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For the Elderly, Being Heard About Life's End

By JANE GROSS

HANOVER, N.H. — Edie Gieg, 85, strides ahead of people half her age and plays a fast-paced game of tennis. But when it comes to health care, she is a champion of "slow medicine," an approach that encourages less aggressive — and less costly — care at the end of life.

Grounded in research at the Dartmouth Medical School, slow medicine encourages physicians to put on the brakes when considering care that may have high risks and limited rewards for the elderly, and it educates patients and families how to push back against emergency room trips and hospitalizations designed for those with treatable illnesses, not the inevitable erosion of advanced age.

Slow medicine, which shares with <u>hospice care</u> the goal of comfort rather than cure, is increasingly available in <u>nursing homes</u>, but for those living at home or in assisted living, a medical scare usually prompts a call to 911, with little opportunity to choose otherwise.

At the end of her husband's life, Ms. Gieg was spared these extreme options because she lives in Kendal at Hanover, a retirement community affiliated with Dartmouth Medical School that has become a laboratory for the slow medicine movement. At Kendal, it is possible — even routine — for residents to say "No" to hospitalization, tests, surgery, medication or nutrition.

Charley Gieg, 86 at the time, was suffering from a heart problem, an intestinal disorder and the early stages of <u>Alzheimer's disease</u> when doctors suspected he also had <u>throat cancer</u>.

A specialist outlined what he was facing: biopsies, <u>anesthesia</u>, surgery, radiation or <u>chemotherapy</u>. Ms. Gieg doubted he had the resilience to bounce back. She worried, instead, that such treatments would accelerate his downward trajectory, ushering in a prolonged period of decline and dependence. This is what the Giegs said they feared even more than dying, what some call "death by intensive care."

Such fears are rarely shared among old people, health care professionals or family members, because etiquette discourages it. But at Kendal — which offers a continuum of care, from independent living apartments to a nursing home — death and dying is central to the conversation from Day 1.

So it was natural for Ms. Gieg to stay in touch with Joanne Sandberg-Cook, a <u>nurse practitioner</u> there, during her husband's out-of-town consultation.

"I think that it is imperative that none of this be rushed!" Ms. Sandberg-Cook wrote in an e-mail message to Ms. Gieg. The doctor the Giegs had chosen, the nurse explained, "tends to be a 'do-it-now'

kind of guy." But the Giegs' circumstances "demand the time to think about all the what-ifs."

Ms. Sandberg-Cook asked whether Mr. Gieg would want treatment if he was found to have <u>cancer</u>. If not, why go through a <u>biopsy</u>, which might further weaken his voice? Or risk anesthesia, which could accelerate her husband's dementia?

"Those are the very questions on my mind, too," Ms. Gieg replied. The Giegs took their time, opted for no further tests or treatment, and Charley came back to the retirement community to die.

Such decisions are not made lightly, and not without debate, especially in an aging society.

Many in their 80s and 90s — and their boomer children — want to pull out all the stops to stay alive, and doctors get paid for doing a procedure, not discussing whether it should be done. The costliest patients — the elderly with chronic illnesses — are the only group with universal health coverage under Medicare, leading to huge federal expenditures that experts agree are unsustainable as boomers age.

Most of that money is spent at certain academic medical centers, which offer the most advanced tests, the newest remedies, the most renowned specialists. According to the Dartmouth Health Atlas, which ranks <u>hospitals</u> on the cost and quantity of medical care to elderly patients, <u>New York University</u> <u>Medical Center</u> in Manhattan, for instance, spends \$105,000 on an elderly patient with multiple chronic conditions during the last two years of life; U.C.L.A. Medical Center spends \$94,000. By contrast, the <u>Mayo Clinic</u>'s main teaching hospital in Rochester, Minn., spends \$53, 432.

The chief medical officer at U.C.L.A., Dr. Tom Rosenthal, said that aggressive treatment for the elderly at acute care hospitals can be "inhumane," and that once a patient and family were drawn into that system, "it's really hard to pull back from it."

"The culture has a built-in bias that everything that can be done will be done," Dr. Rosenthal said, adding that the pace of a hospital also discourages "real heart-to-heart discussions."

Beginning that conversation earlier, as they do at Kendal, he said, "sounds like fundamentally the right way to practice."

That means explaining that elderly people are rarely saved from cardiac arrest by CPR, or advising women with broken hips that they may never walk again, with or without surgery, unless they can stand physical therapy.

"It's almost an accident when someone gets what they want," said Dr. <u>Mark B. McClellan</u>, a former administrator of Medicare and now at the <u>Brookings Institution</u>. "Personal control, quality of life and the opportunity to make good decisions is not automatic in our system. We have to do better."

The term slow medicine was coined by Dr. Dennis McCullough, a Dartmouth geriatrician, Kendal's founding medical director and author of "My Mother, Your Mother: Embracing Slow Medicine, the Compassionate Approach to Caring for Your Aging Loved One."

Among the hard truths, he said, is that 9 of 10 people who live into their 80s will wind up unable to take care of themselves, either because of frailty or dementia. "Everyone thinks they'll be the lucky one, but we can't go along with that myth," Dr. McCullough said.

Ms. Sandberg-Cook agrees. "If you're never again going to live independently or face an indeterminate period in a disabled state, you may have to reorganize your thinking," she said. "You need to understand what you face, what you most want to avoid and what you most want to happen."

Kendal begins by asking newcomers whether they want to be resuscitated or go to the hospital and under what circumstances. "They give me an amazingly puzzled look, like 'Why wouldn't I?' " said Brenda Jordan, Kendal's second nurse practitioner.

She replies with CPR survival statistics: A 2002 study, published in the journal Heart, found that fewer than 2 percent of people in their 80s and 90s who had been resuscitated for cardiac arrest at home lived for one month. "They about fall out of their chairs when they find out the extent to which we'll go to let people choose," Ms. Jordan said.

Kendal, where the average age is 84, is generally not a place where people want heroics. Dr. George Klabaugh, 88, a resident and retired internist, found himself at the center of controversy a few years back when he tried to revive a 93-year-old neighbor who had collapsed from cardiac arrest during a theatrical performance. Dr. Klabaugh, who was unaware that the man had a "Do Not Resuscitate" order, said he regretted his "automatic reaction," a vestige of a professional training that predisposes most physicians to aggressive care.

Ms. Jordan surveyed Kendal residents and found only one that wanted CPR — Brad Dewey, 92, who dismissed the statistics. "I want them to try anyway," he said. "Our daughter saved a man on a tennis court. Who's to say I won't recover?"

Some of the 400 residents, who pay \$120,000 to \$400,000 for an entry fee, and monthly rent from \$2,000, which includes all health care, pursue no-holds-barred treatment longer than others. One woman, for example, arrived with cardiac and pulmonary disease but was still capable of living in her own apartment. First, she had <u>cataract surgery</u> that left her vision worse. Next, during surgery to replace a worn-out artificial hip, her thigh bone snapped. She spent a year in bed and wound up with blood clots. Then she broke the other leg.

Only then, Ms. Jordan said, did the woman decide to forgo further surgery or hospitalizations. The woman was too ill to be interviewed.

Some of those most in tune with slow medicine are the adult children who watch a parent's daily decline. Suzanne Brian, for one, was grateful that her father, then 88 and debilitated by <u>congestive heart failure</u>, was able to stop medications to end his life.

"It wasn't 'Oh, you have to do this or do that,' "Ms. Brian said. "It was my father's choice. He could have

changed his mind at any time. They slowly weaned him from the meds and he was comfortable the whole time. All he wanted was honor and dignity, and that's what he got."

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