THIRD WAY

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Local Examples: Innovations in End of Life Care

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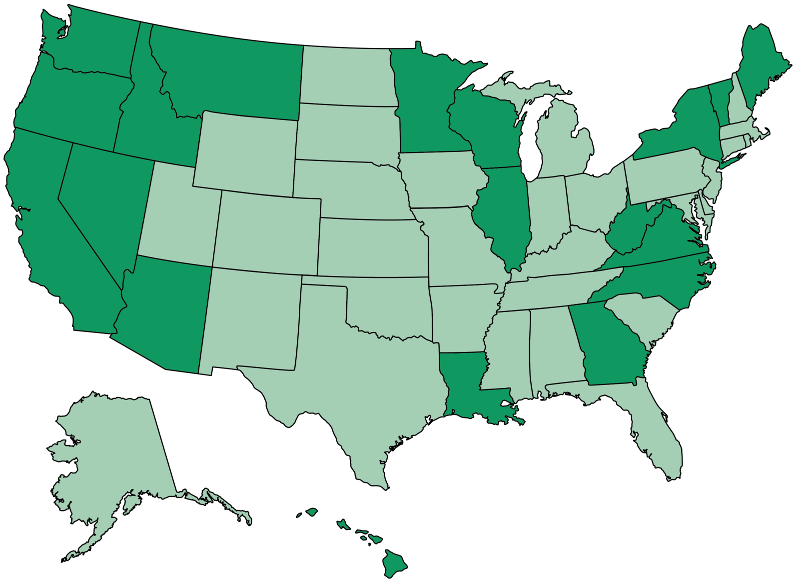
For many Americans, the care they want near the end of their lives is not the care they get. They often die in a hospital or nursing home despite their preference to die in their homes, and they may receive life-extending care when they would prefer to simply be comfortable. While the conversations can be difficult, discussing and documenting end of life goals and wishes reduce uncertainty for both families and healthcare providers and ensures that patients receive the care that is right for them. Experts estimate that only 18-36% of American adults have an advance directive (AD)—written instructions that allow patients to make decisions about their care ahead of time in case they become incapable of participating in these decisions later.



Health systems across the country are recognizing the value of advance care planning and incorporating it into new care models. Now, patients need to be counseled and encouraged to use ADs, and doctors enabled to access and use them.

Nationwide

MyDirectives, an online service, allows patients to record their medical treatment wishes, including audio and video messages, and share them with anyone at any time. The emergency, critical, and advance care plan incorporates elements of a living will, a healthcare power of attorney, as well as a patient's own thoughts on medical treatments and preferences. Patients can answer questions about care preferences in their own words or select from commonly used answers, and can prioritize their wishes. Health care providers that work with MyDirectives only see a patient's most recent, signed document. MyDirectives recently announced a partnership with Humana, which will provide the digital directive service to select members, and with Cerner and Coordinated Care Oklahoma, a health information exchange, to help consumers create and share their advance directives with whom they choose.

My Health Care Wishes App, developed by the American Bar Association, allows patients to store their directives and care preferences for themselves and their family members on their smartphone. Documents are stored only on the smartphone, and not on a server or cloud service, and storage is limited only by space available on an individual device. Documents stored using the app can be immediately viewed, or emailed, texted, or faxed to health care providers the moment they are needed. The app also stores contact information for a patient's primary contacts, health care power of attorney, and primary care physician.

Sometimes, just starting a conversation about end of life wishes can be difficult and painful. When 12-year-old Nazea Twiggs was diagnosed with osteosarcoma, he, his family, and his health care providers thought about the possibility of Nazea's death, but no one was talking about it. "We definitely needed to have a conversation," Nazea's dad, Stephan said, "but I was totally against it." Then, Nazea's doctor and nurse came to his home to play a game, My Gift of Grace, which helps facilitate conversations about "living and dying well." Through the game, Nazea's parents learned for the first time of his wish to be cremated and where he wanted his ashes to be spread. "The game allowed us to have conversations that we wouldn't have had," said Nazea's mom, Darnella. For Nazea's doctor, the game provided clear insight into Nazea's and his family's wishes for his end of life care. "I learned more from playing that game with that family than I've ever learned, honestly," she said. A recent study found that 74% of people who played My Gift of Grace went on to complete and advance care planning activity.

