What the Media Said about End-of-Life Care This Week
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THE END-OF-LIFE DIGITAL BOOM

The end-of-life industry is in the midst of a digital boom, seeing the introduction of a multitude of new apps and services. For many families and caregivers, the administrative and emotional burden is overwhelming, and digital services seek to offer convenience and clarity in uncertain times. Writing for *Observer*, Katie Bishop details these emerging options, their users, and the impact it may have on the experiences around the end of life.

While 90% of Americans believe that thinking through end-of-life logistics with a loved one is important, less than a third have actually done so. The goal of emerging digital products is to bridge that huge gap between belief and action. “Whether it’s noting what healthcare that you’d like to receive, recording memories so that a curated legacy is left behind, or uploading important documents, there are plenty of options on offer,” Bishop writes.

The death planning process is a primary focus for many apps. *Cake*, for instance, offers “planning as a gift to yourself and your loved ones” as a way to celebrate milestones, honor life, and plan ahead. The service has a free tier that provides health, legal, financial, legacy, digital, and funeral planning, as well as digital storage and sharing options. Paid plans bump up that storage, but more importantly provide “access to end-of-life experts.” Another app, *Safe Beyond,* offers a site where people can record future messages to leave for those they love.

***Lantern* launched in 2019, offering pathways to both manage a death and plan ahead.** Within months, the pandemic hit and founder Liz Eddy found the app flooded with users. In two months, the user base increased 450%. Interestingly, the majority of new users didn’t come from people at the end of life, but rather aged 20-45. “People are aware of their mortality and the need for pre-planning,” Eddy says. While only 14% of Americans under 30 have wills, offerings like *Lantern* could re-shape attitudes and norms.

Other apps focus more squarely on logistical issues. *Empathy* offers “guidance and peace of mind, leveraging the huge capacity of technology to assist with the details,” and provide tools to help people deal with loss. David Kessler, who lost his twenty-one-year-old son suddenly, and struggled with bureaucratic nightmares, joined the company as Chief Empathy Officer. He says, “technology can’t promise to take the pain away, but it can hold your hand through the process whilst also offering guidance in the often unknown terrain of grief.”

For family members and those near the end of life, no tech solution will resolve the emotional upheaval. Still, these new platforms find their own ways to open up space for those feelings by starting planning early and addressing stressful logistics. Technology is not a solution for answering “existential questions,” Kessler says, but it can “nudge us into asking the right questions about what we’d want towards the end-of-life.” It can “prompt people to take control and actually tell their clinicians what they would and wouldn’t want, [...] pushing us further into that openness and peer-supported patient empowerment.” (*Observer*, 7/5, https://observer.com/2021/07/planning-death-has-gone-digital-inside-the-apps-that-prepare-you-for-loss)

HOSPICE & PALLIATIVE CARE NOTES

* ***Hospice of the Western Reserve* launched the *Hospice of the Western Reserve Foundation*, a nonprofit public charity.** The foundation will provide financial support to programs supporting end-of-life care patients and their families. “Many of the special services provided by the agency-- such as music and pet therapies-- bring meaning, joy and healing during a very difficult time,” said joining board member Dr. Alfred F. Connors. “These services are not reimbursed by Medicare or commercial insurance, so they rely on philanthropic support.” (*The Morning Journal*, 7/4, www.morningjournal.com/news/cuyahoga-county/hospice-of-the-western-reserve-announces-creation-

of-a-nonprofit-foundation/article_bf5aeb6d-a6cd-5d4d-90fb-4268dd03e424.html)

* **Nashville-based hospice care provider *Compassus* is partnering with *Empathy*, a digital platform that offers logistical and emotional support to family members of end-of-life patients.** Empathy provides resources for funeral arrangements, validating wills, estate administration, benefits claims, and property clean-outs. *Empathy* says it also "offers human support to provide users both emotional and practical assistance, creating a hybrid experience to help families navigate arrangements and grief." *Compassus* will offer this service to its 200-location network across 30 states. (*Nashville Post*, 7/1, www.nashvillepost.com/business/health_care/compassus-partners-with-end-of-life-support-platform/article_fbf2a1ec-da60-11eb-b7e9-53fed331c6e3.html)

