

What the Media Said about End-of-Life Care This Week August 31, 2021 A Service of Your State Association

RESEARCHER ASKS “WHY PSYCHEDELICS AND DYING?”

Megan Miller is founder of the Creative Dying Project which works “to start conversations about death, encourage end-of-life planning and establish a network of inclusive, community-based, psychedelic-friendly dying centers and home care options.” She is also author of “Creative Dying: Why Psychedelics and Dying?” The article is on the blog of Creative Dying Project’s website. Miller is both a researcher at the University of Wisconsin-Madison School of Nursing and a trainee in the California Institute of Integral Studies Certificate in Psychedelic-Assisted Therapies and Research program.

In a recent conversation with a hospice nurse, Miller realized the need for more education and information about the use of psychedelics in end-of-life care. The nurse asked if psychedelic-assisted therapy is similar to taking Vicodin after surgery, and if people are commonly addicted to psychedelics? In response to this conversation, Miller pinned “Creative Dying: Why Psychedelics and Dying?” First, she says, people who are seriously ill often suffer from anxiety, depression and demoralization. Psychedelics, for many years, have been used in healing to bring “self-transcendence, reductions in egocentric concerns and broadened perspectives about life and death.”

Even one session of psychedelic-assisted therapy, according to studies, can show significant decreases in depression, anxiety and “death anxiety.” Usage of psychedelics can also lead to increased sense of quality of life, optimism, and sense of meaning. Generally, Miller says, the use of psychedelics in therapy is preceded and followed by personal therapy.

In interviews following the use of psychedelic-assisted therapy, people report a number of positive experiences. Such results include “exalted feelings of joy, bliss, and love; embodiment; inability to describe the experience in words; alterations to identity; movement from feelings of separateness to interconnectedness; experiences of moving through psychological distress; the appearance of loved ones as guiding spirits; catharsis of powerful emotion; surrender or ‘letting go’; forgiveness; improved relationships; and continued challenges to integrate the experience into their everyday lives.”

In long-term follow up with cancer patients who use psychedelic-assisted therapy, sustained lessening of ‘anxiety, depression, hopelessness, demoralization, and death anxiety’ continued even three to four and a half years later. Overwhelmingly, participants responded positively and rated the experience as among the “most personally meaningful and spiritually significant experiences of their lives.”

Miller does note that most of the studies thus far are on participants who are “white, cisgender, able bodied, have high levels of education and [have] higher socioeconomic status.” For those seeking more information, she refers readers to Horizons Media’s video of “Death, Dying, and Psychedelics” which is free online at the second link below. (*Creative Dying*, 8/1, <https://www.creativedying.org/blog/2021/3/26/why-psychedelics-and-dying?fbclid=IwAR3wI8SAoNsB81EO4poaO8XFnlhIGZLFxqVQ0YrzCOUC-74TPm19INdPkKc>; *Horizons Media*, <https://horizons.nyc/films/death-dying>)

HOSPICE NOTES

* An article in *Wisconsin News* examines hospice music therapist Nicholas Scholtz’s work with St. Croix Hospice. Scholtz uses his classical guitar skills and his music therapy degree to work to provide pain relief, and to help patients recall memories. (*Wisconsin News*, 8/10, <https://www.wiscnews.com/baraboonewsrepublic/news/local/watch-now-music-therapist-eases-pain-brings-back->

memories-for-baraboo-area-hospice-patients/article_54f0063f-79e3-52e3-addb-66f386536d23.html)

* **An article in *Physician's Weekly* explores the “Health Inequities in Hospice and End-of-Life Care.”** A 2020 study said, “Discrepancies in end-of-life treatment persist along racial lines.” The exact barriers to equity are “varied and complex,” and include lack of primary physicians for those who need care, lack of trust of the healthcare system, and lack of understanding of hospice care.” The article encourages providers to establish safe and respectful relationships with patients, avoid assumptions, respect varied cultural attitudes and expectations, be aware of our biases, and become educated about hospice and palliative care. (*Physician's Weekly*, 8/14, <https://www.physiciansweekly.com/health-inequities-in-hospice-end-of-life-care>)

