

A Beautiful Death

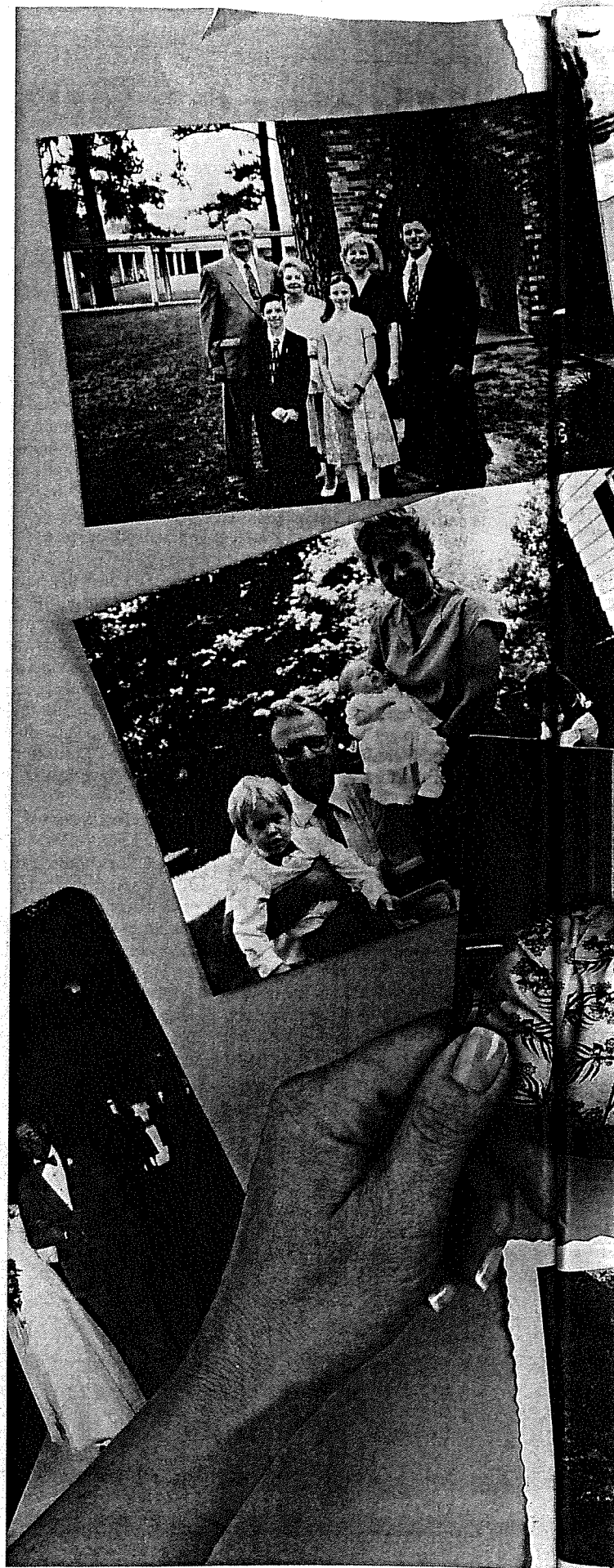
Paul Scheier lived a full and loving life. So when his cancer returned at age 86, he said no more hospitals, no chemo. He faced the end on his own terms—something that's not easy to do in America today. But he showed that it *can* be done.

P **AUL SCHEIER KNEW** how he wanted to die long before he did: at home, with his wife and children. And last July, that's exactly what happened. The retired dentist from Orchard Park, N.Y., a Buffalo suburb, succumbed to lung cancer in his bedroom with Lorraine, his wife of 62 years, nearby, and having spent his final days with their four grown children, Kathy, Lynn, Debbie, and Tom.

That didn't happen by accident. Always a practical and decisive man, Paul had begun sharing his end-of-life wishes with his daughters more than a decade earlier: No ventilators, he told them; no major surgeries except to alleviate pain; no brink-of-death resuscitations. They took good notes.