* ***ChristianaCare* has formed a joint venture with *Seasons Hospice & Palliative Care*, a subsidiary of *AccentCare*, to expand in-home hospice and palliative care services throughout Delaware.** The financial terms of the partnership are confidential, though the organizations say it will build on an existing relationship in which *Seasons Hospice & Palliative Care* managed hospice patients at *ChristianaCare* facilities. *Seasons Hospice & Palliative Care* CEO Todd Stern says the joint venture gives the organizations the "rare opportunity to shape the future of post-acute care so people who need our services can receive them on their terms and where they want them." (*Philadelphia Business Journal*, 7/8, www.bizjournals.com/philadelphia/news/2021/07/08/christianacare-seasons-hospice-jv-delaware.html)

* ***Husch Blackwell's* hospice podcast offers a podcast titled "Strategic Restructuring for the Future: Exploring How Hospices Are Using Joint Ventures, Mergers and Acquisitions, and Service Diversification to Transform."** Meg Pekarske is joined by Noreen Vergara to discuss ways that hospices can join forces to "succeed in the value-based care landscape." They explore options from "messenger-model networks to networks that are clinically and financially integrated all the way to common ownership through merger or acquisition." (*Husch Blackwell*, 7/1, www.healthcarelawinsights.com/2021/07/strategic-restructuring-for-the-future-succeeding-in-value-based-care-how-hospices-can-collaborate-through-network-models)

* ***Computers Informatics Nursing* publishes "Reducing Hospital Visit Rates in Hospice Patients Using Telemedicine."** The authors found statistically significant differences in the number of emergency department visits and 911 calls following education with *Doxy.me* telemedicine. The study was conducted with 44 adults 35 years and older, following them in the 8 weeks after education. (*Computers Informatics Nursing*, 6/16, https://journals.lww.com/cinjournal/Abstract/9000/Reducing_Hospital_Visit_Rates_in_Hospice_Patients.99248.aspx)

* ***NHPCO* released a resource guide for better providing hospice and palliative care services to LGBTQ+ individuals.** The content, developed by *NHPCO's* Diversity Advisory Council (DAC), covers LGBTQ+ healthcare disparities, offers suggestions for providing better LGBTQ+ patient care, and suggests outreach strategies. "Hospice providers have a history of meeting the unique needs of diverse communities going back to the early days of the AIDS pandemic in the 1980s when compassion, dignity, and care were so desperately needed by those marginalized at the time," says *NHPCO* President and CEO Edo Banach. "With a strong foundation and the support of resources like this LGTBQ+ resource guide, we hope all hospices and palliative care providers will provide the best care possible to LGBTQ+ patients and families." The guide is online for download at the bottom of the press release cited below. (*NHPCO*, 6/22, www.nhpco.org/new-hospice-and-palliative-care-resource-guide-for-lgbtq-communities)

* **The *Optum Hospice* Annual Conference will be available online until July 18.** The conference features a keynote talk from Dianne Gray, Chief Innovation Officer of *Acclivity Health Solutions*, titled "Compassionate Communication & Active Listening: Key to Effective, Efficient Care of the Seriously Ill." The agenda includes hour-long educational talks from a variety of speakers on topics including hospice nursing, end-of-life expectations, end-stage disease management, hospice nursing basics, and the future of hospice quality reporting measures. (*Optum*, 6/18, https://optumhospicerx.vfairs.com)

* ***WellSky* released "The Value-Based Insurance Design Model: What your hospice needs to know to succeed," a tip sheet from three hospice experts.** The tip sheet covers: 1) The timeline of the VBID model rollout through 2024 and key dates to know. 2) How to determine patient eligibility in an MA plan. 3) The difference between in-network and out-of-network relationships with MA plans. 4) Four steps your hospice can take now to thrive under VBID. 5) Questions to ask your software vendor to ensure you are prepared for success. Download is

free, but dependent upon providing some personal information. (*WellSky*, 7/4, https://info.wellsky.com/062921-VBID-Tip-Sheet.html)

