

# COMPASS

As my mom dug through her deceased mother's closet, sifting through clunky typewriters and 40-year-old bridesmaid dresses, she sighed and reflected, "Your dad and I are classic examples of the baby boomer generation—we're aging and starting to realize the things we should have done by now." Caring for her mother, who suffered from advanced dementia, took a heavy toll on her emotions and physical health, an occurrence many experience when helping a loved one through their final days. "We don't view death as our future or as something to prepare for—instead we think, 'I hope I go peacefully in my sleep' as opposed to 'I should put things in order in case I go next week.'"

Preparing for end-of-life transitions can make them less stressful and more positive. It starts with acknowledging and accepting death as part of life and having meaningful conversations about it before an emergency room crisis.

"We think it's human nature to avoid the topic of death because we cherish life so much, but in large part it's cultural," says Myra Christopher, the Kathleen M. Foley chair of pain and palliative care at the Center for Practical Bioethics. "A Japanese physician once told me that he thought Americans were the only culture that thought death was an option."

## Considerations & Planning

Contemplating death is not just for the elderly. At 16, you can get a driver's license and are asked whether or not you'd like to be an organ donor. Putting some thought into the fact that life can turn on a dime may help circumvent the scenario of a family in disagreement with a physician over the care of a patient who cannot speak for themselves.

Advance directives, medical and financial powers of attorney and living wills are important documents to have in place. "We all need advance planning if we care how our wishes are going to be carried out," says Elaine Procter, attorney specializing in elder and disability law at Procter and Callahan, LLC.

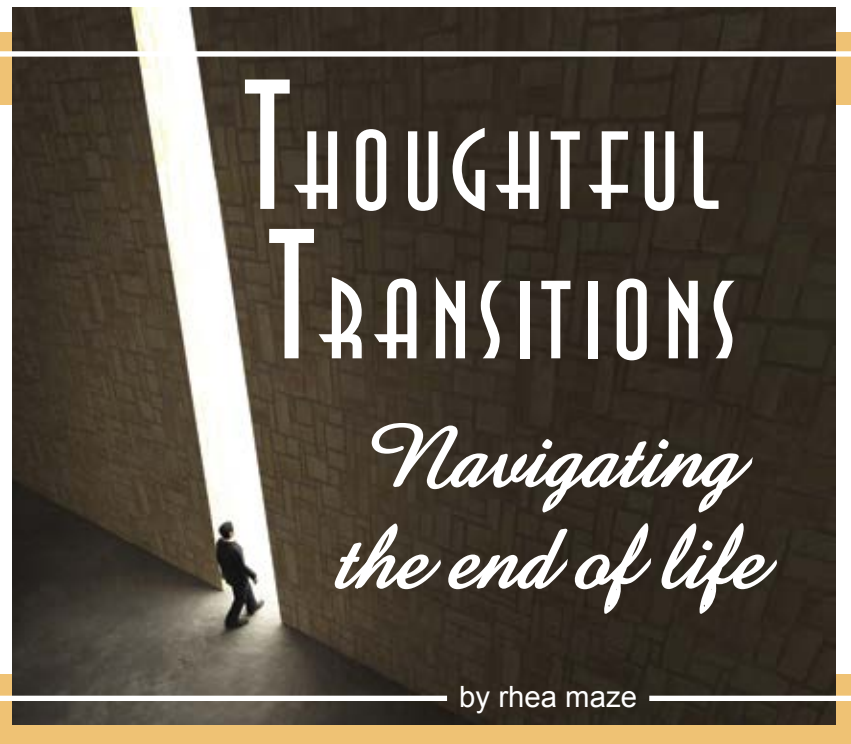
It's critical that people 18 and older at the very least name a durable power of attorney for

*"Not having talked ahead of time with loved ones about personal wishes complicates decision making and can result in communication struggles in a highly emotional situation."*

— Marney Komives, social worker in counseling services at Poudre Valley Hospital

health-care decisions so that families are better prepared to deal with unforeseen accidents and events.