Arizona

Arizona is one of nine states that collects some form of advance directive other than organ donor designation in a registry. The Arizona Advanced Directive Registry electronically stores medical directives, including living wills, medical power of attorney, and mental health power of attorney documents, free of charge. Directives can be filed either by mail or in-person in Phoenix or Tucson. Once a patient registers, she is issued a password that she can share with family members, doctors, and other advocates.

California

Mark Saylor was diagnosed with a brain tumor at 58, but it was his regimen of chemotherapy and radiation, not the tumor, that left him unable to walk. In his final days, he was unable to get out of bed. In retrospect, his wife, Nora, wonders why the option for less treatment never came up in conversation with Mark's doctors. If it had, they may have made different decisions about his care, which may have offered Mark more peace at the end.

Providers in California, such as Sutter Health, a non-profit health system in Northern California, are working to help patients make the right end of life care decisions for them. Sutter Health developed the Advanced Illness Management (AIM) program to bridge the gap between acute care and end of life care for Medicare patients with late-stage chronic illnesses. The program focuses on helping patients clarify their care goals and design care plans to support those goals, in addition to managing symptoms, facilitating transitions from hospital to home, providing home-based care, and supporting the transition to hospice care as needed. Over several meetings, care managers work with patients and their families to create advance directives and Physician Orders for Life Sustaining Treatment (POLST) forms through motivational interviewing techniques and conversations that center on the patient's personal values and emotions. Sutter Health found that the program generated high levels of patient, caregiver, and physician satisfaction and also increased use of hospice care, reduced inpatient and ambulatory care utilization. This decline in utilization translates into average cost savings to Medicare of $760 per AIM enrollee per month.

Another association of private practice physicians in California, Monarch HealthCare, incorporated advance care planning into its transitional care model for frail elderly patients at high risk of complications after their return home from the hospital. The transition team works with patients to create advance health care directives or Physician Orders for

Life Sustaining Treatment (POLST) forms, which are then included in each person's personal health record. Patients are also encouraged to share their records with their primary care physicians and specialists.

Georgia

Since 2000, the non-profit organization Georgia Health Decisions has worked with health systems, financial planners, and estate attorneys to help citizens discuss and document their goals for end of life care through a community education program called Critical Conditions. The Critical Conditions Planning Guide combines a three-step process to guide families through a conversation about their health care decisions and fill out the Georgia Advance Directive for Health Care, the legal documentation necessary to record those decisions.

Hawaii

Lena Katakura's father was 81 when he was diagnosed with esophageal cancer. Faced with the necessity of making decisions about the end of his life, the family found that they did not know how to answer many of the questions surrounding his care. A nurse showed them an informational video to supplement their discussions, and the family was able to complete Mr. Katakura's advance care directive confident that he was getting the care that was right for him.

The video the Katakuras watched was developed by the non-profit ACP (Advanced Care Planning) Decisions for use by healthcare providers to supplement difficult conversations about advanced disease and goals of care. Every health care provider in Hawaii has access to the videos through the Hawaii Medical Service Association, and the impact on patient choices will be studied for three years.

Hawaii residents can download advance care directive forms that were developed by Kokua Mau, an end of life care coalition, and the Executive Office on Aging, and indicate on their driver's licenses that they have them. In the event of an accident that renders the individual unable to communicate, the note on his license will prompt medical personnel to look for the directive in the patient's medical records or contact family members for a copy.

Idaho

Starting July 1, 2014, Cambia Health, which provides health insurance to 2.2 million members in Oregon, Washington, Idaho, and Utah, began reimbursing providers for palliative care services for individuals at any life stage. New benefits include in-home care, counseling, advance care planning, and interdisciplinary meetings involving a patient's nurse, chaplain, and social worker—all services not typically covered by insurance plans. Cambia has also invested in training for doctors and caregivers regarding how to facilitate appropriate conversations about end of life care.

Illinois

In Chicago, a group from Rush University Medical Center provides basic palliative care skills to local physicians and advanced practice nurses by pairing them with "mentors, hosting conferences, and offering online learning." The goal is for those trained to create a network of providers who can learn from each other and also train other providers in their own networks on how to communicate well with patients and families about advance care planning.

Louisiana

Louisiana is one of nine states that collects some form of advance directive other than organ donor designation in a registry. It was the first to create such a registry in 1991, permitting citizens to file "living will" declarations which direct caregivers to withhold or withdraw life sustaining procedures. The fee to register a declaration is $20, and the state issues a laminated wallet ID card and an engraved "Do Not Resuscitate" bracelet to indicate that the person has a document registered with the state.

