that care would continue – safe and secure.

Crescent Cove leaders and staff acknowledge that the world outside of the home was whirling and swirling with uncertainty and fear. The predictability of life changed abruptly as cases of the virus began weaving closer to home. However, we were committed to be a safe haven for our families and if needed, for the community at-large. The staff would carefully screen all who entered the home--themselves, the families, and the children--to keep our setting free of the virus.

Crescent Cove serves families and vulnerable children who face unpredictability every day. A sense of social distancing and isolation is part of their life. And they live not knowing when an unanticipated crisis may occur.

The coronavirus added yet one more challenge. Knowing this, we wanted to extend support and reassurance. Crescent Cove did not affix a sign on the door – “Closed due to Covid-19.” In contrast, we called families and said- “We are here for you.”

And the staff have been here for them, in unique and creative ways, providing care for our kids and their families. Some of the staff shared some reflections on what it has been like to work at Crescent Cove during the pandemic:

Working at Crescent Cove through this pandemic has been nothing short of unique. In some ways it has been an escape from the worries of the outside world. Gina, RN

Work at Crescent Cove has been the highlight of my day because it involves seeing my work "family." During quarantine this has provided the most socialization available and pushed me to soak up each minute with both the kids & my co-workers. This has made us stronger. Allie, RN

A challenge has been wearing masks - I feel like our kids depend on our facial expressions SOOO much, and "smizing" (smiling with your eyes) isn't always enough to convey that we are happy and caring. Leah, RN

Working for me during the pandemic as the care coordinator and continuing to schedule kids means families still have respite and a break in this crazy time. I can still brighten a kid's day; they don't know it's a pandemic, they don't care, they are still wanting to have fun. Jenny, RN

Working at Crescent Cove during this pandemic has been a light in a dark time. I look forward to coming to work to not only bring joy to the children, but also



fill my own cup by experiencing the joy, love and happiness of the kids who come to stay with us! Their paths have been paved with hills and mountains, yet they still only have an unconditional joy in their hearts and I think everyone needs to experience that positivity during this time and every

day! Andrea, RN

I am able to see creative sides of people I hadn't seen before. Watching our team bring in their hidden talents in order to provide the same excellent, holistic care that we promise has been incredible! Whitney, RN

I love that we are being creative and embracing our new reality during the pandemic. I love that we are committed to making the best days ever even in a time of uncertainty and fear. I am so proud of our team, our brave kids, and families! Michaela, CNA

Some of the joys have been the little moments; rocking a child in the chair watching the sun rise and listening to the birds chirping in the moment. I have also loved getting to see and hear of all the creative ways the day staff have been engaging with the kids with dress up themes and camp outs! Michaela V, CNA

It has been amazing to see all of the creative things done to have fun activities for our children. Themed days, music therapy through Facetime, meeting their favorite character through videos... so many great ideas to make moments count and still keep our children safe. Hannah, CNA

I have been especially grateful to be working during this time. Knowing so many people are losing their jobs means that me having hours is something to be extremely appreciative for. And I am grateful that we've still been able to have respite patients come stay. Erika, RN

Thank you to Kathryn Koehne for submitting this article. She can be reached at Kathryn.Koehne@crescentcove.org. And thank you to the incredible staff at Crescent Cove for the work they do every day.



The Pandemic Should Change the Way We Talk About Dying

My patients and their families are facing the sudden decline that can occur in people with COVID-19, and many are not prepared.



Emergency medicine physician Joel Row wrote the following piece for the Atlantic about how one of the lasting effects of the COVID-19 pandemic might be--and hopefully will be--an increased willingness for families and health care providers to talk about end-of-life wishes and to make advance care plans.

Joel Rowe | *The Atlantic*
July 3, 2020

I am a resident emergency physician in New York City, and I've lost count of the number of times I've had to pick up the phone to inform the family of a patient with the coronavirus that their loved one was close to death. Recently, when an elderly woman arrived with what my colleagues and I identified as severe COVID-19, her prognosis was grave. I went to the ambulance bay, away from the cacophony of the emergency department, to call her relatives to tell them that even our most advanced interventions would not help her. The news was understandably difficult to absorb. The family reflexively asked us to "do everything," rather than heeding the gentle recommendation that we focus on preserving her comfort.

We placed a tube in her throat to connect her to a ventilator, inserted catheters in her veins to administer medications that would sustain her heart, and performed chest compressions to temporarily supply blood to her vital organs. Our team tried for 45 minutes

to resuscitate the patient as her lungs and heart gave out.

The number of coronavirus cases in New York City has declined, but COVID-19 is on the rise in many other states. Doctors across the country are in the same situation I was in just a few weeks ago—overwhelmed by a large number of patients whose conditions deteriorate rapidly, and responsible for guiding relatives who must make incredibly important decisions over the phone. I wonder whether people are receiving the type of care they truly wish for in their final moments of life and what can be done to preserve a dying patient's autonomy during this pandemic. Advance directives are one of the most important gifts people can give to their loved ones before they die. But few people actually have them in place.

Discussing our own death with those we love and with health-care providers, let alone confronting it ourselves, is difficult. Yet death is a part of life, and planning for it can help those you love.

My family's confrontations with unexpected death inform the way I think about caring for critically ill patients. When I was 9, complications from a perforated intestine, sudden lung failure, and multiple strokes nearly killed my father. In the face of tremendous odds, he survived to lead a semi-independent life, before dying from a heart attack 15 years later.

