



FINDING YOUR WAY

These nonprofit organizations can provide a wealth of state-of-the-art resources to help you make informed health-care decisions for yourself and your family at the end of life:

Finding Our Way: Living with Dying in America: Get up-to-date information on all advanced illness and end-of-life care, including links to all of the resources in this series. www.findingourway.net

Partnership for Caring: America's Voices for the Dying: Download forms for advance directives in your state; join a consumer advocacy group focused on improving end-of-life care. www.partnershipforcaring.org

The Last Acts Campaign: Research latest news on legislative, educational and policy initiatives from local, state and national organizations. www.lastacts.org

The National Hospice and Palliative Care Organization: Search for hospice and palliative care, two types of care offering comfort and pain management at the end of life. www.nhpco.org

Growth House: Search this "Yahoo of Death and Dying" for comprehensive links to end-of-life care, with an emphasis on diversity. www.growthhouse.org

The Center for Advanced Illness Coordinated Care, in collaboration with the Veteran's Administration Healthcare Network of Upstate New York at Albany: Find guidance on coping with the complexities of serious illness through the "Walking the Advanced Illness Road" section. www.coordinatedcare.net

AARP: Find extensive support for and information on caregiving, illness, grief, widowhood, funerals, wills and estate planning, and advance directives. www.aarp.org/endoflife

Ageing With Dignity: Provides Five Wishes, a planning document. www.ageingwithdignity.org

Center to Advance Palliative Care: Search the latest resources in palliative care available to hospitals and health-care systems. www.capcmssm.org

Missoula Demonstration Project: Research tool for communities interested in setting up models for improved care at the end of life. www.dyingwell.com

Community-State Partnerships to Improve End-of-Life Care (funded by the Robert Wood Johnson Foundation): Find out what individual states are doing to organize health-care professionals, educators and policymakers. www.midbio.org

Project on Death in America: Lists innovations in the arts, social work, education and public policy. www.soros.org/death

Promoting Excellence in End-of-Life Care: Research programs that have received grants and technical support for innovative ways to change the face of dying in America. www.endoflifecare.org

Americans for Better Care of the Dying: Track changes in public policy, as well as reforms in pain management and support for family caregivers. www.abcd-caring.org

For more resources, go online to www.findingourway.net

ABOUT THE AUTHOR

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Vision for the future

Taking control at the end of life

BY DAN TOBIN

The passion to help others started smoldering inside Laura Letson a long time ago. Her father fueled it as a firebrand union man. Her mom stoked it by fighting on behalf of fellow civil servants.

As the only girl and the baby in the family, she grew up tough as the New York City she was raised in.

So a few years ago, when her dad's heart first began to fail and his health steadily worsened, that passion quickly became fully engulfed: She would do whatever it took to ease her dying hero into a good and graceful farewell.

It's a duty millions of aging Americans are about to learn firsthand.

After pushing for everything from natural childbirth in the 1960s to longer, healthier lives in the decades since, 76 million baby boomers soon will be demanding information, guidance and relief in what will be their ultimate transition — moving from advanced illness into dying.

A generation that grew up listening to the Rolling Stones and Led Zeppelin will expect innovative products to help relieve severe pain at the end of life. And in a cultural sea change, Americans as a nation will revisit the way they think about death.

This is a generation comfortable taking control, and Letson was no exception. In her role as mother and wife, and as an advocate fighting on behalf of nonprofits and state government agencies, she showed others what dedication and drive could do.

So when her 75-year-old father, William Rosenblatt, developed advanced heart disease in September 1999, Letson hurried from her home in Albany, N.Y., to Florida and stepped in to manage his case.

"There was never any question," Letson said, "that if I did my homework, and generally made my presence known throughout my father's illness, the people caring for my father would have no choice but to be attentive and responsive to his needs."