"We tend to put these decisions off in our culture," says Dr. David



Allen, executive medical director at Pathways Hospice. "People seem to think that if they have a will that might mean they're dying or that it's going to hurry the process along."

A living will is different from a will that deals with the distribution of assets in that it allows you to talk about how you want to have your doctor respond under certain medical situations or treatments. Such considerations become increasingly important as most people today die of advanced age and multiple chronic illnesses.

Some also consider getting long-term care insurance, typically around the age of 50. "As you get older, it becomes more expensive," says Christopher. "If you do purchase a long-term care policy, make sure it's flexible and will pay whether you are at home or in assisted living, not just when you're in a nursing home."

Stress over insurance and finances can cloud the end-of-life process. Medicare, Medicaid, private insurance and long-term care insurance are the primary ways people access care at the end of life. Read your insurance benefits cover-to-cover and work to thoroughly understand them.

"It's kind of a shame that at the end of your life, so much of it comes down to a phenomenal number of financial decisions," says Evelyn Swiss of Fort Collins, whose parents live in a nursing home in New Mexico. "I'm looking into long-term care insurance because I'd like to know that my husband and I wouldn't be a burden on our daughter—but I feel too young to be paying into something for so many years. It seems

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like our society could do better for older people but I don't know what the cultural solution will be to these issues."

## Caregiver Support & Connection

"One in four U.S. families is actively involved in caring for an elderly loved one," says Christopher. "When someone is ill, families want to be there but they need to get help and they need to rest. If you become responsible for someone, you have to be able to function."

Though self-care can be difficult for caregivers to prioritize, the role is near impossible without an adequate support system. "There can be a lot of burnout and health issues that arise because (caregivers) put their own health needs to the side," says Tammy Brannen-Smith, director of the grief and loss program at Pathways Hospice. Options like sharing responsibilities with other family members and friends and utilizing community in-home services, volunteer respite and other resources can help ease the burden.

"You can't always simultaneously be the daughter/son and the caregiver—they are two separate roles," says Yvonne Myers, health systems director at Columbine Health Systems. "It's hard to sit down and go through the family photo album when you're exhausted and have to get the meds ready." Doing things like helping a family member bathe and go to the bathroom can also be extremely uncomfortable. When possible, it's wise to bring in outside help such as a non-medical home care provider or certified nursing assistant to help with those duties.

"Create your own support team, take care of yourself in healthy ways and join a caregiver support group," recommends Marney Komives, a social worker in counseling services at Poudre Valley Hospital. If an elderly family member is going to live with you, find out what services and home adaptations will be necessary, look into respite support and research and visit different housing options and levels of care. If setting up a loved one to live independently, consider the safety factors, equipment and in-home services that will be needed such as Lifeline, transportation services and meals.

## Hospice & Palliative Care

Palliative and hospice care are highly-regarded models that are becoming more commonly utilized. Included in most insurance plans, these methods focus on caring, not curing, through an interdisciplinary team of health-care professionals and trained volunteers. Services are also avail-

able on a sliding scale basis and through uncompensated care programs.

Palliative care is used for treating serious illnesses, not just at the end of life, and focuses on the physical, psychological and spiritual needs of the patient by relieving pain, managing symptoms and maintaining a high quality of life. Hospice helps patients and their families navigate the end of life and provides them with quality care. Services include nurses, social workers, chaplains, volunteers, medication and equipment, bereavement and counseling services, respite and in-patient care and 24-hour support. They also provide play, music and art therapy programs.

"People deal with the same quandary of issues with a serious or advanced illness as they do with a terminal illness," says Allen, noting that there are many studies showing that life is extended in patients referred to both palliative and hospice care.

"We as a society don't want to stop medically treating things," says Myers. "But I think the baby boomers, 10,000 of whom turn 65 every day, will help change the landscape of that conversation."