That experience shaped how my mother and I approached her own advancing liver disease as I entered adulthood. We took time to discuss what it meant to her to be alive: to laugh with others, share a drink or meal together, and meaningfully interact with the world. She decided that, if her condition was irreparable, she wouldn't want to be kept alive on life support. Days before she was supposed to board a flight to New York City for specialist care, she suffered a massive stroke. A helicopter transported her to a hospital with neurosurgical capabilities as I rushed to be with her.

When I arrived, she was different, not "there"—dependent on the same machine to breathe and medications that my COVID-19 patients are now on. Even so, her heart kept pumping as her breathing was maintained by the ventilator.

I was an emergency medical technician at the time, able to grasp the reality of her dire condition, and yet I still doubted myself. As her only child and legal next of kin, was I to allow her to die when there was even an infinitesimal chance that things could be different? Could she survive like my dad did years before?

I didn't have to make any of these heart-wrenching decisions. My mom had prepared me for the worst day of my life. I was equipped with her advance directive, stating that after a short trial of invasive measures, she did not wish to remain on life support. She was made comfortable with medications. After the machines were disconnected and her heart stopped beating naturally, doctors did not perform chest compressions or any further interventions. For the rest of my life, I'll live in gratitude for her last, invaluable gift—readying us both for her death before it happened.

Six years later, my patients and their families are facing the sudden decline that can occur in people with COVID-19, and many are not prepared. Before the pandemic, my colleagues and I conducted end-of-life conversations or delivered bad news over the phone only in very rare circumstances. I would take a patient's family to a quiet room, sit face-to-face with them, and offer a hand to hold. Now the comfort I can offer the family, in some cases living mere blocks away, is limited, since relatives are rarely allowed in the hospital during coronavirus surges. Such restrictions exist for everyone's safety, but they can make end-of-life decisions that much more difficult. When family members see the physical condition of their loved one, that's often when the gravity of an acute situation truly sinks in. Without witnessing this reality, disbelief is common. "You can't

be talking about my dad," one family member said to me over the phone. "There's no way you have the right person. Please tell me this is a mistake." No one should be making decisions about end-of-life care under such stressful circumstances.

In the absence of an advance directive, physicians always "do everything" to save someone's life; it is our ethical and legal mandate. But in the final days or hours of an illness, when the body is permanently failing, disrupting the dying process without an advance directive in place can feel especially troubling. CPR is not like it is in the movies. Effective chest compressions, for instance, regularly break ribs. Invasive measures are justified when a patient has decided that they want them—and many patients choose that route. But they aren't what everyone might wish for as they lie dying. When I know a patient's wishes, I can work with a family to achieve them, even over the phone. In the end, I want my patients to die with dignity, whatever that means to them.

End-of-life conversations are hard. Yet the coronavirus is with us, and we should use this period of collective grief and suffering to reflect and plan. A patient's wishes, written in the form of an advance directive and made known to those who would make decisions for her in the event she's unable to, can empower those she loves most and offer some certainty during one of the most challenging times in their life.

JOEL ROWE is a resident physician in emergency medicine at Mount Sinai Hospital, Elmhurst Hospital, and Mount Sinai Beth Israel in New York City.



Death Cafes Help Ease Grief, Loss in the Time of Coronavirus

Death Cafes are not new, but they are taking on a new significance--and a new medium--during the COVID-19 pandemic. Death Cafes, their history, and their new role were highlighted in this Associated Press piece published by the New York Times.

The Associated Press
July 1, 2020

Panic attacks, trouble breathing, relapses that have sent her to bed for 14 hours at a time: At 35, Marissa Oliver has been forced to deal with the specter of death on COVID-19's terms, yet conversations about her illness, fear and anxiety haven't been easy.

That's why she headed onto Zoom to attend a Death Cafe, a gathering of strangers willing to explore mortality and its impact on the living, preferably while sipping tea and eating cake.

"In the Death Cafe, no one winces," said Oliver, who was diagnosed with the virus in March. "Now, I'm writing down everything in my life that I want to achieve."

Death Cafes, part of a broader "death-positive" movement to encourage more open discussion about grief, trauma and loss, are held around the world, in nearly 100 countries. While many haven't migrated online in the pandemic, others have.

The global virus toll and the social isolation it has extracted have opened old, unresolved wounds for some. Others attending virtual Death Cafes are coping with fresh losses from COVID-19, cancer and other illness. Still more bring metaphorical death to the circles: The end of friendships, shattered romances or chronic illness, as Oliver has endured.

At one recent virtual Death Cafe, a 33-year-old man spoke of refusing to pack up his wife's belongings six months after her death from cancer. A woman who underwent a heart transplant 31 years ago described her peace with the decision not to have another, as her donated organ deteriorates.

For Jen Carl in Washington, D.C., the pandemic has



intensified memories of her 11 years of sexual abuse as a child, her father's drug and alcohol abuse, and his death about six years ago. She said sharing and listening to the stories of others in Death Cafes have helped.

"I feel just really so at peace and relieved when I'm in circles where folks are talking about real things in life and not trying to move away from the uncomfortable," Carl told a recent group.

"I've been on a couple of Zoom calls with close friends who aren't worried about talking about difficult things most of the time but then when COVID'S come up it's like, 'Oh well, we're partying right now. Let's not talk about that,' and that just triggers me so much."

Inspired by Swiss sociologist and anthropologist Bernard Crettaz, who organized his first "cafe mortel" in 2004, the late British web developer Jon Underwood honed the model and held the first Death Cafe in his London home in 2011. The idea spread quickly and the meetups in restaurants and cafes, homes and parks now span Europe and North America, reaching into Australia, the Caribbean and Japan.

Underwood died suddenly as a result of undiagnosed leukemia in 2017, but his wife and other relatives have carried on. They maintain a website, Deathcafe.com, where hosts post their gatherings.