* ***NHPCO* issued a public comment on the *OMB* notice entitled "Methods and Leading Practices for Advancing Equity and Support for Underserved Communities through Government."** The comment thanked the Administration for its leadership in addressing health and social inequities, which were exacerbated by COVID-19. The comment offers recommendations on determining barriers to care, understanding social factors, developing a universal database, and other topics. The recommendations included removing the six-month prognosis requirement for hospice, as well as the ban on concurrent care in hospice. (*Insurancenewsnet*, 7/10, https://insurancenewsnet.com/oarticle/national-hospice-palliative-care-organization-issues-public-comment-on-omb-notice)

* **As former Louisiana Governor Edwin Edwards announces that he's entering hospice care, New Orleans' *WGNO* aired a story discussing what starting hospice care means.** Edwards says his choice is aimed at "good and convenient care" and does not simply signal the end of life. Hospice care providers explain that the hospice benefit includes a continuum of care. It's not to cure the underlying illness, the segment says, but about providing the highest quality of life for that person's remaining time. "There's no timetable on how long someone can be on hospice care." (*WGNO*, 7/7, https://wgno.com/news/louisiana/discussing-hospice-care-and-what-it-means)

* **Medical researchers from the *University of Ottawa* developed the Risk Evaluation for Support: Predictions for Elder-life in the Community Tool (RESPECT). The tool can help frail and older adults calculate six-month life expectancy in order to help plan palliative care.** The researchers write that their "primary objective was to develop and validate a model for predicting mortality risk among the general population of community-dwelling adults with and without cancer that spans an actionable period for end-of-life planning (5 yr to imminent death)." The RESPECT investigation found the best predictors of palliative care needs were a decline in a person's ability to perform basic daily activities. (*CMAJ*, 7/5, www.cmaj.ca/content/193/26/E997; www.respect.projectbiglife.ca; McKnight's www.mcknights.com/news/clinical-news/calculator-predicts-elders-life-expectancy-needs-for-palliative-care)

END-OF-LIFE

* **New York Governor Andrew Cuomo signed an end-of-life care bill sponsored by Senator Michell Hinchey. The legislation allows hospice facilities to certify up to 100% of their beds to be used for general inpatient care, a vast increase from the previously allowed 25%. "**Too often, [...] palliative care is interrupted by unnecessary and stressful hospital transfers, which can be harmful to a person's declining health," says Hinchey, and this bill will "help more New Yorkers receive the end-of-life services they need in a home-like setting." (*Daily Freeman*, 7/9, www.dailyfreeman.com/local-news/cuomo-signs-end-of-life-care-legislation-sponsored-by-sen-hinchey/article_5b6cfae2-e00a-11eb-9d11-b7a3ff4b1187.html)

* **Death doulas have adapted their services in response to COVID-19, according to *AARP*. This includes moving to remote video consultations and providing increased emotional support to caregivers**, who may feel increasingly isolated or overburdened. "I do miss the intimate connection established between myself and the dying person through quiet conversation, presence and touch," says Virginia Chang, a certified end-of-life doula in New York City. "However, I have always said that empowering the caregivers to better care for their dying loved one meets my goal of better care for the dying person. So, I'm still doing my job." (*AARP*, 7/9, www.aarp.org/caregiving/home-care/info-2021/death-doulas-adapt-during-covid.html)

* ***Endwell* will host "The End In Mind," a free virtual conference centered around psychedelic medicine on October 14.** Speakers include Ira Byock, Chris Adrian, Dingle Spence, Francoise Bourzat, and more. "Everyone is invited to discuss the future of psychedelic medicines for those facing serious illness and at the end of life. We'll hear from academic researchers, policymakers, patients, entrepreneurs, funders, clinicians and more!" Registration is online at the link below. (*Endwell*, 7/7, https://endwellproject.org/the-end-in-mind; https://endwellproject.org/the-end-in-mind/)