## Challenges & Change

When dealing with end-of-life transitions, there are going to be unforeseen challenges. "You have to think about a continuum of care because the end of life is a progression of constantly changing needs," says Richard Riddoch, social services director at Pathways Hospice. "Having a consistent team of professionals dealing with the medical, emotional and spiritual aspects of that process is very important."

Your loved one's wishes may change as the state of their health declines. And it can be especially difficult when a family member loses their mental faculties and is no longer the person you knew. They may lash out at you, call you names or flat out fail to recognize you.

Most hospitals now have ethics committee consultations that can help families work through difficult situations. "The team comes together to address what the concerns are and helps people identify ethical issues and tensions in order to help them find common ground," says Christopher. "It's also critical that patients and families push to have complete medical information."

As health conditions deteriorate, it's important to consider and respect how different family members need to process the experience. Before Myers' father was taken off life support, she warned her sister and nephews that he was virtually brain dead and lying in a hospital bed with lots of tubes. This gave everyone permission to say goodbye in their own way, which for some meant not going into the room at all. "It's tricky—you need to let people be where they are and work with it."

While difficult, most people still find being involved in the end-of-life journeys of their loved ones to be among the most rewarding experiences of their lives. "It's a privilege to support patients and families in accessing their personal resources and strengths to cope with medical crises and end-of-life planning," says Komives. "They have taught me so much about courage, grace, spirit, dignity and living while facing the inevitability of life's end." ✨

**Advance care planning is not costly or complicated and there are many resources available that walk families through this process, which includes reflecting on what's most important to you and what your quality-of-life standards look like.**

- The Center for Practical Bioethics provides free resources (including a durable power of attorney and a health treatment directive) for helping people of all ages have the necessary conversations regarding end-of-life issues and making their health-care wishes known: [practicalbioethics.org/resources/caring-conversations](http://practicalbioethics.org/resources/caring-conversations)
- Five Wishes is a popular living will resource used all over the country that can help you and your family discuss health care in the time of illness and put your wishes into place: [agingwithdignity.org/five-wishes.php](http://agingwithdignity.org/five-wishes.php)

**The many aspects to consider when putting these plans together include:**

- Your desire for or against resuscitation and organ donation
- What serious illness or injury scenarios might affect your wishes about continuing medical treatment
- Where you want to be when you die
- Your thoughts on burial and cremation
- How you want to be remembered
- Who you want to be your agent(s) in the event that you cannot speak or make medical decisions for yourself and appointing them as your durable power of attorney for health-care decisions. "You need to designate someone who understands your preferences and is going to do what you want to have done," says Procter. Your decisions should then be shared with family, friends, healthcare providers and other relevant people and periodically reviewed and updated throughout your life.



## Additional tips & local resources

- Form a partnership with a physician you trust and take an active and involved role in your own health care and in the medical decision-making process.
- In a hospital setting, "make a list of all the questions you have for the doctors and the specialists and ask for family care conferences," says Komives. "Strive to keep family communication open, making sure everyone has thorough and correct medical information."
- Solicit expert guidance and explore local resources, including:
  - ▶ The Larimer County Office of Aging: [larimer.org/seniors](http://larimer.org/seniors)
  - ▶ Answers on Aging directory: [larimer.org/seniors/aoa\\_guide.pdf](http://larimer.org/seniors/aoa_guide.pdf)
  - ▶ The Elder Care Network of Northern Colorado: [eldercarenet.org](http://eldercarenet.org)
  - ▶ Senior Alternatives in Transportation (SAINT): [saintvolunteertransportation.org](http://saintvolunteertransportation.org)
  - ▶ Meals on Wheels: [fcmow.org](http://fcmow.org)
  - ▶ United Way's local resource referral service: [uwaylc.org](http://uwaylc.org), or dial 2-1-1
  - ▶ Pathways Hospice: [pathways-care.org](http://pathways-care.org)