One important difference between Death Cafes and traditional support and bereavement groups is the range of stories. But the cafes also offer the freedom to approach the room with levity rather than stern seriousness, and extraordinary diversity: a mix of races, genders and ages, from people in the moment with terminal loved ones to those who have lost classmates or relatives to suicide.

Death Cafes aren't intended to "fix" problems and find solutions but to foster sharing as the road to support. They're generally kept to 30 or so, meet monthly and also include the "death curious," people who aren't dealing with loss but choose to take on the topic anyway.

Psychotherapist Nancy Gershman, who specializes in grief and loss, has been hosting Death Cafes in New York since 2013, the year after they made their way to the U.S.

"Death Cafes are a place where strangers meet to talk about things regarding death and dying that they can't bring anywhere else, that they can't bring home or to co-workers or to best friends," she said.

Registered nurse Nicole Heidbreder is a birth and end-of-life doula. She also trains others as doulas and has been hosting Death Cafes in Washington, D.C., for about five years.

"I was working as a full-time hospice nurse and I very quickly recognized how many families I was sitting with whom this was their very first time talking about the end of life. I just felt it was such an absolute shame," Heidbreder said.

"One of the parallels between birth and death is that a little more than 100 years ago in our country, all of us would have been very well versed in what birth and death literally looked like," she said. "We would have seen our family and neighbors do the tasks of tending to people who are giving birth or families who are losing someone. And now we simply aren't exposed to that."

Heidbreder said the coronavirus has changed the conversation yet again. She said she shifted to offering the virtual cafes "on a weekly basis at the time of peak COVID in the country."

She now hosts people not just in the D.C. area, as she did before the pandemic, but across America, from California to North Carolina. More health care workers have shown up, too.

J. Dana Trent is a professor of world religions at Wake Tech Community College in Raleigh, North Carolina. She served as a hospital chaplain in a death ward at age 25 after graduating from divinity school, assisting in 200 deaths in a year.



The ordained Southern Baptist minister used her experiences in the hospital for a 2019 book, "Dessert First: Preparing for Death While Savoring Life," which offers a view of how "positive death" can be achieved.

"COVID has certainly brought death to the forefront. It has brought the death-positive movement to the forefront, but we're still scared," Trent said. "What I'm grateful for is that COVID has awakened society to the possibility of death. None of us is getting out of here alive."

RESOURCE OF THE MONTH



Using Palliative Care to Support Equitable Care in the Midst of COVID-19

Stacie Sinclair and Brittany Chambers, from the Center to Advance Palliative Care, have compiled a deep dive into data and resources related to disparities in health care and health outcomes for members of different racial groups.

The blog post contains information, analysis, and references to provide a starting point for a critical examination into inequities in health care and how palliative care teams could be natural leaders in meeting the needs of those communities disproportionately affected by COVID-19.

[Click here to learn more](#)

WHAT WE'RE LISTENING TO

The Loved and Lost Project is the brainchild of Manchester based freelance documentary photographer Simon Bray. The project is a series of photographs of people who have lost a loved one. Participants in the project are each asked to find a photograph of themselves with their lost loved one, and then Bray and the participant return to the location to replicate that image.

Some of the photographs are somber, and some are joyful. But all tell a story of love and loss. Bray was inspired to begin the project by the death of his father in 2009. About the loss he says, "When my dad died, it wounded me in the deepest part of my being. The loss shaped the following few years of my life and will continue to do so, but I don't have to let it define who I am. Through this time, it was really helpful to be able to talk about my Dad. I wanted to share with others about the person he was, the emotions I was feeling as I processed the grief, and talk about the influence he had - and continues to have - on my life. Those conversations were often hard and few and far between, mainly because people just didn't quite know how to respond."

In addition to the photographs, the Loved & Lost podcast shares the stories of those in the photographs. Series 1 features five stories from the project. Introduced by the project creator, Simon. Each episode features an interview with a participant from the project, allowing them to share their story, memories of the person that they have lost and what it was like to return to the location to re-stage the photograph.



[Click here to visit the Loved & Lost Project website and to learn more.](#)

POETRY CORNER



George Marion McClellan
1860–1934

Born in Belfast, Tennessee, the minister, teacher, writer, and poet George Marion McClellan received a BA and an MA from Fisk University and a bachelor of divinity from Hartford Theological Seminary. He married Mariah Augusta Rabb in 1888 and served as a minister in a Nashville, Tennessee, Congregational church from 1892 to 1894.

After his time as a minister, McClellan pursued a career as a teacher and principal at schools in Louisville and Los Angeles. A difficult period in his personal life followed the death of one of his sons and was further complicated by financial difficulty, marital conflict, and a sense of alienation fostered by a society divided sharply along racial lines.

McClellan's poetry, composed from the 1880s onward, shows a sensitive ear to meter and rhyme and addresses religion, nature, and romantic love while only occasionally revealing an emotional struggle against racial discrimination. He is perhaps best remembered for his blank-verse epic, "The Legend of Tannhauser and Elizabeth."

McClellan published two collections of poetry: *Poems* (1895), which was retitled *Songs of a Southerner* in 1896, and *The Path of Dreams* (1916). A favorable review of his work, comparing his skill to that of Paul Laurence Dunbar, appeared in the *New York Times* after his poetry was included in a 1901 exhibit at the Pan-American Exposition.

from the Poetry Foundation

The Sun Went Down in Beauty

George Marion McClellan

The sun went down in beauty
Beyond the Mississippi side,
As I stood on the banks of the river
And watched its waters glide;
Its swelling currents resembling
The longing restless soul,
Surging, swelling, and pursuing
Its ever receding goal.