So in the spring of 2013 when malignant nodules appeared in Paul's right lung, where a large cancerous tumor had been removed a year earlier, he was ready. His doctors told Paul that he had between six and 12 months to live and that chemotherapy might buy him a little more time. Paul said no.

He knew how debilitating chemo could be. He had recently



A GUIDE TO THE
END OF LIFE

weathered a terrible infection stemming from a hernia and gallbladder operation—and he didn't want to sign on for more pain. Better, he reasoned, to spend his remaining days playing golf, having lunch with old friends, and enjoying time with his wife and children.

"At my age, I wasn't going to go through chemo," he said in an interview last summer. "I felt it was getting close to my time, so why not live happily for the next six months or year? We knew what the end result was going to be anyway."

Paul was lucky: He died peacefully at home, not in the clinical, often chaotic atmosphere of a hospital. A recent Consumer Reports survey of 2,015 adults suggests that Americans would prefer to die at home: 86 percent said they would consider receiving end-of-life-care at home, but just 36 percent said the same about getting that care in a hospital.

Indeed, a good death is hard to achieve. According to a September report from the Institute of Medicine, the health arm of the National Academy of Sciences, the U.S. health care system is poorly designed to deal with end-of-life concerns, particularly when it comes to considering the wishes of terminal patients.

That's why it's crucial that all Americans think about end-of-life concerns long before a crisis arrives. That thinking should start with an honest talk with your family about the kind of care you want during your final months and days. It should involve creating a living will (also called an advance directive) that specifies what procedures you want and don't want if you have a terminal condition. And you should appoint a health care proxy, someone who knows your desires well and who can make medical decisions for you if you become incapacitated.

Having such a plan in place eases the burden on family members and improves the odds that your passing will be under circumstances of your own choosing. (See "Going Your Way," on page 52.)

The Blessing of Hospice: "Anyone Who Does This Work Is an Angel"

In September 2013, six months after he learned that his cancer had returned, Paul

entered a hospice program run by the Center for Hospice and Palliative Care in Buffalo. That development, he later told his hospice doctor, Bethany Calkins, M.D., was "one of the best things that's happened to me in the last I don't know how many years."

He was also grateful to learn that his hospice expenses were covered by Medicare and that his wife, Lorraine, who suffers from multiple sclerosis, would not be left with financial burdens. "We always complain about government programs, but this one is just so wonderful," Paul said. "The hospice workers walked into our home and became part of our family, and we know they're going to take care of us until my last breath."

Lorraine was even more effusive: "Anyone who does this work is an angel," she said. "We have been very fortunate to have a wonderful team. They're kind, they're compassionate, they're loving."

"We're all going to die," Calkins said, "and it is my job to make sure that people do so in as calm and beautiful a manner as possible."

The Scheiers' experience shows hospice care at its best. It's reserved for patients with terminal illness who have, their doctors estimate, six months or less to live (though patients who survive longer can be "recertified" for continued care).

Once a patient is "in hospice"—which can take place at home or in a hospital, a stand-alone hospice unit, an assisted-care facility, or a nursing home—he or she forgoes all therapies aimed at combatting the disease itself. The care includes visits from doctors, nurses, social workers, and, if needed, home health aides, faith counselors, and music and massage therapists. (Paul, a World War II veteran whose stoicism and good humor rarely deserted him, even in his toughest moments, chose to have his hospice care at home and mostly did without those last three services.)

Hospice always involves palliative care—the use of medication or other therapies to ease the pain and symptoms of disease but not to heal it. And it incorporates regular medical care for symptoms or conditions that don't arise from the terminal illness itself, such as insomnia, high blood pressure, and anxiety. Palliative care is also used for patients suffering from serious but not necessarily terminal illness, such as Parkinson's disease or advanced heart disease.

In either case, "the focus is on optimal pain and symptom management," said Calkins, who formed a deep bond with the Scheier family and whose first pregnancy paralleled exactly Paul's eight-and-a-half months in hospice. Within 24 hours of Paul's death, Calkins gave birth to her son, Oliver.