* **Staff turnover and growing staffing shortages are resulting in consequences. “Some hospice providers and health systems are starting to shut down their programs or sell off their operations because they cannot recruit or retain a sufficient number of employees.”** One example is the closure of Minidoka Memorial Hospital home health and hospice program, based in Idaho. The hospice has not been able to fill staff positions. Another example is the Grande Ronde Hospital and Clinics’ hospice program which also could not fill staff positions. North Carolina’s local hospice and home care, BrightSpring Health Services, plans to sell. (*Hospice News*, 8/6, https://hospicenews.com/2021/08/16/workforce-shortage-shutting-down-hospice-programs/?euid=c545e6d325&utm_source=hspn-newsletter&utm_medium=email&utm_campaign=397dade0cc)

* **An article in *Next Avenue* supports hospice access for all qualified patients. It then offers a look at some of the realities of offering dialysis to eligible patients.** Palliative medicine specialist Dr. Gina Piscitello speaks of a patient with terminal cancer who also receives dialysis for kidney failure. “He should be able to receive care for kidney failure and continue his dialysis,” she says. But, she notes, it may be difficult to find a willing hospice. The dialysis, she argues, can “improve this patient’s breathing discomfort and extend his life.” And hospice is supposed to maximize quality of life at life’s end. She also argues against practices of some hospices that withhold all antibiotics or turn off pacemakers. These decisions, she asserts are ones that patients should make “and should not be made of them by hospice agencies or clinicians who did not receive adequate training about hospice care.” (*Next Avenue*, 8/24, <https://www.nextavenue.org/hospice-care-access/>)

* **A recent *Forbes* explores the differences in hospice and palliative care.** The article describes each service and then offers similarities, differences, and payment methods for each. Finally, the article offers questions to consider when determining which service is best for “your loved one.” (*Forbes*, 8/20, <https://www.forbes.com/health/healthy-aging/palliative-care-vs-hospice/>)

* ***eHospice* features an article by NHPCO’s Edo Banach titled “Moving Beyond the Medicare Benefit in the U.S.”** Banach calls for more flexibility so that people can get curative and palliative care at the same time. He also calls the six months prognosis for hospice eligibility “arbitrary,” saying it has been a financial issue (not a medical one) since the beginning of the Medicare Hospice benefit. It will better serve beneficiaries, he says, if hospice service is based on patient needs and is not a time-limited benefit. Community-based palliative care needs to be defined and implemented. (*ehospice*, 8/25, https://ehospice.com/editorial_posts/moving-beyond-the-medicare-benefit-in-the-u-s-edo-banach-jd/0)

PALLIATIVE CARE AND END-OF-LIFE NOTES

* **Family Practice (FP) physicians say home visits are a vital part of their ability to provide palliative and end-of-life care (PEoLC).** “Providing FPs with tools and resources through education, including why and how to access them, and adjusting the BC compensation model to address home visit’s travel time and time modifiers may better support FP’S to provide PEoLC.” (*Palliative Medicine Reports*, online 7/16, <https://www.liebertpub.com/doi/10.1089/pmr.2021.00210>)

* **New York Time’s “Parenting Through Terminal Illness” explores how to best support children whose parents are terminally ill.** Psychotherapist Andrea Warnick says that supporting grieving children is based on important and simple elements. “Caregivers should work to form a secure attachment with the child and to facilitate open, honest communication.” It is important for a child to be able to depend on “a secure attachment” to one adult, who will accept their questions and their emotions. She encourages honesty, even when that is difficult. Free-flowing communication is vital. Warnick asserts that teaching kids about grief, and teaching them that they can

survive the intensity of their feelings are important. Grief, she says, is not a problem that needs “fixing.” It is a normal reaction to a difficult situation. (*New York Times*, 8/4, <https://www.nytimes.com/2021/08/04/parenting/terminal-illness-sick.html?fbclid=IwAR3XFXZ2Z2dKLKAtp3LqW4-BREru6X2eXb4OIyQkzOoqUHatlvyNgG0derJg>)

* **Brave Healer Productions has published “Sacred Death: 25 Tools for Caregivers.”** The book has 25 chapters written by “25 end-of-life experts, coaches, healers, therapists, and practitioners.” Topics include listening, forgiveness, caregiving and self-care, and rituals. (*PR Newswire*, 8/17, <https://www.prnewswire.com/news-releases/25-end-of-life-experts-share-their-life-affirming-wisdom-in-sacred-death-25-tools-for-caregivers-a-new-book-from-brave-healer-productions-301356726.html>)