The sun went down in beauty,
But the restless tide flowed on,
And the phantom of absent loved ones
Danced on the waves and were gone;
Fleeting phantoms of loved ones,
Their faces jubilant with glee,
In the spray seemed to rise and beckon,
And then rush on to the sea.

The sun went down in beauty,
While I stood musing alone,
Stood watching the rushing river
And heard its restless moan;
Longings, vague, untenable,
So far from speech apart,
Like the endless rush of the river,
Went surging through my heart.

The sun went down in beauty,
Peacefully sank to rest,
Leaving its golden reflection
On the great Mississipi's breast;
Gleaming on the turbulent river,
In the coming gray twilight,
Soothing its restless surging,
And kissing its waters goodnight.

HOSPICE NEWS NETWORK



EXPERTS OFFER ADVICE ON DISCUSSING A COVID-19 DEATH WITH BEREAVED CHILDREN

Communicating with children about the gravity of the coronavirus crisis can be difficult. For adults, the enormity of the pandemic can be hard to grasp. For children it's even harder. Parents may be tempted to shelter their children from the truth of the crisis. However, children are in-tune with changes in adults' emotional states, and we can't entirely hide the health crisis from them. Research shows that being honest with kids about difficult topics such as death and dying is better for them. "How to Talk to Kids About Anything," posted by CNN, features child and teen development specialist, author, and host of the podcast, Robyn Silverman. Silverman shares several guidelines for discussing tough pandemic-related topics with kids.

In speaking with children about death, it's important to assess what topics are age-appropriate for your kids. For example, children between the ages of four and seven are often under the impression that death is temporary. For kids of this age, it's important to calmly clarify with statements such as "once a body stops working it can't be fixed," or "once someone dies, that person can't return." Older kids and teenagers will understand the permanence of death but may question it's meaning, or struggle to process all the information they are hearing about COVID-19-related deaths.

"Ask your children," whatever their age: "What have you heard about the coronavirus and how someone might get it? What do you know about what happens when someone gets sick from it?" After listening to your children, Silverman suggests, do your best to clear up any confusion they have.

When delivering difficult news about a death or a loved one dying, it's important to prepare yourself so you may calmly explain what happened. "Give yourself some time to gather your thoughts and take a couple of deep breaths," she suggests, and consider the best time and place to deliver the news. Be sure to explain a loved one's death honestly, avoiding euphemisms that could cause confusion such as "went to sleep," or "we lost her." Listen to your child's response and give them time to process or ask any questions.

In the grieving process, make space for the ups and downs of your child's grief. Openly share the emotions you're experiencing as well. "Honesty about your own emotions gives children permission to be open about their own confusion, sadness, anger and fear," Silverman says. Joe Primo, CEO of Good Grief, says we shouldn't expect grief to be linear. "Grief is like a roller coaster. It's up, down, all around. For kids and adults alike, every single day is different. And as the grieving person, you have no idea how your day is going to unfold."

Children are likely to have a lot of questions about the loss of a loved one, especially due to COVID-19. "Reiterate that your loved one had Covid-19 and the medical team worked very hard but the disease made it so the body could no longer work," Silverman suggests. They may also have concerns about catching the virus themselves or losing other family members to the disease. Let them know that you are taking every precaution possible as a family and outline what those measures are, reminding them of your care to wash your hands, wear masks, staying away from others, and more.

HNN CONTINUED



Provide ways for your child to honor and remember the loved one lost to COVID-19. Many of our usual traditions of gathering around the death of a loved one have been disrupted by the pandemic. These customs are important to the grieving process, however, and studies have shown that children do better with grief when they've been involved in funerals and celebration of life events. Now it's important to find alternative ways to commemorate a lost loved one. Lead your child in a commemorative art project, tree-planting, poetry reading, letter writing, or Zoom funeral. "Funerals are about mourning," Primo explains, "and mourning is a core component of a child adapting to their new norm, expressing their grief, and getting support from their community." (CNN, 6/30, <https://edition.cnn.com/2020/06/30/health/guide-talk-death-kids-coronavirus-wellness/>)

3 WISHES PROJECT ADAPTS TO THE COVID-19 CRISIS

At UCLA Health, the 3 Wishes Project has supported end-of-life patients and their families since 2017. Now, with COVID-19, the program is being repurposed to best serve current needs. "We've done weddings and mariachi bands and opera singers and 20 to 30 family members who could come in and celebrate," says Dr. Thanh Neville, medical director of 3 Wishes and intensive care physician. "And none of this is possible anymore." COVID-19 has changed everything about their work.

Neville says her hospital system at UCLA has seen more than two-dozen COVID-19 deaths since March. No visitors were allowed at all in the beginning. Now, though some visitation is allowed, Neville says most

don't feel safe coming to the hospital and most of the COVID patients die without their family members present. For a variety of reasons—including their own health, fear of the coronavirus, or need to provide care to others—many people are unable to be at the hospital with a loved one.

The 3 Wishes Project, founded around tenets of palliative care focusing on the humanity of patients amidst intense medical situations, has had to find ways to adapt to the pandemic. The small acts of fulfilling wishes for patients help to balance the environment of the ICU, which can be dehumanizing. This kind of care has been shown to help ease the dying process as well as the grieving process for loved ones. President of the American Academy of Hospice and Palliative Medicine Dr. Rodney Tucker says the care provided helps families and patients alike. In place of riskier wish fulfillments, 3 Wishes has been helping arrange family Zoom calls, playing favorite music of the patient, sitting with them, and producing keepsake items for family members, such as fingerprint keychains and copies of electrocardiograms of the last heart beats.