Maine

Eight years after his ALS diagnosis, Jim Kingsbury had lost nearly every method of communication he once had, including blinking. Thanks to special technology, he can still convey messages to his wife Lisa by a process that relies on staring. Jim had time to plan for the end, so he was able to express his wishes regarding his care. When he can no longer open his eyes, Lisa knows he wants palliative care and can be certain that she is his steward through the end.

Maine residents have resources to help with advance care planning, including the Southern Maine Agency on Aging, where volunteer facilitators help patients learn about the decisions they may face at the end of life and guide them to reflect on their goals and wishes. The Agency offers group sessions as well as one-on-one counseling based on Gundersen Lutheran Health System's Respecting Choices model. Maine Health, a network of health care facilities, continues to fund the in-person and online training of volunteers, which now number in the thirties.

Minnesota

In 2008, the Twin Cities Medical Society (TCMS) adapted aspects of Gundersen Lutheran Health System's program to promote care planning across the state through an initiative called Honoring Choices Minnesota (HCM). After securing support and commitment from both the community and health care systems, TCMS led the collaborative in creating its own governance structure, forms, and patient education materials. Health organization leaders chose patient populations for piloting the program and trained individuals as advance care planning facilitators who would lead discussions with patients and their families. By 2012, HCM had spearheaded seven pilots, including one at a financial services organization offering advance care planning as an employee benefit. The collaborative partners with free clinics and non-profits that serve the homeless, medical schools, and the Minnesota Council of Churches to engage diverse range of communities in discussions about end of life issues. By 2014, the Honoring Choices model had resulted in more than 16,000 advance care planning conversations and 14,000 advance directives.

Montana

Montana is one of nine states that collects some form of advance directive other than organ donor designation in a registry. When submitting an advance directive to the Office of Consumer Protection's End of life Registry, individuals can specify a privacy level for who can view the document: "Standard privacy" allows the individual, registered health providers, as well as anyone with the person's Social Security number, birth date, and mother's maiden name to view the document while "Higher privacy" allows access only to the individual, health care providers, and anyone with the name and access code. Although documents can be viewed online, they can only be filed or changed via mail.

Nevada

Nevada is one of nine states that collects some form of advance directive other than organ donor designation in a registry. Maintained by the Secretary of State's office, LivingWillLockbox.com is a registry for living wills, do not resuscitate (DNR) orders, and durable power of attorney. Once a person's documents are registered, the state issues a wallet-sized card containing a registration number, adhesive labels with Living Will Lockbox contact information, and instructions for accessing the Lockbox, viewing the documents, and making changes. Alternatively, individuals can register advance directive locator forms that store the location of the documents without including the actual content. Medical professionals can register with the Secretary of State for authorized, unlimited access to the entire registry without explicit consent from patients.

New York

Paula Faber's diagnosis of fast-growing, small-cell lung cancer was her third cancer in a decade. Determined to fight the disease, she endured 11 months of chemotherapy, radiation, painkillers, and side effects before she died. After her death, her husband Ron regretted the endless treatments that left her a mere 67 pounds when she died. In fact, chronically ill patients in New York spend more time in the hospital during their last six months of life than their counterparts in the rest of the country.

To help patients determine and communicate their end of life wishes, clinical leaders at Care Support of America of the University at Albany, part of the State University of New York, and Kaiser Permanente collaborated to develop the Advanced Illness Coordinated Care Program—a pilot program that experienced success with coordinated palliative care. The program targeted patients with advanced illness to "better understand their illnesses, communicate with providers, and reduce barriers to palliative care when appropriate." This program involved social workers addressing advance directives with patients. Under this program, patients were 2.23 times more likely to complete an advance directive.

North Carolina

North Carolina is one of nine states that collects some form of advance directive other than organ donor designation in a registry. The state has held living wills and durable power of attorney documents in the Advance Health Care Directive Registry since 2002. Forms can be downloaded online, but must be submitted through the mail along with a $10 per document fee. The state then issues an ID card containing all the necessary access information, and individuals are encouraged to make copies to share with others.