Along the way, she quickly mastered the process: She focused on the person facing a life-threatening illness; she became an educated advocate for her loved one and she talked openly about medical planning most — from doctor to family member — would rather sidestep. And underlying it all, she appreciated the payoff: As her father's illness advanced and subtly evolved into the process of dying, she viewed life's end in a positive and proactive manner.

And, as Letson would come to see it, as a wondrous and priceless gift.

She called her father Willie. He'd been a printer for nearly 40 years and in 1995 developed advanced heart disease. He did well with a pacemaker, and in 1999 his cardiologist put in a defibrillator implant that he said could make him "a new man."

But shortly after surgery, Letson grew worried. Her dad's doctor seemed uncomfortable acknowledging how far the disease had progressed, but Letson felt intuitively that Willie's life was fading. On Feb. 7, 2000, his cardiologist confirmed her gut feeling: Her dad had three to six months to live.

Then something wonderful happened. After huddling with her mother, Claire, and two brothers, Letson brought her dad the news. But instead of being panic-stricken, Willie was relieved. "I thought so," he said, then shared his feelings of "suffocating" when he couldn't speak openly about his prognosis.

For Willie, a dreadful weight had been removed.

The decision to openly face his dying was the crucial first step in an important end-of-life journey.

Letson offers a powerful example: Her prompt action helped her father, family members and even the medical team confront individual and cultural fears that shroud the dying process. Her next move was to forge a treatment plan.

But she quickly discovered what a delicate dance that can be: How do you try to keep someone alive while at the same time guide him or her toward a natural and comfortable death?

"With serious, chronic illness, patients and their families face the challenge of hoping for the best health outcome while preparing for



Laura Letson ensured her father, William Rosenblatt, had emotional support and was kept informed as he faced his death. Below, just days before he died, her father celebrated a new year surrounded by loved ones, including Letson, granddaughter Sarah Letson and friend Deirdre Berger.

Use your time well

End-of-life activist Laura Letson has some tips to help you navigate through the system:

Get a plan. Keep the person with advanced illness at the center of the conversation when orchestrating a plan. Gather information in a calm manner, focusing on one problem at a time. And remember: Each person's situation will be unique, so custom-fit the plan to the individual.

Get informed. Open and maintain a clear channel of communication with your doctors in order to understand your illness and the treatments available.

Keep everyone on the same page. Have frequent conversations with family members so that everyone understands the choices, the planning process and the timetable.

Broaden the plan. From the start, incorporate community services and caregiver support so that family members don't burn out from caregiving just when they're needed the most.

Confront fear. Facing and discussing fears can lessen their power and help smooth planning. Write a list of the biggest fears and discuss them with friends, family and your medical team.

Control the pain. Work closely with your medical team to

make pain-control and symptom management centerpieces of your treatment plan.

Stay calm. Consider using stress-management techniques, such as relaxation or other forms of meditation.

Go with the flow. Monitor medical conditions as the illness changes course. When the time comes for moving beyond cure-based or life-prolonging care, be ready to shift gears into a palliative, or comfort, stage of treatment. Look into the benefits of hospice. Think of dying as a natural part of life, and see these changes as akin to a running river.

Know the power of dying. With attention and sensitivity, this final phase can provide a rich well of life-changing and consciousness-raising experiences, both for patient and family. See it as the precious chapter of life that it is, a time to reach closure with respect and dignity. For many, this is a time to say farewell, to be introspective and to search for meaning in life as well as to find peace of mind.

Use your time well. Look for opportunities for closure — to say goodbye, to ask for forgiveness, to forgive others and to embrace love as the meaning of life.

— Dan Tobin

the possibility death may occur within the next few months," says Dr. Bernard Lo, director of the Program in Medical Ethics at the University of California, San Francisco.