LA Times shares the story of Elishia Breed, who recently benefited from the services of 3 Wishes when her mother, 69-year-old Patti Breed-Rabitoey died of COVID-19 in Southern California. Breed, who lives in Oregon, was separated from her mother by the virus and long distance. The 3 Wishes Project helped Breed and her family through this tough time.

In the weeks leading up to Breed-Rabitoey's death she was lying in her ICU bed, heavily sedated on a ventilator. Nurses helped Breed speak with her mother by keeping a phone propped up near her ear. "I prayed with her. I sang her favorite songs. I read her the Bible," says Breed. When it was clear Breed-Rabitoey wouldn't recover, 3 Wishes helped her family arrange a virtual send-off.

"At 5 p.m. on May 10, Mother's Day, before Breed-Rabitoey's life support was removed, more than a dozen family members from multiple cities and states gathered on a Zoom call to say goodbye," says LA Times. John Denver's 'Rocky Mountain High,' one of her soft-rock '70s favorites, played on speakers. A chaplain prayed. Critical care nurse Genevieve Arriola was one of the nurses who had been caring for Breed-Rabitoey. She said, "This was a very delicate situation for someone who is married to her for over 20 years and a daughter who was miles away in Oregon and couldn't see her mom," she reflects. As Breed-Rabitoey was dying, her husband, Dan Rabitoey,

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asked that Arriola hold her hand, since he could not be there himself. "I pretty much felt honored to be that person," Arriola says. "I couldn't let her be alone. If no one can be there, I can." (LA Times, 6/29, www.latimes.com/california/story/2020-06-29/ucla-program-adapts-coronavirus-helps-dying-patients-families)

HOSPICE NOTES

* In San Antonio, American Medical Hospice and Palliative Care is suing the federal government over the suspension of Medicare payments during the pandemic. CMS cites an ongoing investigation into American Medical for "credible allegation of fraud" as the reason for the suspension of payments to the hospice provider. On May 20th, HHS issued a 180-day extension of the payment suspension. The for-profit hospice provider has not received Medicare payments since December 2nd. American Medical says in their lawsuit that the suspension of Medicare payments – which account for 90% of their revenue – will force the company to close and file for bankruptcy. Due to the pandemic overburdening the healthcare system, attorney Mark Kennedy, who is representing American Medical Hospice and Palliative Care, argues that it will be difficult for patients to find alternate care in the event of the provider being forced to close. "We contend that a hearing must be provided to our client in accordance with the Fifth Amendment of the United States Constitution," he says. (San Antonio Express-News, 6/30, www.expressnews.com/business/health-care/article/San-Antonio-hospice-provider-sues-feds-for-15378109.php)

* In Virginia, Mountain Hospice announced a new assisted living center, Mountain Living Community, expected to open in mid-November. The facility will have the capacity to serve 24 residents. Rooms will feature private bedrooms, bathrooms, kitchens, and living and dining areas. West Virginia has a large number of disabled individuals, and more than 15% of the population is over the age of 65. For reasons such as these, chief executive officer of Mountain Hospice Don Trimble says that more assisted living is needed across the state. "I think assisted living is probably needed everywhere, not just in this area," he says. "We had this land and we've been lucky enough to be able to do this." (WDTV, 6/30, www.wdtv.com/2020/06/30/mountain-hospice-works-to-bring-assisted-living-next-door/)

* President and CEO of Hospice and Palliative Care of Western Kentucky Belinda Blair was suspended indefinitely from after making "racially charged" remarks on social media, Messenger-Inquirer says. Of the posts

in question, Blair says she posted one of them, but does not recall the others, saying her account was hacked. The head of Blair's local NAACP chapter says the posts raise the question of whether Blair can "really identify with everyone" and if she can be trusted to be "fair and compassionate" in her relationships with others. "Hospice does not condone these posts, and they do not reflect the mission or values of Hospice, its Board of Directors, or its employees," reads a statement released by the board of directors of Hospice and Palliative Care of Western Kentucky. The statement also reads, "Our services are provided without regard to race, color, religion, age, gender, sexual orientation, disability (mental or physical), national origin, diagnosis, ability to pay, or membership in any other protected category." Board chairman Tom Maddox says they hope to complete an investigation into Blair's posts shortly. (Messenger-Inquirer, 7/1, www.messenger-inquirer.com/news/hospice-ceo-suspended-while-board-investigates-racially-charged-posts/article_8911a7b4-82a0-53a9-a8b6-374570d56a22.html)

* A recent study finds that end-of-life patients receiving a higher amount of family caregiving may be more likely to receive hospice care. The prospective cohort study examined self-reported hours of family-given care per week, number of caregivers, and specific illnesses of the patients. "In an adjusted analysis, older adults with cancer receiving 40 hours and more of unpaid care/week as compared with fewer than 6 hours per week