* **The Washington Post published, “I had no idea how to talk to my children about a loved one’s death. I’m not alone.”** Our desire to protect children from pain, and our own discomfort with death, often keeps parents from talking about death with their children. With about 1 in 14 children in the US losing a parent or sibling by age 18, death should be recognized as a natural part of our life. Children’s grief is based on developmental age, and is different from that of an adult. Talk clearly to children about grief. Offer simple and honest answers to questions. The article offers numerous other ideas about how to talk with children about grief. (*Washington Post*, 8/14, https://www.washingtonpost.com/health/talking-about-death-to-kids/2021/08/13/2c2fbcf2-efd1-11eb-a452-4da5fe48582d_story.html?wpisrc=nl_sb_smartbrief)

* **An article in *Employee Benefit News (EBN)* explores the practice of employers offering end-of-life planning benefits.** The article highlights Lantern, an end-of-life planning organization, and its recent launch of Lantern at Work. Lantern at work is an employee benefit that supports employees in the process of end-of-life planning and managing grief. Data from outside sources are noted within the article, and the data support the need of employees for this benefit. (*EBN*, 8/26, <https://www.benefitnews.com/news/employees-shouldnt-be-blindsided-by-end-of-life-decisions-how-benefits-can-help-ease-the-burden>)

GRIEF AND ADVANCE CARE PLANNING NOTES

* **“It’s Time to Talk About ‘Hard Things’” appears in *New York Times*.** “Let’s Talk About Hard Things” is a book by Anna Sale. The “hard things” she addresses are death, sex and money,” topics she has addressed for seven years in podcasts from WNYC Studios. (*New York Times*, 8/17, <https://www.nytimes.com/2021/08/17/us/anna-sale-death-sex-money-hard-things.html>)

* ***Washington Post* offers “Covid has brought death and grief. But grief can keep lost loved ones alive in our hearts.”** The article shares the story of Steven Petrow and his grief over the death of his mother. “Grief has long terrified me,” says Petrow. “Too raw. Too uncontrollable.” Grieving includes remembering, and that helps Petrow. Andrew Holleran’s book “Grief: A Novel,” says grief over a person “IS their presence on earth.” (*Washington Post*, 7/23, https://www.washingtonpost.com/health/dealing-with-grief/2021/07/23/8c47f926-e3ef-11eb-8aa5-5662858b696e_story.html)

* **End of Life University offers a podcast titled “Technology and Grief” with Reid Peterson.** Peterson is creator of “Grief Refuge” website, as well as a mobile app to provide daily support to grieving people. He shares about the role of technology in dealing with loneliness and isolation during grief. (*End of Life University*, 8/23, https://eolupodcast.com/2021/08/23/ep-313-technology-and-grief-the-grief-refuge-app-with-reid-peterson/?mc_cid=761c9938e7&mc_eid=d0771da91c)

* ***Geripal* features a podcast focused on loneliness and social isolation.** The speakers clarify the distinctions between the two experiences and talk about clinicians’ roles in addressing these experiences in the geriatric community. (*Geripal*, 8/19, <https://www.geripal.org/2021/08/loneliness-and-social-isolation-podcast.html>)

* **A lengthy article in *NEJM Catalyst* is titled “Systemwide Advanced Care Planning During the Covid-19 Pandemic: The Impact on Patient Outcomes and Cost.”** The article explores a WellSpan Health initiative that analyzes a system developed to “implement team-based advance care planning (ACP) processes.” During Covid, WellSpan “created a remote response team to help high-risk patients with Covid-19 with ACP.” They compared patients who had ACP prior to hospitalization along with others who did not have ACP. The research, findings, and

implications of lessons learned are explored within the article that is online at the link below. (*NEJM Catalyst*, September/2021, https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0188?query=CTOC&cid=DM224274_Catalyst_Non_Subscriber&bid=583893167)

* **A study reported in *Journal of American Geriatrics* shares results of a study about barriers to advance care planning (ACP) of older English- and Spanish-speaking adults over age 55 and with two or more chronic illnesses.** The study used open-ended questions to better understand barriers that prevent ACP. Twenty-six barriers were identified (listed at the link below) and the authors call for more attention to these barriers “when developing customized ACP interventions for diverse older adults.” (*Journal of the American Geriatrics Society*, 6/21, <https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/jgs.17230?campaign=woletoc>)