Calkins considers Paul lucky to have had that time. "In my experience the average hospice stay is too short," she said. "The patients I see generally live weeks to a couple of months before they pass away, and sometimes only days or hours."

She also believes that Paul and his family negotiated the difficult process almost perfectly. "I don't think I would make any different decisions from those they made—they've rolled with the punches and done so with grace."

Lorraine is not certain exactly when she and her husband set down their end-of-life wishes, but she thinks it was when they

HOW WE WANT TO DIE

Consumer Reports' survey of Americans found that ...

86%

would want to spend their final days at home.

50%

prefer pain management and comfort care over other medical treatments.

61%

have never heard of palliative care.

47%

of people 65-plus have completed an advance directive (living will).

42%

have provided end-of-life care for a friend or relative.

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revised their wills a few years ago. And she says that the fact they had done so was a gift to their children.

"I think it makes a tremendous difference," said Kathy, the oldest child. "We're a very close family and we tend to discuss things as a group. I can't imagine the squabbles in a family who are not close and where they don't have those directives," she says. "When it's written down, that's what you have to abide by."

The Final Days: "Sitting With Family Members, Just Talking"

But even a tight-knit family like the Scheiers, who addressed most of the big questions in advance ("our family is not very normal in this day and age," said Paul's son, Tom, "because we're very close, still"), can be unnerved by some of the curveballs that get lobbed at them when a parent or spouse is near death.

Kathy and her dad stopped talking for several days after arguing about his decision to stop taking one of his medications—a turn of events that upset everyone and complicated matters for Calkins and the other hospice team members.

Lorraine Scheier confesses, with tears in her eyes, to feeling upset when her husband would say he wanted to die, which happened more and more often as his final summer progressed. And she admits that she felt hurt and left out by his insistence on meeting his friends for their regular lunches at a local restaurant—a decades-old tradition that Scheier continued until just a few days before his death.

Paul himself, while betraying little fear of death and expressing confidence that he was "good with God," was distressed by his on-and-off hallucinations, which appeared as his illness advanced. But above all, he was troubled by the hardships he believed he was imposing on his family as they waited for him to die. He knew that they had time demands of their own—Kathy as a nuclear medicine technologist in Pennsylvania, Lynn driving a school bus in Ohio, Debbie as a nurse in Texas, and Tom running a hot dog stand from his boat in Florida.

Paul worried that his kids put their lives on hold whenever they made the trip to the family home in Orchard Park. "This has been going on for three or four years now," he told Calkins, his voice breaking. "That's a lot to put anybody through."

Sitting by his side, the hospice doctor would reassure Paul that his wife and children were doing what they needed—and



FAMILY MAN

Paul Scheier died on July 26, a week after celebrating his 62nd wedding anniversary with wife Lorraine.

wanted—to do. She knew that not just from her work over the years, shepherding dozens of patients and families through the process of dying, but from her own personal experience. Fifteen years earlier, her grandfather had died in hospice.

"When else do you get to sit for days on end in a room with family members that you rarely see just talking about where you've been as a family and where you're going?" Calkins said. "It was the hardest journey I've ever walked with my family, but it was also the most beautiful."

Paul's family agrees. "Dad always told us that he wanted to teach us how to die," Paul's daughter, Debbie, said a few weeks after his death. "And what a great teacher we had."

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Going Your Way

The most effective way to enforce your end-of-life wishes is to create an advance directive or a living will and to appoint a health care proxy.

Start Now It's never too early to prepare an advance directive and designate a proxy, says Howard Krooks, past president of the National Academy of Elder Law Attorneys. Even children as young as 18 should complete one: Once children reach 18, you have no legal authority to make medical decisions for them unless you are their health care proxy or a court makes you their legal guardian.

You Don't Need an Attorney You can complete a living will and appoint a health care proxy on your own. Get state-specific forms at caringinfo.org. Note that the site uses the term "health care agent" instead of "health care proxy," but they mean the same thing.