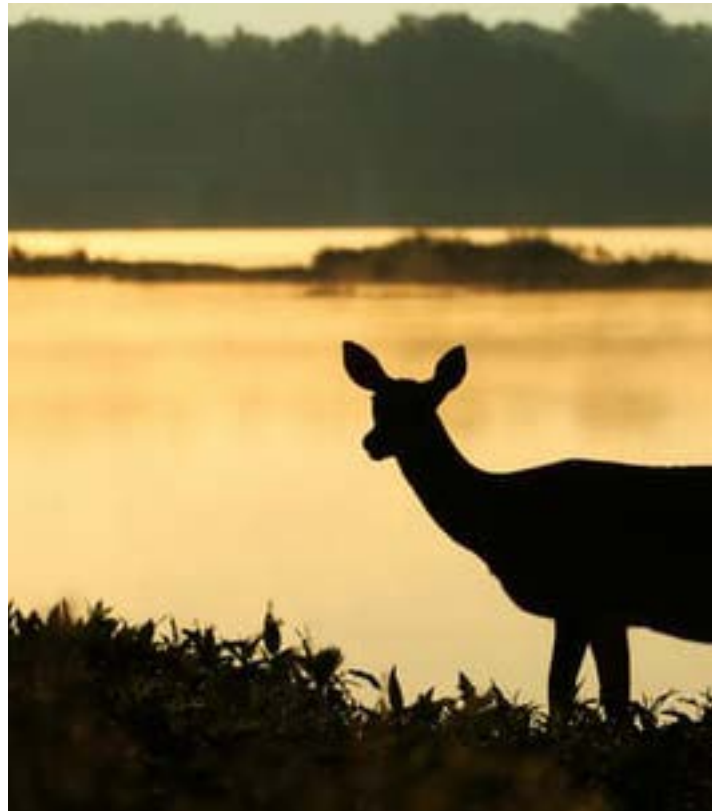


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were twice as likely to receive hospice care at the end of life," researchers say. The amount of family caregiving varies widely across disease. Though dementia patients receive the highest number of hours of care, the association between amount of caregiving and likelihood of receiving hospice care is not observed in these patients. (DocWire News, 6/30, www.docwirenews.com/abstracts/hem-onc-abstracts/family-caregiving-at-the-end-of-life-and-hospice-use-a-national-study-of-medicare-beneficiaries/)

* A recent installment of Good Morning America (GMA) showcases home health nurses at Visiting Nurse Association (VNA) Health Group in New Jersey, and highlights the important services they're providing during the pandemic. Nurses featured on the show demonstrate how they work in teams of two to safely carry out patient visits during the COVID-19 pandemic. One nurse dons full PPE to visit with the patient while the other stays outside communicating by phone. The outside nurse records and monitors information about the patient's condition, then helps the other nurse decontaminate when they're finished visiting. They even have a hand-washing station installed into the back of their work vehicle. VNA nurses also rely on telehealth to reach their patients – especially those patients who are known to have COVID-19. "It doesn't take the place, of course, of hands-on with someone, or holding their hand," says VNA chief nursing officer Ellen Gusick. "But in this pandemic when there are so many patients to get to, it was a gamechanger for all of us." GMA host T.J. Holmes announced to Gulick that to help reach more patients in need of telehealth, Verizon is making a donation to VNA of \$10,000 and 100 smart phones. (Good Morning America, 7/3, <https://www.goodmorningamerica.com/living/video/gma-surprises-nurses-treat-covid-19-patients-homes-71551120>)

* An annual Virginia summer camp for bereaved youth, Journeys Summer Camp, will take place virtually this year. Hospice of Piedmont, who hosts the yearly camp, says the camp allows young people to socialize with their peers who have also lost loved ones. They will "share in some virtual fun" and process loss with the help of grief counselors and art therapists. The camp is open to children ages four to 18 at no cost. Each participant will receive a box with materials for activities. Those activities will include "drumming, equine therapy, art therapy, music therapy and more." The week will conclude with a candlelight ceremony for lost loved ones. (CBS 19 News, 7/1, www.cbs19news.com/story/42318016/hospice-of-the-piedmont-offering-virtual-summer-camp-for-grieving-youth)



* In Georgia, students of Savannah College of Art and Design (SCAD) are using virtual reality (VR) to create helpful experiences for hospice patients. Their project, "VR for Good," has resulted in the creation of three VR experiences which can decrease patients' pain and anxiety. These include a virtual hot air balloon ride, an interactive underwater adventure, and a farm experience which can double as a physical therapy tool. Hospice Savannah, one of the partners in the project, expressed their admiration of the students leading the project. "We are seeing that beautiful community go beyond SCAD and Hospice Savannah — these students are from all over the world, and they are working in sync for the good of others," says Hospice Savannah President and CEO Dr. Kathleen Benton. A replay of WTOC's video broadcast featuring VR for Good can be viewed at the link provided. (WTOC, 7/2, www.wtoc.com/2020/07/02/vr-good-virtual-reality-program-helping-hospice-patients/)

* Many hospices and palliative care providers are having to find new and creative ways to support patients and families during the coronavirus crisis, says an article in Hartford Courant. Seasons Hospice and Palliative Care is expanding education and connection through new virtual bereavement support groups, window visits, birthday parties, and fulfillment of last wishes. "As much as a crisis event, natural disaster, or pandemic presents a need for greater flexibility and creativity,

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it also helps to further reinforce the fundamental purpose of our role and responsibility – to provide compassionate care towards a good end-of-life journey for patients and families alike,” says Seasons VP of Patient Experience Yelena Zatulovsky. To work around concerns of exposure to the virus, many of these offerings are moving online. Facebook Live discussions with bereavement experts and an online hub of resources support patients and families. Free online education, including Continuing Education courses, support healthcare professionals. The National Seasons COVID-19 Task Force has turned the physical distancing requirements of the pandemic into an opportunity to expand their support of families, patients, and care providers by increasing communication, ensuring transparency, and decreasing anxiety. (Hartford Courant, 6/29, www.courant.com/community/killingly/hc-pk-seasons-hospice-2020-07-09-20200629-3zlj5rkxtzeiborxnt4ceijqgm-story.html)