* **The *End of Life University* podcast, Episode 306, "Providing Hospice Care for Those Without a Home," is**

now online. Guest Penny Davis, a former hospice nurse and retired executive director of a hospice, shares "why it's important to combine business knowledge with a charitable heart in order to create a successful organization" when providing end-of-life care. "Learn how a retired hospice director turned a failing hospice home into a thriving charitable organization providing housing for homeless people at the end of life." Davis is also author of *PJs, Pearls, and Fishing Poles: Life Lessons of Style and Substance*. (*End of Life University*, 7/5, https://eolupodcast.com/2021/07/05/ep-306-providing-hospice-care-for-those-without-a-home-with-penny-davis)

* ***Supportive Cancer Care* published "'Don't forget the children': a qualitative study when a parent is at end of life from cancer," a study exploring how parents with cancer can best be supported in relation to their children.** The interpretive qualitative study conducted 79 semi-structured interviews with parents, bereaved parents, health and social care professionals, and funeral directors. The authors conclude that "parents should be reassured that by involving the children early in the end of life experience when the ill-parent is 'well enough' to parent enables them to be actively involved in supporting their child through one of the greatest life changing event." The study provides further recommendations for professionals." (*Springer Link*, 7/5, https://link.springer.com/article/10.1007/s00520-021-06341-3)

OTHER NOTES

* **A medical marijuana bill passed a major hurdle in North Carolina. A Senate panel passed "North Carolina Compassionate Care Act" (SB 711), which would legalize marijuana for people with debilitating or end-of-life medical conditions.** The bill has bipartisan support, but will need to pass through more committees to reach the Governor's desk. A dozen people, mostly in support of the bill, spoke before lawmakers prior to the vote. The speakers included pharmacists, cancer survivors, and veterans who detailed positive changes in their lives or the lives of loved ones. Republican Senator Kathy Harrington said that while she wouldn't have voted for the bill six months ago, her husband's experience with cancer treatment changed her mind. (*CBS17*, 7/1, www.cbs17.com/news/north-carolina-news/medical-marijuana-bill-passes-major-hurdle-in-nc)

* ***CMS* announces Dr. Meena Seshamani, M.D., Ph.D. as Deputy Administrator and Director of the *Center for Medicare.*** "Dr. Meena Seshamani brings her diverse background as a healthcare executive, health economist, physician and health policy expert to *CMS*," says *CMS* Administrator Chiquita Brooks-LaSure. "I am delighted to say Dr. Seshamani will bring her unique perspective on how health policy impacts the real lives of patients to her leadership role as Deputy Administrator and Director of the Center for Medicare." Dr. Seshamani previously served as Vice President of Clinical Care Transformation at *MedStar Health* and has cared for patients as an Assistant Professor of Otolaryngology-Head and Neck Surgery at the *Georgetown University School of Medicine*. (*CMS*, 7/6, www.cms.gov/newsroom/press-releases/cms-announces-director-center-medicare)

* **The *Santa Fe New Mexican* covers the impact of New Mexico's aid-in-dying law as it goes into effect.** Lawmakers passed the Elizabeth Whitefield End-of-Life Options Act one week before Glenn Buckland, who was battling with leukemia and supported the bill, died. "If I had access, today would be the day," he reportedly told his wife the day before he passed away. It's unclear how many patients will request physician aid in dying under the law, the article says, but "some healthcare institutions are preparing for the change while others say they won't offer the service." Presbyterian Healthcare Services say they are providing education and resources to their clinicians to follow the provisions of the new End-of-Life Options Act. Christus St. Vincent Regional Medical Center, on the other hand, will not prescribe lethal medications, but instead upon request "transfer the patient to an appropriate facility and according to their wishes." (*Santa Fe New Mexican*, 6/28, www.santafenewmexican.com/news/legislature/new-mexicos-aid-in-dying-law-takes-effect/article_d367876c-d36f-11eb-8c84-9f459b233443.html)

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