* **“Are You Unvaccinated? It’s Time to Make an End-of-Life Plan” is an opinion article in *Newsweek*.** Written by physicians Shoshana Ungerleider and Jesse O’Shea, an infectious disease physician, the article identifies COVID-19 as a deadly virus and reports that 99% of all deaths from COVID-19 are, at the time of the article, are unvaccinated persons. The article and an audible version are online at the link below. (*Newsweek*, 8/25, <https://www.newsweek.com/are-you-unvaccinated-its-time-make-end-life-plan-opinion-1622867>)

OTHER NOTES

* **“America isn’t taking care of caregivers” appears in *Vox*.** The article explores ways that we can better support caregivers. The article explores how the pandemic has impacted caregiving, the burdens of caregiving, and the role of caregivers. “Caregiving may be a labor of love,” says the article, “But it’s still labor.” There is also an exploration of efforts to impact policies to support caregivers. (*VOX*, 8/4, https://www.vox.com/22442407/care-for-caregivers-mental-health-covid?mc_cid=2008f30980&mc_eid=d67266dfca AND <https://www.thectac.org/2021/08/c-tac-strongly-supports-cmmis-new-vision/>)

* **Past New York Giants’ coach Tom Coughlin writes for *New York Times* about his caregiving for his wife.** Coughlin talks about watching her “slip away” as she suffers with progressive supranuclear palsy, a brain disorder. Coughlin recalls the earlier vibrancy of his wife Judy, and of his frustration and pain in caring for her. He says caregiving is “mentally and physically exhausting.” Coughlin asks others to not forget about the caregivers. (*New York Times*, 8/24, <https://www.nytimes.com/2021/08/24/opinion/tom-coughlin-wife-ppsp.html>)

* **Seven months after COVID-19 vaccinations were offered, only 59% of staff who work in the country’s nursing homes have been partially or completely vaccinated.** Where vaccination rates are highest, vaccines were often brought to the facilities and offered there. Recently, President Biden and Senator Mitch McConnell both urged people to get vaccinated. AARP says “only one in five of the nation’s more than 15,000 nursing homes were able to hit a goal, set by two industry trade groups of vaccinating 75% of their staff by the end of June.” An AARP spokesperson calls for sounding the alarm over the need for vaccinations, adding that “nursing homes were devastated by COVID-19, and many residents remain highly vulnerable to the virus.” (*ProPublica*, 7/23, <https://www.propublica.org/article/dont-you-work-with-old-people-many-elder-care-workers-still-refuse-to-get-covid-19-vaccine>; *AARP*, 6/25, <https://www.aarp.org/caregiving/health/info-2021/nursing-home-staff-still-unvaccinated-for-covid.html>)

* **The National Association for Home Care and Hospice (NAHC) and the National Minority Health Association (NMHA), and the Flex for Checks program have teamed up to encourage COVID-19 vaccinations.** After the FDA’s full approval for Pfizer’s coronavirus vaccine, NHPCO released a statement supporting a national requirement for healthcare workers to be vaccinated. The full statement is online. (*Home Health Care News*, 8/23, <https://homehealthcarenews.com/2021/08/nahc-national-minority-health-association-announce-new-vaccination-program-for-the-home-based-care-workforce/>; *NHPCO Statement*, 8/23, <https://www.nhpc.org/statement-on-covid-vaccine-and-testing-requirements/>)

* ***Philadelphia* magazine shares the work of physician Hannah McLane who has opened SoundMind Center in West Philadelphia.** The Center provides psychedelic-assisted therapy. Patients are being treated ketamine, and there are plans to use MDMA and psilocybin once it is legal to do so. The psychedelics serve as adjunct to ongoing

therapy. The article shares the beginning of SoundMind and its vision for the future. (*Philadelphia*, 8/26, <https://www.phillymag.com/news/2021/08/26/psychedelic-therapy-philadelphia-soundmind-center/>)

* **“Dying for a Better Life” appears in the Boston Globe.** The article explores the work of the Death Café. The article explores the history of the Death Café, its transition to an online presence, and what the Death Café experiences are like. “Death Cafes are a rebellion against our own alienation from death.” (*Boston Globe*, 8/1, https://www.bostonglobe.com/2021/08/01/opinion/dying-better-life/?outputType=amp&__twitter_impression=true&fbclid=IwAR1ApFbhFQjvi8ImbxeOnDMB8fGQD2o8ci4Ly2OWxALkuqO2Shp4HHwjmbI)

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