END-OF-LIFE NOTES

* A study published by the Journal of the American Geriatrics Society examines diabetes medication deintensification in patients with dementia. The aim of the study was to assess how often older veterans with dementia and/or limited life expectancy were overtreated for diabetes in VA nursing homes. Findings show potential overtreatment of diabetes in more than 40% of participants. Of those found to be potentially overtreated, deintensification of the treatment happened with less than half. “The only resident factor associated with increased likelihood of deintensification was documented end-of-life status,” researchers say. The full study article is available to read online. (Journal of the American Geriatrics Society, 2/17, <https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.16360>)

* Episode 253 of the End of Life University podcast titled “Natural Birth, Natural Death: Healing our Broken Medical System with Nathan Riley MD” is available now on their website. Riley specializes in obstetrics and hospice and palliative care. Riley discusses how the medical system often fails to honor the sacred nature of both the beginning and end of life and what needs to change. Topics covered include the mystery and taboo of both birth and death, the medicalization of birth and death, implicit bias in medicine, the problem with placing focus on a “good outcome” rather than a patient’s needs, “why doctors fear emotional closeness with patients,” and other topics. (End of Life University, 6/29, <https://eolupodcast.com/2020/06/29/ep-253-natural-birth-natural-death-healing-our-broken-medical-system-with-nathan-riley-md/>)

* The Journal of the American Geriatrics Society published a letter to the editor from Catherine Choi, M.D. in which she reflects on two experiences she had saying goodbye to her COVID-19 patients. Through telling the stories of the end of these two patients’ lives, Choi illustrates the importance of adequate end-of-life planning and discussion. “I witnessed challenges in arranging appropriate end-of-life conversations and preparing the patients and their beloved families for a dignified death,” she says. While one patient’s family was able to receive frequent communication from Choi and the palliative care team, the other family was less prepared for their loved one’s death. The contrast between the two families’ experiences stand out to her as an important example of the effectiveness of communication and preparedness at end-of-life. “Everyone defines a good death differently; for me, it is when both the patient (if lucid) and family are prepared for the death and conclude the last chapter of life peacefully,” she says. “It can be achieved through a process of working together to understand the severity



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of the patient's condition." (Journal of the American Geriatrics Society, 6/5, <https://onlinelibrary.wiley.com/doi/full/10.1111/jgs.16637>)

* COVID-19 should change the way we talk about and prepare for dying, says resident physician in emergency medicine Joel Rowe. He describes how his own experiences with his parents' deaths and advance care planning has taught him how difficult end of life decisions can be – and how helpful it is to plan ahead. When his mother suffered a stroke and was reliant on a ventilator, Rowe knew his mother wouldn't choose further treatment. "For the rest of my life, I'll live in gratitude for her last, invaluable gift—readying us both for her death before it happened," he says. Now, as he treats COVID-19 patients similarly reliant on ventilators, he sees how many families are not prepared for the decisions they have to make. Further complicating these decisions is the distance from which they must be made, as families can't visit their dying loved ones in the hospital. Rowe says he is witnessing a lot of disbelief and distress. "No one should be making decisions about end-of-life care under such stressful circumstances," he says. As our country faces this crisis, "we should use this period of collective grief and suffering to reflect and plan," he says. "A patient's wishes, written in the form of an advance directive and made known to those who would make decisions for her in the event she's unable to, can empower those she loves most and offer some certainty during one of the most challenging times in their life." (The Atlantic, 7/3, www.theatlantic.com/ideas/archive/2020/07/pandemic-should-change-way-we-talk-

[about-dying/613618/](#))

* Nurses have been reporting a lack of end-of-life education for years, says professor and director of the Pre-licensure Undergraduate Nursing Program at the Widener University School of Nursing Stephanie Jeffers, Ph.D. Now they must work amongst the alarming rate of COVID-19 deaths in hospitals across the country, she says in her blog post for Daily Nurse. Jeffers says third and fourth-year nursing students at her university who are working in COVID-19 hospital units report difficulties in managing end-of-life communication with patients. "It is imperative that nurse educators in both academia and healthcare systems provide additional and continuing education and support to nursing students as well as nurses practicing at the bedsides of the dying," she says. "The high stress environment of a COVID-19 unit paired with critically ill patients who may die unexpectedly may cause burnout in nurses." Jeffers shares a few resources for nurses, such as the End of Life Nursing Education Consortium (ELNEC) and virtual support groups. A recording of Jeffers' post is also available on the Daily Nurse webpage. (Daily Nurse, 7/2, <https://dailynurse.com/death-and-dying-in-a-pandemic-preparing-nurses-for-end-of-life-care/>)

* Researchers at University of Alabama at Birmingham (UAB) created and published the first culturally informed protocol for seriously ill and end-of-life patients. Researcher in the Division of Gerontology, Geriatrics and Palliative Care at UAB Ronit Elk, Ph.D. led the development of the protocol over three years, along with a multi-racial Community Advisory Board. The board consisted of bereaved caregivers, hospital staff, and community leaders – with equal numbers of black and white members. "End-of-life care values in the United States are historically rooted in values that represent the cultural and religious values of the white middle class, values that often do not apply, or even contradict, the values of people of different cultures or ethnicities," says Elk. "Lack of respect for cultural differences may compromise care for seriously ill minority patients. Until recently, culturally appropriate models of palliative and end-of-life care have not been available in the United States." The protocol is now being tested in a randomized controlled trial across rural hospitals in Alabama, Mississippi, and South Carolina. Elk will also be mentoring physicians in Ghana, Puerto Rico, and South Africa in how to employ the cultural protocol. The complete protocol publication can be read online at Health Equity. (UAB News, 6/30, www.uab.edu/news/research/item/11409-first-culturally-based-end-of-life-care-protocol-created-by-community-members-