Oregon

Starting July 1, 2014, Cambia Health, which provides health insurance to 2.2 million members in Oregon, Washington, Idaho, and Utah, began reimbursing providers for palliative care services for individuals at any life stage. New benefits include in-home care, counseling, advance care planning and interdisciplinary meetings involving a patient's nurse, chaplain and social worker—all services not typically covered by insurance plans. Cambia has also invested in training doctors and caregivers in how to facilitate appropriate conversations about end of life care.

Vermont

Vermont is one of nine states that collects some form of advance directive other than organ donor designation in a registry. The state operates an electronic database to store advance directive documents free of charge. Individuals can also register advance directive locator forms that provide the location of the documents without including the actual content. Although participants are encouraged to share copies of their directives with family and care providers, doctors and hospitals are also required to check the registry.

Virginia

The Advance Care Planning Coalition of Eastern Virginia, a collaboration between four health systems and four area agencies on aging (AAA), aims to increase the number of people creating advance directives through a campaign called As You Wish. Providers within the participating health systems hold end of life care conversations with patients in the medical setting, while the AAAs' network of home and community-based service providers reach out to individuals where they live.

Washington

After Bryan was diagnosed with a chronic illness, life with his family went on mostly as usual for several years, although he increasingly found himself in the hospital. For many reasons, including not wanting Bryan to think they had given up hope, his family never discussed the "what ifs" about the end of his life. One day, Bryan was admitted to the hospital for what turned out to be the last time. At this point, he was too sick to talk about his wishes and it ultimately fell to his younger sister to make his care decisions. Three weeks after his admission, Bryan's family enrolled him in hospice, where he died 48 hours later. In retrospect, they wondered if they had waited too long for hospice care, where he was able to eat all the foods he liked and his family was all together. Not knowing what Bryan wanted made his family's decisions more emotional and uncertain.

A partnership between Washington State Hospital Association and the Washington State Medical Association, Honoring Choices Pacific Northwest (HCPN), works with patients like Bryan and their families "to create their personal end of life care plans and connect people to the tools they need to get started." Organizations participating in HCPN offer facilitated advance care planning conversations to patients based on the Respecting Choices model, and agree to use standardized forms and informational materials, openly share lessons learned from the process, measure outcomes, and include community outreach. HCPN also connects health care professionals with training opportunities to improve their skills for engaging patients in advance care planning.

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Washington, DC

In order to address the racial disparity in palliative and hospice care—African Americans often do not seek or receive such care—Providence Hospital initiated a culturally sensitive end of life education program for patients, their families, and medical residents. As part of the program, hospital staff worked with patients to explore end of life wishes and incorporate them into care plans. Support group meetings for caregivers included sessions on advance care planning that explained the purpose and legal ramifications of directives in laymen’s terms. Medical residents were taught skills that helped them have discussions about dying with patients. Satisfaction surveys indicated that families appreciated staff’s compassion and listening abilities.

West Virginia

The West Virginia Center for End of life Care, an agency funded through the Department of Health and Human Resources' Bureau for Public Health, operates an opt-in database of advance directives accessible to health care providers at hospitals, nursing homes, home care agencies, and private practices. When completing their living wills, medical power of attorney, or Physician Orders for Scope Treatment forms, patients can indicate their permission to have the documents included in the e-Directive Registry. After National Health Care Decisions Day in 2013, the West Virginia Center for End of life Care, saw a 35% increase in the filing of advance directives.

Wisconsin

Gundersen Lutheran Health System, located in La Crosse, has successfully expanded the use of advance medical directives through a community-wide advance care planning program called Respecting Choices. The program incorporates disease specific planning and a medical home for patients’ last two years of life that includes primary care, hospice, social services, and home health. The program is integrated into Gundersen Lutheran’s routine primary care visits, as well as non-clinical, community settings via trained advance care planning “facilitators,” so that advance directives are discussed, considered, and created well in advance of end of life care. The advance directives are maintained in Gundersen Lutheran’s electronic medical records.

Since its creation in 1986, the program has been enormously successful. In 2010, among adult La Crosse residents who died over a seven month period, 96% had some form of advance care plan, 99% of those plans were available in patients' medical records, and treatment was consistent with the advance directives in 99% of cases.

The Wisconsin Medical Society is now using Gundersen's Respecting Choices program to promote advance care planning across the state. Organizations participating in Honoring Choices Wisconsin commit to facilitating conversations with patients about their goals for end of life care, use patient-tested forms and informational materials, support community outreach, and share lessons learned through the program.

Research and case study composition by Nikki Metzgar.

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