But there are signs that Americans are on the verge of a collective breakthrough, beginning with the sort of structured conversations that Letson had with her family. Experts describe this new end-of-life landscape:

Pain management will become a touchstone of medical plans: "As they age, baby boomers have high expectation for attention to pain control and other quality-of-life issues by their doctors and they will expect their doctors, among other health care professionals, to be knowledgeable, skilled and caring," says Dr. Perry Fine, professor of anesthesiology at the University of Utah and a national expert in pain management and palliative care.

A new vocabulary will evolve addressing patients' psychological and spiritual needs and honoring

their cultural traditions.

New job descriptions will emerge for nurses and social workers as care coordinators, guides for people navigating the health-care delivery system.

From the grassroots will grow an extensive community network to support caregiving to ailing parents, as well as demand reforms in insurance coverage and in local and state laws.

Current research funded by foundations will bear fruit by changing the way hospitals and major medical organizations are accredited and deliver care.

And as more patients use hospice and palliative care for longer amounts of time, they will become household words.

Fashioning a plan for her father put Letson in this movement's vanguard. After her conversation with Willie, she had hospice aid brought in. She wrote Willie's doctor, stressing the importance of in-home care. And she explained how the death of her brother, David, from a diabetic coma had taught



PHOTO COURTESY OF THE PARTNERSHIP FOR CARING

her the value of emotional support.

By May 2000, it was obvious Letson's mother needed help with the caregiving. With the blessing of her husband and daughter, Letson moved her parents in with her. Willie now had the best of both worlds: hospice care in his daughter's house and, when necessary, visits to the inpatient hospice unit in Albany.

By June, Willie felt at peace with dying but wanted to live the best he could with his remaining time. Tears welled up in his eyes when he spoke to a visitor about David, the son he had lost. He shared regrets about mistakes he had made with Claire; family members encouraged him to ask for forgiveness.

"Life is so precious," he told a visitor. "I only want my family to see how much I love them."

Willie stayed at Letson's home until year's end. Nearly a year had now passed since doctors told him he had three to six months to live. At a final gathering on New Year's Eve, the same day Letson's daughter turned 13, Willie's family honored his legacy.

By the next day, Willie's kidneys were failing rapidly. Letson brought him back to the hospice inn. Just before the ambulance pulled up, Willie looked at his daughter.

"Will I be coming home?" he asked.

"Not this time, Dad." "That's what I thought," said Willie.

Letson, like her father, knew in her heart this was the way to live with dying — sheltered with dignity and calm, not battered by last-minute turmoil in which dying is considered a medical emergency instead of a time of love and reflection.

On Jan. 3, Willie told Letson he was ready to join David in heaven. He said he had seen his son in a vision.

"The next time you see David," she replied, "take his hand and fol-

low him home."

But Willie wasn't quite ready to let go. He was worried about leaving his wife. Claire knew: She had to give him permission to die.

"Willie," she asked her husband. "Can you hear me?"

Willie nodded. "Are you still fighting, Willie?" Again, he nodded.

Then she said gently, "I want you to stop fighting, Willie, and go with the flow. Do you understand?"

Another nod. Finally, to be sure, Claire asked, "Are you still fighting, Willie?"

This time, he shook his head no. Several hours later, Willie took in his last breath, then let it out.

The lessons Letson learned are those that millions of Americans will one day face. She speaks of "the importance of embracing death as an extension of living." She talks about "looking beyond the surface to the gifts that the dying process has to offer."

And, as Letson now knows: "You will not get these gifts anywhere else in life. They are reminders of all the little blessings we can miss if we don't pay attention."

Willie had left a letter and asked that it be read aloud upon his death. In it, he spoke of his unconditional love for his family. He apologized for any disagreements they may have had.

Finally, like the daughter who had helped him die with grace, Willie described lessons he, too, had learned in life:

"Nothing is more important in a person's time on earth than love, happiness and health," Willie wrote. "Thank you for sharing my life and giving me my greatest moments. I will love you forever."

Then he signed it: "Willie, Dad and Grandpa."

For more resources and contacts on end-of-life issues, go to www.findingourway.net.