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published; Health Equity, 3/20, www.ncbi.nlm.nih.gov/pmc/articles/PMC7104898/)
PALLIATIVE CARE NOTES

* The first issue of the free access publication Palliative Medicine Reports is available now online. Included are palliative medicine case discussions, personal reflections, original articles, brief reports, and more. The issue features titles such as “Hospice or Hospital: The Costs of Dying of Cancer in the Oncology Care Model”; “The Photographs of Meaning Program for Pediatric Palliative Caregivers and Its Impact on Meaning, Well-Being, and Perceived Social Support”; “How Confident Are We at Assessing and Managing Fatigue in Palliative Care Patients? A Multicenter Survey Exploring the Current Attitudes of Palliative Care Professionals”; “Breaking Bad News: A Study on Formal Training in a High-Risk Obstetrics Setting”; “In Search of Hospice Information: Consumer Information Available on Hospice Compare and Yelp”; “Best Case/Worst Case: ICU (COVID-19)—A Tool to Communicate with Families of Critically Ill Patients with COVID-19”; and many others. All are available as open access at the provided link. (Palliative Medicine Reports, 7/20, www.liebertpub.com/toc/pmr/1/1)

ADVANCE CARE PLANNING NOTES

* NPR shares simple, straightforward steps toward making plans for end-of-life. Guest Betsy Simmons Hannibal, a senior legal editor at NOLO, and medical oncologist and University of Pennsylvania palliative

care physician, Pallavi Kumar, share ideas on the tasks that are important in this process.. A recording of the segment can be played on the NPR website where it is accompanied by a written transcript. (NPR, 6/30, www.npr.org/2020/06/26/884051182/end-of-life-planning-is-a-lifetime-gift-to-your-loved-ones)

* Building on discussions from their recent Policy Forum, the Coalition to Transform Advanced Care (C-TAC) and Harvard Law School will host a virtual panel discussion “Advance Care Planning in the Age of COVID: Lessons Learned and Policy Implications.” The online event will be on July 8. The COVID-19 crisis has exposed the many barriers and gaps that still exist in advance care planning, despite years of education promoting it, C-TAC explains. “Federal and state regulators have implemented ACP waivers to address some of these concerns, but these waivers are temporary,” C-TAC says. Panelists for the webinar include Stephanie Anderson of Respecting Choices, Marilyn J.D. Barnes of Mission and Spiritual Care and AdvocateAuroraHealth, Marian Grant of C-TAC and Johns Hopkins University, Sarah Hooper of the Hastings Consortium, and Shoshana Ungerleider of the End Well Foundation and Sutter Health. Registration is available now from the provided links. (The Petrie-Flom Center at Harvard Law School, 7/2020, <https://petrieflom.law.harvard.edu/events/details/advance-care-planning-in-the-age-of-covid>; Coalition to Transform Advanced Care (C-TAC), 7/2020, <https://mailchi.mp/a207ff95e4da/acp-and-covid-19-policy-lessons-learned>)



OTHER NOTES

* As part of a notice issued June 25th, CMS announced a proposed rule to make provisions of the COVID-19 crisis response permanent. Included in this proposed rule is a permanent expansion of telehealth coverage for home-based care services. However, this proposal will still not allow for reimbursement of telehealth services, for which the National Association of Home Care & Hospice is lobbying. Reportedly, CMS officials are open to extending further telehealth allowances past the pandemic. "The use of technology may not substitute for an in-person home visit that is ordered on the plan of care and cannot be considered a visit for the purpose of patient eligibility or payment; however, the use of technology may result in changes to the frequencies and types of in-person visits as ordered on the plan of care," the CMS notice reads. "This rule also proposes to allow HHAs to continue to report the costs of telecommunications technology as allowable administrative costs on the home health agency cost report beyond the PHE for the COVID-19 pandemic." (mHealth Intelligence, 6/26, <https://mhealthintelligence.com/news/cms-moves-to-make-covid-19-home-health-telehealth-expansion-permanent>)

* The Coalition to Transform Advanced Care (C-TAC) and Home Centered Care Institute (HCCI) announce their free upcoming July 15th webinar. The event focuses on the role of faith community leaders in working to encourage advance care planning. "During this webinar, experts will discuss the role of faith leaders in supporting those in their communities affected by serious illness," C-TAC explains. "Speakers will also explore how faith leaders can engage with parishioners affected by serious illness. Lastly, our speakers will share strategies with community organizations that they can use to engage with faith communities." The discussion will feature panelists Elder Angela Overton of the C-TAC Interfaith and Diversity Workgroup, Gloria Thomas Anderson of Heart Tones, Rev. Dale Susan Edmonds of Trinity United Church of Christ, and Lauryn Valladarez of Interfaith Community Service. Registration is required and is now open on the HCCI website. (Coalition to Transform Advanced Care (C-TAC), 7/15, <https://mailchi.mp/2306630ec9a1/faith-and-community-organizing-amid-covid-19>; Home Centered Care Institute, 7/15, <https://education.hccinstitute.org/Public/Catalog/Details.aspx?id=hMMPHJiux2XEG8FDWH5NRg%3D%3D>)

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July 16--From Referral to Admission: The Secret Ingredient to Compliant Growth

July 20--Virtual Sales: Perfect the Art & Science of Selling & Social Distancing

July 23--The Denial Myth: Skillfully Working with Real or Perceived Denial

July 30--Navigating the Hospital Partnership Part 1: Working with the Hospital Community, What You Need to Know & How to Reach Out

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