Prepare the Paperwork Complete several originals of your living will and other legal papers, with original signatures. That can include a Do Not Resuscitate order, or DNR, which instructs health care providers not to perform cardiopulmonary resuscitation (CPR) if breathing stops or if the heart stops beating.

Keep the Documents Close and Available An advance directive locked in a safe-deposit box won't help in an emergency. Give copies to your health care proxy, your family, and your doctors to add to your medical record. The American Bar Association has an app called My Health Care Wishes (Android and iOS) that lets you store advance directives and related legal documents on your mobile device.

Discuss Your Wishes Talk with everyone in your family, not just your health care proxy. They may have different perspectives about your care, Krooks says, which can complicate matters if the advance directive is ever activated. But our survey of more than 200 caregivers found that disagreements among family members about treatment choices were not common.

Find the Right Hospice For You

Most people are referred to hospice by their doctor. Patients, family members, even friends can also make referrals. If you're looking for a program, check with the National Hospice and Palliative Care Organization (nhpco.org). But beware: More than half of U.S. hospice programs are for-profit, according to Medicare figures, and several recent news reports have highlighted problems at some of those programs.

Here's what to look for in a hospice:

- Not-for-profit status and 20 or more years of experience.

- Hospice-certified nurses and doctors on staff and available 24 hours per day.
- Palliative-care consultants who can begin care if you're not yet ready for hospice.
- An inpatient unit, where patients can go if symptoms can't be managed at home.
- Ability to provide care in nursing homes and assisted living facilities.
- Social workers and chaplains.
- Medicare approval. That way, Medicare will cover services, including equipment and home health aides as needed, plus counseling and grief support for the patient and the family.

When End of Life Is Messy

Paul Scheier's death represents a best-case scenario. He had his paperwork in order, a loving family that supported his wishes, and his cognitive abilities intact. As difficult as his diagnosis was, his prognosis was predictable and clear. But what happens when things don't go so smoothly? Here's what to do:

Your loved one has no end-of-life legal documents. Only about one in five adults in a Consumer Reports survey had an advance directive (living will) or a health care proxy. Even among people 65 and older, less than half had those safeguards. That presents big problems if a person suddenly becomes incapacitated, says elder law attorney Howard Krooks. Many states have laws defining who can make health care decisions in that situation.

Things can break down if the doctors and the person designated by the state disagree, or if another family member objects. Your best bet is to work things out within your family first, because health care providers are more likely to support your wishes if you all agree.

If you run into roadblocks, try these resources:

- The National Association of Professional Geriatric Care Managers (caremanager.org) can direct you to a geriatric care manager, who can help you resolve conflicts within your family or with your health care providers, and provide guidance on other legal, financial, and emotional challenges.
- The National Academy of Elder Law Attorneys (naela.org) lists lawyers who specialize in end-of-life legal concerns.

Your loved one suffers from a protracted illness. The course of disease and the timing of death are rarely predictable. And that can lead to a cascade of problems for patients and caregivers alike, even if your end-of-life legal documents are in order, says Joanne Lynn, M.D., director of the Center for Elder Care and Advanced Illness at Altarum Institute.

Those problems include poorly coordinated care and multiple admissions to hospitals and nursing homes for the patient, and burnout and disrupted lives for the caregivers.

Consider these resources:

- The American Geriatrics Society's Health in Aging Foundation (healthinaging.org) can help you find a geriatrician, a physician with special training in helping frail, older people. "Look for somebody with experience with home care and nursing homes, somebody who will be kind but honest about what you're going to face," Lynn says.
- The Caregiver Action Network (caregiveraction.org) offers comprehensive, practical information for caregivers.
- The Administration on Aging (eldercare.gov) can point you to state and local services for older adults and their families.

A Complete Online Guide

Comprehensive information about end-of-life issues and concerns can be found at ConsumerReports.org/endoflife. This includes:

- An 18-minute documentary chronicling Paul Scheier's final weeks.

- Resources and advice to help with the difficult medical and personal decisions patients and caregivers often face.
- A place to share memories, even painful ones, about what you learned as you helped a friend or family member at the end of life.